

***Retooling Employment:
A Systems Analysis
Including Promising Practices
for Advancing
Supported Employment for
Citizens of Illinois with
Developmental Disabilities***

An Investment of the
Illinois Council on Developmental Disabilities,
Springfield, Illinois

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January 9, 2008

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Acknowledgments

Public Policy Impacts of Washington, D.C. and the Association for Community Therapeutic Supports, Raleigh, North Carolina expresses its gratitude and appreciation to so many people in Illinois and across the nation who have generously and enthusiastically provided technical assistance and support to this investment of the Illinois Council on Developmental Disabilities.

We thank Lester Pritchard, Chairman, Sheila T. Romano, Executive Director, Kerry Flynn, Director of Operations and the members of the Council for your ongoing faith, support and counsel on Retooling Employment: A Systems Analysis including Promising Policies and Practices for Advancing Supported Employment for Citizens of Illinois with Developmental Disabilities. We also thank Margie Harkness, Project Liaison for your many hours of meetings with project staff, conference calls and electronic messages in guidance, technical assistance, support and furtherance of this Analysis. You have been a great asset.

Since June 1, 2007, there have been hundreds of people in Illinois and states across this country who have provided advice, enthusiasm, best and promising policies and practices and technical assistance on advancing supported employment for people with developmental disabilities. We especially appreciate the assistance of the many self-advocates, parents, friends, and supporters from across the state that provided such valuable information at our public forum meetings. There are simply too many of you to mention by name, but your contributions are invaluable.

Special thanks for the extraordinary efforts of Linda Rolfe, Director of the Washington Developmental Disabilities Division, Jeanne Cusson, Program Planning and Review Specialist, New Hampshire Division of Developmental Disabilities, Jennie Masterson, Supported Employment Coordinator, Vermont Division of Disability and Aging Services Division of Disability and Aging Services, and Thomas Hughes, Assoc. Executive Director, Westchester Arc for arranging multiple meetings over several days with a variety of key stakeholders in your states and agencies.

We recognize the many contributions you have made in so many ways by acknowledging you here by name, title, the organization you represent and your location. All of you have had a positive impact in the completion of this initial Systems Analysis including Promising Policies and Practices in advancing supported employment for youth and adults with developmental disabilities in Illinois.

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January 9, 2008

Executive Summary

The Illinois Council on Developmental Disabilities made an investment in Public Policy Impacts of Washington, D.C. (PPIWDC) and the Association for Community Therapeutic Supports (ACTS) of Raleigh, North Carolina in May 2007 to develop, produce, and deliver for Council a blueprint for Illinois...

...of strategies and approaches to overcome barriers to shifting from segregated sheltered workshops and developmental training programs to individually supported employment models in integrated environments for people with developmental disabilities.

Within this document is the Systems Analysis including Promising Policies and Practices for retooling employment in Illinois.

Methodology for the Systems Analysis

The methodology for the Systems Analysis including Promising Policies and Practices for retooling employment in Illinois toward advance supported employment focused on people.

Meetings were scheduled and conducted with a representative sample of employment stakeholders including key appointed state and local officials, planning councils on developmental disabilities, schools and provider agencies, staff members, universities, businesses, advocacy organizations representing individuals with developmental disabilities, professional organizations, etc. to have dialogue about this initiative.

The process used by PPIWDC was to conduct face-to-face interviews, phone conferences and group meetings with a wide range of stakeholders within Illinois and in other key states and communities in Connecticut, New Hampshire, New York, Ohio, Oklahoma, Oregon, Tennessee, Vermont and Washington.

Innovative public policies and practices that advance supported employment and self-employment as a priority including programmatic and funding arrangements in support of such approaches were reviewed and included where appropriate with the mission of this analysis.

Chapter I. Introduction

We begin by describing where we have come from in providing services to individuals with developmental disabilities. The action of Congress to pass the Individuals with Disabilities Act and the Supreme Courts certification of the rights of these individuals lays the groundwork for the next step in creating a more inclusive and independent society for all. The gap of opportunities for individuals with disabilities provides a chance now to learn from our mistakes of isolationism and bring people with disabilities into the mainstream. There needs to be a connection between working, living and lifestyle choices, even when discussing programs operated by the State.

Chapter II. Barriers to Employment for Individuals with Developmental Disabilities

The barrier to assisting individuals with disabilities into their chosen employment situations has been an uphill battle. The identified barriers include a lack of knowledge, lack of resources, lack of information about the opportunities individuals with disabilities could positively present to an employer, poor coordination and collaboration among service providers and a perceived lack of available talent.

These barriers combined with aversions to change or new ideas on the part of both employers, individuals with developmental disabilities and others in the disability system have made making changes difficult. However, these are all barriers that can be overcome and knowing what they are is the first step.

Chapter III. The Perceptions of Illinois Stakeholders including 123 Individuals with Developmental Disabilities and 46 Family Members on Advancing Supported Employment

In September and October 2007, fifteen (15) regional dialogue meetings were conducted by ACTS with individuals with developmental disabilities, their families, and chosen advocates/representatives about their interests, needs, preferences, and desires for participation in supported and competitive employment programs and community inclusive non-work programs.

To effectively change a system that people use and depend on requires information about the attitudes and perceptions of some of those people. Stakeholders from various groups participated in a number of focus groups across Illinois.

The attitudes of the people in the focus groups were mostly positive about the prospective changes to the system in advancing supported employment.

Remarkably, this attitude was consistent whether the individuals were from urban, suburban or rural areas. There are some reservations about changes to the Illinois developmental disabilities system, especially related to policy and funding considerations, which will have to be addressed and communicated to gain even greater confidence in supported employment.

Chapter IV. Effective Systems Change Advancing Supported Employment: Managing at the Speed of Change: How Resilient Managers Succeed and Prosper Where Others Fail

While there is no front-page news of crisis in the lives of individuals with developmental disabilities, it has become apparent that there is need to reform and expand the current system of employment services.

Using ideas from Darryl Connor in the book, “Managing at the Speed of Change”, the focus for system change is on resilience of people. Fostering effective change can be greatly facilitated by people who are flexible, focused, organized, proactive and positive. These are the people who as stakeholders will be the pioneers in seizing new opportunities and moving systems toward improved ways of doing business.

The first step is to overcome the resistance to change and learn from the mistakes of others when making system wide change for necessary reform. When making any change there must be the knowledge that there will be some pain involved, but that pain is less than the pain of continuing on with an outdated and antiquated system. Ultimately success will depend on how each individual is able to make changes and realize their potential.

Chapter V. Promising State Policies Advancing Supported Employment

Several states have already made changes from segregated day services to a system of integrated supported employment for individuals with disabilities.

- The State of Washington is an example of a state that removed their workshops entirely.
- The State of Vermont has also done away with sheltered workshops and has become a model of how supported employment arrangements can be successful in a rural state.
- The State of Oregon has a policy of enhancing the quality of life of its citizens. Oregon is a leader in person-centered planning and community inclusion.
- In addition the state of Tennessee has a model, which is useful for designing a comprehensive supported employment system.
- New Hampshire, also a high performing state on supported employment, has done more by practice and actions than by written policies.

Chapter VI. Promising State Practices Advancing Supported Employment

Several states have practices that are highly important in advancing supported employment. They are reviewed as critical methods for ensuring successful outcomes and continued progress within and among agencies at the state and local levels. They are highly oriented to the fabric of advancing supported employment, self-determination, person-centered planning, system collaboration, data collection, outcomes surveys/evaluation and funding innovations. It is anticipated that in any implementation of this initiative that these practices will serve as key models for replication by the state and affiliated agencies.

Chapter VII. Advocating for and Advancing Supported Employment and Related Services

There is much need to develop effective ways to center fully on individuals with developmental disabilities in advancing supported employment. Self-advocacy and peer mentoring were identified as key strategies to assist the challenges, fears, and opportunities that these individuals face in making major life changes. Parent support and active listening were also advanced as key to the systems changes that are envisioned within this Systems Analysis to retool employment services and advance supported employment.

Chapter VIII. Examples of Best and Promising Practices on Integrated and Inclusive Supported Employment and Related Supports Among Local Agencies

The role of the local community provider agencies must be thought through and adapted, especially in a state with communities as diverse as those in Illinois. The best practices of localities mean they all exhibit features to ensure that the individuals are employed by the business and not by the support agency whenever possible.

The providing agency is also intended to greatly reduce services that represent congregate care such as sheltered workshops, enclaves, and provider driven residential services. PPIWDC found high performing agencies in Midtown Manhattan, White Plains and Troy, New York, Cleveland and Cincinnati, Ohio, Bellevue and Sumner, Washington as major urban and suburban adult employment agencies as well as several in Illinois.

Rural high performing agencies were found in Littleton, New Hampshire, Burlington and Middlebury, Vermont. All of these agencies demonstrated success in facilitating the community inclusion of individuals with developmental disabilities including their acquisition of gainful employment.

The success of major urban, suburban, and rural employment agencies to facilitate the acquisition of gainful employment by thousands of individuals with developmental disabilities is instructive for all such agencies in Illinois no matter where they are located.

Chapter IX. Best Practice on Support Agencies, Technical Assistance and Training on Supported Employment

PPIWDC has found a wide range of promising practices that support the employment of individuals with developmental disabilities in their quest for employment. Among the identified organizations in Illinois and other states are ones oriented to impart business connections, affiliated technical assistance on supported employment initiatives, individual and workplace accommodations, professional training approaches, and federal benefits management with coordination with wages earned. These identified agencies provide effective models of such technical support models and should be replicated or utilized within this Blueprint.

Chapter X. Lessons Learned

It was learned that there is tremendous enthusiasm for this Council initiative advancing supported employment across all stakeholders in Illinois.

Supported employment is very complicated and complex but emanates one person acquiring a job at a time. Agencies and states lose ground in this employment venture if they lose focus or are distracted to other issues.

Expectations are often a poor vehicle for assessing future job performance. Funding in Illinois for developmental disability supports needs to be addressed to meet successful supported employment outcomes. Collaboration between agencies and elimination of silo mentalities is essential.

The skills associated with sheltered employment are drastically different than the skills for supported employment for both individuals and employees of the adult service providers.

There is need to understand that businesses have a mission of service and profitability which changes the mode of operation for adult support agencies from human services to a business perspective.

There is a need to constantly focus on employment so that if an individual loses a job, the efforts to gain a new position through training and application is immediate.

There is also clear definition of what constitutes supported employment and what it is not within standards and policies.

These thirteen lessons learned are instructive within our analysis that seeks to advance supported employment as an effective policy, practice and as a preferred way of doing business.

Concluding Comments

Within the Concluding Comments on Systems Change, the notion of a “Burning Platform” from the book “Managing at the Speed of Change” was used to establish the parameters for systems transformation as required for advancing supported employment. The agencies visited by PPIWDC and identified as high performing related to supported employment each demonstrated their transformation from being a human service organization to being a business and operating with a business mindset and imperative. While they have transformed how they do business with successful outcomes, the vast majority of adults with developmental disabilities are still served in segregated programs.

Unfortunately, as Houtenville’s statistic’s demonstrated in Chapter 1, these high performing supported employment agencies and the states that lead them are few and far between. Most individuals with developmental disabilities have yet to experience integration and inclusion even though self-determination and person-centered planning have been “practiced” for over twenty years.

To break out of the chains of segregation and congregate care, bold action must be taken and...a burning platform mentality must exist. The cost in human lives and the lost opportunities for them and employers is too great not to take this approach. When this project is implemented and supported employment is advanced as the primary way of doing business in ten pioneering agencies, and when the Illinois policy makers see this work and the outcomes anticipated are realized, there will be momentum and policy incentives that will be assistive for other stakeholders to “jump from the platform”.

Methodology for the Systems Analysis

The Illinois Council on Developmental Disabilities made an investment in Public Policy Impacts of Washington, D.C. (PPIWDC) and the Association for Community Therapeutic Supports (ACTS) of Raleigh, North Carolina in May 2007 to develop, produce, and deliver for Council a systems analysis including promising policies and practices and a blueprint for Illinois of...

...strategies and approaches to overcome barriers to shifting from segregated sheltered workshops and developmental training programs to individually supported employment models in integrated environments for people with developmental disabilities.

PPIWDC will recommend proven strategies for systems change in Illinois for retooling employment. The process used by PPIWDC was to conduct face-to-face interviews, phone conferences and group meetings with a wide range of stakeholders within Illinois and in other key states and communities in Connecticut, New Hampshire, New York, Ohio, Oregon, Tennessee, Vermont and Washington. Stakeholders are key to ensuring the success of this investment.

Meetings were scheduled and conducted with a representative sample of employment stakeholders including key appointed state and local officials, planning councils on developmental disabilities, schools and provider agencies, staff members, universities, businesses, advocacy organizations representing individuals with developmental disabilities, professional organizations, etc. to have dialogue about this initiative. These meetings were individualized by stakeholders.

We have identified innovative public policies and practices that advance supported employment and self-employment as a priority including programmatic and funding arrangements in support of such approaches. Of particular interest are approaches successful in employing individuals who have significant, challenging, and severe developmental disabilities in the mainstream workforce.

In September and October 2007, fifteen (15) regional dialogue meetings were conducted by ACTS with individuals with developmental disabilities, their families, and chosen advocates/representatives about their interests, needs, preferences, and desires for participation in supported and competitive employment programs and community inclusive non-work programs. A series of questions were used to also identify barriers, obstacles, and fears related to their acquisition of gainful employment. The results of these meetings are reported in Chapter III.

Site visits were made by PPIWDC to adult employment agencies across the country who were identified as being promising and best practice based on their capabilities to have high performance in supported employment with integrated one on one employment as the prevailing priority. Many key documents and reference materials were obtained from the states and agencies as examples of promising and best practice and these are assembled in applicable appendices for reference by participants in the Systems Analysis.

A survey has been submitted to all of the promising practice agencies to gain comparative information. We are looking at factors such as the type of work, degree of integration with other typical employees, compensation, hours of work, inclusion of the individuals within the mainstream workforce, socialization activities/programs, residential supports and how the employment meets the preferences and enhanced outcomes for all such individuals.

Chapter I Introduction

“We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness.

That to secure these rights, Governments are instituted among Men, deriving their just powers from the consent of the governed, — That whenever any Form of Government becomes destructive of these ends, it is the Right of the People to alter or to abolish it, and to institute new Government, laying its foundation on such principles and organizing its powers in such form, as to them shall seem most likely to effect their Safety and Happiness.”

Thomas Jefferson, Declaration of Independence, 1776

These words have become the mantra for women’s rights, the rights of African-American’s, Latino-Americans, and other historically disenfranchised groups. They are reiterated here to provide emphasis to the rights of individuals with developmental disabilities, rights that are generally ignored or obviated.

Within this Systems Analysis for Retooling Employment in Illinois for individuals with developmental disabilities, we highlight the fact that the rights of such individuals must be assumed and promoted pursuant to the words under this declaration so that the individuals can pursue “life, liberty and happiness” where they live, work and play like anyone else in the United States and other countries of the world. The range of federal laws and decrees is as follows:

- The Americans with Disabilities Act (ADA) was passed in 1990 and provides civil rights protection to person's with disabilities in the area of employment, public accommodations such as restaurants, services made available by state and local governments, transportation, and telecommunications. The ADA prohibits discrimination on the basis of disabilities by calling for the removal of communication and architectural barriers.
- Originally passed in 1973 and amended in 1992, the Rehabilitation Act focuses on requiring non-discrimination and affirmative action in federal employment, guaranteeing access in all federal buildings and ensuring that all entities receiving federal funds do not discriminate in employment practices and provision of services.

- The Individuals with Disabilities Education Improvement Act (IDEA) of 2004, which traces its legislative history back to the Education for All Handicapped Act of 1975 requires that states provide a free and appropriate public education to children age three through 21 years old, which have a disability.
- The Developmental Disabilities Assistance and Bill of Rights Act, amended in 1994, provides assistance to states and public and private nonprofit agencies and organizations to assure that all persons with developmental disabilities receive the services, assistance, and opportunities necessary to enable them to achieve their maximum potential through increased independence, productivity and integration into the community. Additionally, the Act enhances the role of the family in assisting persons with developmental disabilities to achieve their maximum potential and makes grants available within states to support a system that protects the legal and human rights of persons with developmental disabilities.
- The Technology-Related Assistance for Individuals with Disabilities Act Amendments of 1994 serves to provide financial assistance to states to support systems change and advocacy efforts, which assist with developing and implementing a consumer-responsive program of technology-related assistance for individuals with disabilities. Additionally, the Act will ensure timely acquisition and delivery of assistive technology devices and assistive technology services to individuals in need of such services and/or devices.
- The Federal Rehabilitative Services Administration (RSA) on August 19, 1997 issued a Policy Directive, RSA-PD-97-04, which governs state Vocational Rehabilitation (VR) agencies. This new directive requires state VR agencies to approve vocational goals and services to enable persons with disabilities to maximize their employment potential.
- The United States Supreme Court in Washington, DC, on June 22, 1999 rejected the state of Georgia's appeal to enforce institutionalization of individuals with disabilities. The Supreme Court affirmed the right of individuals with disabilities to live in their community in its 6-3 ruling against the state of Georgia in the case *Olmstead v. L.C and E.W.* Under Title II of the federal Americans with Disabilities Act, Justice Ruth Bader Ginsburg said, in delivering the opinion of the court, "*states are required to place persons with mental disabilities in community settings rather than in institutions when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the*

resources available to the State and the needs of others with mental disabilities...

...The 'integration mandate' of the Americans with Disabilities Act requires public agencies to provide services "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." The high court affirmed the right of individuals with disabilities to live in their community in its 6-3 ruling against the state of Georgia in the case Olmstead v. L.C and E.W.

All of these laws and decrees have advanced the rights of individuals with developmental disabilities to overcome barriers to their integration and inclusion in community life.

However, the prevailing barriers in spite of these laws and judicial decrees remain strong against them and the outcomes are less than what probably was envisioned by the sponsors of the legislation and the writers of and proponents of judicial decrees.

This is especially true when looking at their application in regards to employment where 67% of all people with intellectual disability are under-employed or unemployed.

According to Cornell University researchers as released on November 8, 2007, the employment gap between working-age people with and without disabilities continues with a dramatic...

42 percent employment gap separates working-age people with and without disabilities in the workforce. The report states that 37.7 percent of people with disabilities are employed, compared with 79.7 percent of people without disabilities, making a gap of 42 percentage points.

There are 22,382,000 people with disabilities of working age (21-64), 12.9 percent of the total working age population.

The finding is part of an ongoing series of reports released by Cornell University in collaboration with the American Association of People with Disabilities (AAPD). "The longstanding employment gap between people with and without disabilities appears to be getting wider. People with disabilities are not keeping pace in this economy. This employment gap has severe consequences for poverty. People with disabilities are much more likely to live in poverty," said Andrew Houtenville, director of Cornell's

Rehabilitation Research and Training Center on Disability Demographics and Statistics (StatsRRTC).

The researchers found that the poverty gap is 15.9 percent, that is 25.4 percent of working-age Americans with disabilities live in poverty compared with 9.5 percent of those without disabilities. The report also noted that people with disabilities constitute 28.4 percent of the working-age American population living in poverty.¹

Summary Comments Chapter I. Introduction

In spite of all the laws and mandates, old practices and policies often die slowly or they overtly prevail.

Historically, individuals with developmental disabilities have been served in segregated settings without the rights to determine for themselves the basic conditions of their lives.

Other, often well-intentioned, people have made choices for them in the interest of protection, avoidance of risk, and ensuring health and safety.

Meanwhile, the lives of many hundreds of thousands of such people across the United States have been less than fulfilling.

They live at or very near poverty levels, with high economic and social dependency, with high unemployment or under-employment, less than challenging lives, segregated amongst others that are often ones they would not commonly choose if given alternatives and given no voice to change their situation.

When individuals make choices for themselves without being fully informed, without knowing fully the opportunities that could exist, they choose segregation out of fear and misunderstanding and lack of knowledge of what can be instead of what is. They unwittingly and unfortunately, perpetuate their poverty and segregation. Unfortunately, this is likewise the case for many families and advocates as well.

¹ Houtenville, Andrew J. 2007. "Disability Statistics in the United States." Ithaca, NY: Cornell University Rehabilitation Research and Training Center, www.disabilitystatistics.org. Posted May 15, 2003.

If this were understood by the general population they would most probably, and with few exceptions, find such treatment abominable and intolerable and would demand change.

Change can happen for individuals with developmental disabilities within Illinois utilizing the dynamic actions that have resulted in substantive accomplishments in locales and state governments across the United States.

These actions have resulted in integrated employment, people living in their own homes under their control, and being included in their communities in meaningful ways.

From New Hampshire to Washington and many states in between, promising policies and practices are creating the conditions that Jefferson envisions for “all men”. A major premise of this systems analysis is that there must be connectedness between one’s work, one residential situation, and one’s community connections ensuring that the individual controls each aspect of one’s life for sustained success in each area. This is an interdependent dynamic.

The focus of this report will be on advancing employment supports and the redevelopment of historic developmental training and sheltered employment into meaningful activities enhancing lives that enable lives that are valued and desired by people who have developmental disabilities. Notwithstanding this attention, the importance of developments for individuals to control housing and their residential supports is the third leg of the stool and a major premise of this report.

Chapter II. Barriers to Employment for Individuals with Developmental Disabilities

There are many barriers or “reasons” why individuals with developmental disabilities do not acquire real jobs, for real wages, with real employers. These are summarized as follows:

1) Expectations.

What we expect of people can be nurturing of that outcome. It has become unfortunately a standard expectation that stakeholders in the developmental disability system focus on *disabilities* and not *abilities* when thinking of possibilities for people with developmental disabilities.

Stakeholders, who often have low expectations, include the gamut of persons and agencies involved in the lives of individuals with developmental disabilities: families, guardians, friends and advocates; state education, human service and rehabilitation agencies, elected and appointed officials, schools and adult services providers, and employers.

As long as we think “can’t” the possibilities of “can” are not considered. Individuals with significant and challenging conditions are most vulnerable to what one expects and often do not enjoy even the opportunity to prove what they can do.

In a plenary address at the National Association of State Directors of Developmental Disabilities Services held on November 9, 2007, James Salzano, Executive Vice-President of the Clarks Companies addressed how his company provides six-month internships for individuals with developmental disabilities in Wellesley, Massachusetts. Clarks, which is headquartered in the United Kingdom, offers individuals paid internships so they can acquire key skills for advancing their marketability in the labor market. Mr. Salzano stated, *“I find the term “disabilities” to be disturbing and don’t like its use. I prefer the term “differing abilities” and will use it throughout the rest of my presentation.”* It is noteworthy that Mr. Salzano is trained in finance not human services but yet demonstrates some of the best values in facilitating the gainful employment of individuals with differing abilities.

Expectations are usually developed out of what is known. The work in sheltered employment settings is usually “cast off” work that the typical employee would find boring and difficult to routinely perform. It is usually not the work of typical businesses and many times involves skills that are not prevalent in individuals with developmental disabilities such as fine motor skills.

Thus, it is often assumed that individuals who are not highly productive in sheltered employment cannot work in real jobs, even though it has been repeatedly demonstrated that real jobs can be carved to meet the individual's capabilities.

Further, people in sheltered employment settings are trained for positions (doing this cast off work) that generally do not exist in the community.

2) Lack of Knowledge of the Possible, and Lack of Individual Advocacy Networking with Individuals with Developmental Disabilities.

A corollary to others' expectations of individuals with developmental disabilities is often the lack of knowledge by the person who has a developmental disability of the "possible and being able to speak for what one wants". Life goals and outcomes have usually been determined by others. As we see, historically individuals have experienced "fostered dependence" by stakeholders, again often with good intentions but with low expectations.

Even with the advent of self-determination and person centered planning twenty or more years ago, most individuals with developmental disabilities are still sequestered in congregate care residentially, in employment and in activities.

When individuals agree to person-centered plans, are they able to really give informed decisions where alternatives are clearly known and able to be fully considered? Have they been trained in advocating for what they really want and have they been encouraged to demonstrate these skills or has dependency become so much of a standard that the "possible" becomes an unfulfilled and unspoken dream? Is networking with individuals with developmental disabilities who have acquired real jobs being facilitated for those who want to be employed but have doubts, fears, concerns, and issues?

These barriers can be overcome through effective facilitation of the peer supports and advocacy by key stakeholders including adult service providers and families.

3) Segregation is Easier Than Integration and Inclusion.

Many well-intentioned stakeholders have done segregation of individuals with developmental disabilities as their practice for generations. Families have been told to institutionalize their sons and daughters for the “best of care” and their own personal well-being and that of their child.

Forty or more years ago, large state operated institutions and segregated educational facilities were the rule. While this segregation has been largely replaced with community care, it remains pre-imminent that the majority of care remains provider-controlled in group homes, intermediate care facilities, and sheltered employment in workshops or large enclaves.

Preferred outcomes enjoyed by adult mainstream society are those where one is appropriately educated and trained for employment, acquires a desired job and is economically self-sufficient, is able to live in a residence of one's choosing and self-controlled according to one's means, has friends and is included in community life. A small minority of individuals with developmental disabilities achieves this standard of typical adult life.

A major reason for this has been historic practice, continued (and excessive) professional control of services and supports, its financial rewards for providers, and the ease of congregate care as compared to the challenges of developing individualized supports leading to integration and full inclusion in employment, residential supports and community activities. Each of these is supported by the federal and state funding structures, which are easier to maintain on a group/facility basis than on an individual need basis.

4) Funding and Financial Incentives/Disincentives.

Tremendous resources are usually dedicated by state government to state operated and private institutional care because of a) the need for serving individuals with the most challenging conditions; b) historic practice; c) the state's “obligation”; d) the high cost of professional care; and e) the lack of leadership to promote innovative practices and new ways of doing business.

This is done despite the clear evidence of the failure of traditional approaches to reach desired outcomes and the success of newer approaches, like supported employment and supported living to attain substantial improvements in the quality of life and to decrease costs over time. A major statistic is how a few people can get a majority of the state and federal resources within these institutional environments.

Even within “community support systems” strong incentives remain for congregate residential care and sheltered employment with few resources being dedicated to residential, activity, and employment supports controlled by the individual. Unwittingly, financial incentives typically foster segregation.

If a provider can get \$13 per hour for one-on-one integrated job supports but can get \$88-104 for an eight-person enclave with a single job support employee, it becomes economically feasible and prudent to promote the latter and not the former. Similar examples can be found in residential and day/developmental training, as well as transportation. It is hard to break past practices without changes in policies that incentivize funding or cause a break from the past segregation practices. Historically, funding policies have caused providers to develop services and supports that respond to the funding direction. Funding can promote segregation or integration and it depends on what direction policy makers want to prioritize and pursue.

A lack of prioritization of state and federal matching resources toward community inclusive and integrative employment and residential supports with related non-work activities creates a powerful barrier for the employment and inclusion of individuals with developmental disabilities.

States that are high performing in supported employment, meaning they have a higher than average number of individuals with developmental disabilities who have acquired and are gainfully employed, have prioritized and directed resources for these employment and inclusive outcomes.

There are also barriers when financial allocation systems allocate resources to individuals on considerations other than assessed needs. Such archaic systems provide too many scarce resources to some and not enough resources to others. High performing states on supported employment have found ways to allocate resources in accordance with identified needs.

Another fiscal issue occurs when individuals with developmental disabilities live in congregate residential settings and have their income seized by providers to meet state requirements for “share of care” payments (pay for room and board expenses, etc.). When all but \$50 a month remains for the individual to spend as they want, it is hard to be (or stay) motivated to become (or stay) gainfully employed. Individuals must be given opportunities to make these room and board decisions.

5) Lack of State and Local Collaboration.

Policies and funding for services and supports for individuals with developmental disabilities are typically handled by multiple state agencies including education, developmental disabilities, mental health, Medicaid, vocational rehabilitation, youth services and corrections, planning councils for developmental disabilities, governor's agency for people with disabilities, commerce/economic development and housing. It is highly dysfunctional for these agencies to maintain a silo way of doing business, each unto its own, with all of the other barriers against including individuals with developmental disabilities in community life.

Unfortunately, concerted, collaborative action is often the exception as opposed to the rule, which does not lend itself to seamless transitions and plans of actions reducing duplicative use of resources to meet the same outcome. High performing states in supported employment have highly collaborative relationships.

The lack of collaboration at the local level is equally perilous for the gainful employment of individuals with developmental disabilities. The local provider and agency counterparts of the state agencies who are functionally islands unto themselves perpetuate dysfunction in the same way as the state agencies engaged in silo implementation.

On the contrary, high performing states in supported employment have local agencies that enjoy collaborative relationships with one another and it creates great rewards for individuals with developmental disabilities advancing inclusion and integration.

6) Provider Workforce Limitations.

Increasingly, human service, health and educational agencies are becoming taxed to find qualified employees due to worker shortages caused by a declining workforce and wages that are typically below the prevailing wage for similarly educated people in other industries. Residential and employment supports vested in integration and inclusion may spread the paid and available workforce thin and may contribute to a return to segregated practices for expediency and necessity.

Further, the skills needed to deliver integrated services (i.e., job coaches) are typically higher than those required of staff providing services in segregated environments.

High performing states in inclusive employment supports have included natural supports from family, friends, advocates, and employers to reduce the need for an expanded workforce that cannot be effectively or efficiently obtained.

7) Maintaining Status Quo; Change Avoidance.

Decision makers, policy implementers and other stakeholders including individuals with developmental disabilities are often comfortable and content with the status quo, which requires less effort, and therefore seek to avoid change.

With change comes a certain amount of confusion, dysfunction, and uncertainty leading to fear. Current environments offer stakeholders largely known circumstances, conditions, risks, and relationships. Change will upset all four of these and it is natural even for innovators to have fear of undertaking new ventures because the status quo is so familiar.

There are many risks that can be assumed in undertaking change within the developmental disabilities system toward integration and inclusion for individuals so served. Among the most important to people who have developmental disabilities are the loss of valued social relationships and loss of important governmental benefits due to employment.

There might be assumption of higher risk to health and safety in the new environment. It may upset current routines and practices for caregivers. There may be loss of safety nets that protect one when one fails to reach desired outcomes.

There are more than likely a variety of new circumstances like traversing public or alternative transportation systems, developing relationships with new supervisors and employees, potential for negative reactions, and the inherent anxiety that must be addressed. All of these factors induce fear and change avoidance.

For other stakeholders, these factors may be important as well. Provider staff transition from coming to work at one site (such as a sheltered workshop) to now

traveling to multiple sites and dealing with a far broader group of people in a less controlled/controlling manner, namely employers and employees of businesses. It is more difficult to assist ten individuals to acquire real jobs than it is to assemble piece-rate enclave work or work in sheltered environments.

It is also far more difficult to logistically oversee forty individualized residential supports for eighty individuals than it would be to have eight ten-bed group homes. Developmental training for one hundred individuals in a large facility is far easier, and at least initially less expensive, to implement than would be implementation of individually chosen activities for each of one hundred individuals in the community with integration and inclusion.

8) The Lack of Clear Definitions and Standards.

When public policies and desired ways of doing business are unclear or left open to what the implementer believes to be the desired way, differences in implementation occur. Well-intentioned stakeholders can “transform” an institution serving hundreds of individuals with developmental disabilities to a community inclusive environment, just by saying it’s so (despite the evidence to the contrary).

Stakeholders can regard an enclave for eight people, doing piece-work, paid by a provider agency at sub-minimum wage, as integrated supported employment because it happens to be within an industrial (non-disability) setting.

Lack of clearly defined policies and standards in terms of what truly constitutes integration and inclusion in residential and employment supports as well as related community activities can lead to ineffective, misinterpreted and unintended outcomes.

9) Stakeholder Control.

Many stakeholders exercise their status through control, decision-making, serving and placing. These behaviors foster dependency of the individual with developmental disabilities.

High performing states and agencies in supported employment and community inclusion have changed their mindset through being facilitators, supporters, and community integrators assisting individuals to acquire their own employment and selecting job supports as needed, facilitating residential supports and serving as integrators in inclusive community life.

Traditional stakeholder control needs to be replaced by stakeholder facilitation while actual control of the services and supports is transferred to people who have developmental disabilities.

10) Fears and Uncertainty.

There are fears of individuals with developmental disabilities and their families/representatives of:

- a) loss of significant federal and state benefits;***
- b) loss of a safe haven within a facility;***
- c) loss of friendships and long time social relationships;***
- d) fear and uncertainty of the future and changing relationships; and***
- e) fear of taking risks.***

Some of these same fears may be evident in professional staff from facility-based programs now having to work in scattered sites and develop relationships with employers and employees in a totally different milieu.

In Chapter III, the perceptions of Illinois stakeholders including 123 individuals with developmental disabilities and 46 family members on advancing supported employment are identified and there is a more complete listing of the fears and concerns. This chapter follows next.

Summary comments Chapter II. Barriers to Employment for Individuals with Developmental Disabilities

These ten major barriers must be addressed as a major part of any systems change that advances supported employment. Many of the barriers can be addressed through comprehensive and effective public policies.

Among these are funding and financial incentives/disincentives, lack of state and local collaboration, maintaining status quo with change avoidance, provider workforce limitations and the lack of clear definitions and standards. Other states have adopted public policy strategies to overcome these barriers.

The strategies will be identified within promising policies and practices in Chapters V and VI.

Fears and uncertainty as well can oftentimes be addressed by policies and practices that address the fears such as loss of benefits or one's safety net. Effective advocacy and communication of what has been accomplished when individuals gain employment can go far to eliminate low expectations, change avoidance, fears, lack of knowledge of the possible by individuals with developmental disabilities...

...as identified in Chapter VII. Advocating for and Advancing Supported Employment and Related Services.

Staff training and vesting individuals with developmental disabilities control over their plans of support and funding can go long toward shifting away from stakeholder control to individual control. High performing states and local agencies on advancing supported employment have been able to routinely address these barriers evidenced by the numbers of individuals who have acquired employment along with the effectiveness of these programs over the long-term. Promising policies and practices in later chapters, V, VI and VII show how these entities successfully met these challenges.

Chapter III. The Perceptions of Illinois Stakeholders* on Advancing Supported Employment (*including 123 Individuals with Developmental Disabilities and 46 Family Members)

Beginning in September of 2007 and ending in early November, 15 focus group sessions were held across the state to address issues related to community employment. 240 people attended these sessions with an average attendance of 16 people. Of these 240, people who have developmental disabilities numbered 123. 46 family members attended, as did 44 people who are paid to provide some type of support to people who have developmental disabilities. 23 people that attended identified themselves as administrators and 30 additional people fell into a category other than those above. It should be noted that the above sub-total numbers add up to more than 240 because some people identified themselves as having multiple roles (i.e., paid staff at an agency and a sibling of a person who has a disability).

The Sessions were held at the dates and locations identified in Appendix A.

Questions were asked to focus dialogue and the responses for each of these questions are below. A summary of the topics, questions and responses is located in Appendix B.

Further, four intensive interviews were also completed. As with the focus groups, these interviews were held in various locations across the state attempting to be representative of the population distribution across Illinois as well as to obtain information from individuals who represented each of the key stakeholder groups. In total, seven individuals were interviewed. The distribution representation by stakeholder group is as follows:

1. Consumer currently minimally employed at workshop (formerly worked in the community).
2. Consumer currently not involved in any work activities (community or sheltered)
3. Family members (3)
4. Paid support person (Direct support)
5. Administrator

Again, a narrative summary of critical issues from the intensive interviews follows this section.

A. Focus Group Critical Issues Narrative Summary

Perhaps the most interesting outcome is the consistency of response across settings throughout Illinois. This was true regardless of whether the focus group was held in a rural or urban area. The data summary report (separate sheet) prepared for this Systems Analysis shows the frequency that each topic was identified across the Focus Group meetings. There was also not any significant difference in interest in community employment based upon the attendees at the

focus groups. Admittedly, these meetings may have attracted those who are more interested in community employment than sheltered services thus, skewing any of the results. Most of the sessions that had more than just a few participants (>4) typically had one person who could be identified as skeptical of the ability of the community to meet the needs of their family member (or themselves) and thus would have been seen as pro-sheltered services. However, the vast majority of the attendees (>93%) would be identified as being pro-community employment.

Another interesting factor is that the comments of family members, friends, advocates, and those who are paid to support individuals with disabilities (regardless of their role), did not vary in any significant manner from the comments of people who have developmental disabilities. There was also a noticeable absence of differentiation across age differences as well as gender.

We had expected that older parents would be more supportive of sheltered employment. While virtually every one of the 12 or 13 “pro-sheltered service” participants would be considered in the oldest group of participants, there were a far greater number of people of similar age that were very positive about community employment.

One interesting piece of data that emerged was that without any prior “education” about Customized Employment, virtually every focus group identified the key elements of customized employment as something that would be necessary or would be good to have in place to assist with success in community employment (using their own words of course).

Likewise the themes regarding employment goals and desires as well as their concerns and fears about community employment were consistent across virtually every focus group. All comments were clustered as to the general theme of the response so that we could track the frequency with which comments with similar themes were brought up by the participants.

Finally, in general, people of all classifications were weary of the promises for supported employment because of the lack of stable and consistent support for it. In short, they were tired of waiting for the manifestation of the promise that would help them break out of the “sheltered rut” as one parent put it. The frustration of people who had been employed in the community but lost their jobs for any reason who could then not get help to be re-employed in the community was also quite significant.

A summary of the questions and responses is included in Appendix A.

1. What are your employment goals?

The goals identified by the participants at the focus groups are virtually identical to the questions one might anticipate if they were to ask the same question of members of the general population. The first cluster of answers focused on the conditions of employment and issues associated with continued employment.

Specifically, they wanted to get the same benefits that all other employees got.

This was especially important because of the concern with a loss of public benefits when they began earning a wage (the single largest concern of all expressed).

They also wanted to be paid fairly for the work they did, and to have some degree of stability in their employment (not getting fired or laid off with the first mistake or being the first to be let go when finances got tight for the employer).

Many people expressed a desire to have a career and not just a job.

Specifically this included the possibility of being promoted and getting better jobs, increased pay, etc. The hope was that they would eventually no longer be given worst schedules.

Another major desire had to do with having a meaningful job. This was expressed in many ways, including: Having a job that I like; meaningful work, and a job that uses my skills. Clustered with this section was “Make my own work choices” which people explained that...

...if they were really given choices about jobs they would pick different jobs than what has been offered to them in the past.

The social aspects of work showed up in two different ways. One was the emphasis on how they would be treated by co-workers and supervisors.

The goal of being “treated well by co-workers and boss” or “be respected” was stated in virtually every situation.

The bottom line on this section was the goal of “no prejudice’ in the workplace where “people treat me as normal.”

The second way that the social aspect of work was expressed was to be liked (especially by co-workers) and to make new friends.

They also wanted to be able to like their co-workers and not be afraid of them. Again, because of its importance relative to the concept of “friendship” and the proximity of mention on several occasions, the phrase “Not be known as a person with a disability - but a coworker” was included in this cluster as well.

Working near home was important for many people for many different reasons. Transportation (time, cost, location, availability, safety, scheduling) and feeling comfortable in the place (town/city/neighborhood) and knowing people there were among the most frequently identified reasons for this item.

As one person put it, “If I work near home and I get to be friends with someone I work with then maybe it will be easier to see them when I am not at work.”

The single most frequently stated and strongest embraced goal was to “make better money”.

A remarkable number of people pointed out that they could never be independent of parents/staff until they were able to “meet my financial obligations”.

The next goal of being “engaged in the community” or “valued by the community” fit closely with the goal of working near home but it was more about how people would think about them when they were NOT at work that was more of the emphasis here. The thought being if a fellow member of the community saw the person who has a disability working at the drugstore during the week they might talk to them when they saw them at Wal-Mart on the weekend and that might grow into something else more substantive.

A clear goal of virtually every individual who has a disability and their family members was “individualized supports for as long as I need them”.

Specifically stated on several occasions was the concept of “career support” - not just job support. The goals also included finding employers that customize work and support agency creativity to facilitate workplace success.

Many people expressed the desire to have opportunities to explore/try out jobs so that they could make informed decisions. Another frequent topic of concern was that “everyone who wants a job can get one” - even people with major challenges.

Finally, and because of both the frequency and intensity of the conversation surrounding transportation problems, it is identified here as a distinct item.

Virtually every setting had concerns about transportation.

In the rural areas it was the lack of access more than anything.

In the urban settings it was the unreliable nature of door-to-door service, the cost of transportation, and fears surrounding transportation such as safety, getting lost, missing the exit or connections, etc.

2. Why might someone want community employment?

The answers to this question corresponded directly to the answers received to the first question.

The belief that pay and benefits would be better in the community was a major factor for participants at literally all settings. A surprising number of people were specifically interested in retirement benefits so that they did not have to attend the workshop when they are old.

Clearly the value of “new experiences/opportunities” was important to the vast majority of the focus group participants who had disabilities but it was also frequently mentioned by others participating as well. Fighting boredom was a significant theme associated with this desire. As was indicated above, the social aspects continued to be important as people talked of their desire to “meet new people” and to build relationships with them. The sense of “feeling normal” again appears as does the concept of being included/valued.

Similarly, productivity, meaningful work, and not being bored during the day were identified as important as was the desire for better outcomes, all of which the participants felt could be more effectively achieved in community workplaces.

There was also a strong advocacy angle to wanting to work in the community in many of the sessions. “Breaking down stigma” by helping others learn about people with disabilities” was a frequent reason given for wanting to be in the community as was the ability to increase independence/self-determination.

People expressed the belief that they could “be near home” if they worked in the community and several noticed “help wanted signs that staff would never see ‘cause they don’t live near me”.

The vast majority of participants either said, or agreed when another participant said, that working in the community would “help my self-respect” (or, self-esteem).

3. Why might someone not want community employment?

Benefit/income loss was one theme that permeated all of the topics and answers to questions during the focus groups. Many people with disabilities are acutely aware that their family is only surviving because of their SSI check.

Many are afraid of what will happen if they lose their public benefits and then later lose their jobs.

Several reported that they did not think they would survive that experience.

The concerns about not being able to manage discrimination, prejudice, mean people was present in every situation.

People clearly are also afraid of being taken advantage of and picked on or scapegoated. They see tokenism, unfair treatment in the workplace (such as getting the worst schedules), artificially high expectations for people with disabilities, and being the first person to be laid off/fired or being passed over for promotions as examples of this concern. Said in many ways by many people: “We don’t know whom to trust.”

Again, transportation issues and the associated problems with schedules arise as an issue, this time as a major impediment to employment.

“Only being offered jobs I don’t like” was a frequent reason why people refused, or might refuse, community employment.

Another factor that was mentioned in virtually every setting was the fact that some people are familiar/comfortable with the current workshop setting. As more than one person said, “I like my current routines”.

While none of the participants would admit to believing the following statements themselves, it was presented numerous times as a reason that someone might not want community work: Work is too hard. Some don't want to make money/be successful. Finally, in a couple of locations...

...it was expressed that some (especially staff and parents) are afraid that without workshops some people who have disabilities will sit at home and do nothing - i.e., some people can't work in the community with the current support system.

"Liability" was raised in a number of settings. People were afraid that they would do something that might cause a major problem, especially causing their family a significant expense that they would have to pay because of the mistake. Being "afraid to fail" or make mistakes was a common theme. An interesting point was made by some who...

... "don't want to be dependent in public" because it makes them feel bad (not respected by others) means that they will reject job coaches out of potential embarrassment.

One woman clearly expressed, "I am scared of getting confused" and virtually all of the people who had disabilities in the room (and there were many) agreed.

This category also relates directly to what people want in their jobs (stability and fair treatment). Thus, job loss when economy goes bad or subsidies end, getting stuck doing the same job forever, needing to keep a bad job because there are no other choices/no more help, and no promotions are all indicative of this.

Inadequate support was one of the most common reasons given as to why people would refuse to work in the community.

The real fear that that they will fail in the community without sufficient support and they have heard from others (real or imagined) tales that the job coaches don't work long enough with you for you to actually know how to do the job well enough to not make major mistakes and get fired.

Health concerns was the final category and, again, were often mentioned as a major reason why the focus group members thought someone with a disability might refuse work in the community.

Frequently expressed were such things as seizures, fatigue, heart problems, asthma/breathing problems and the like.

4. What are your fears about community employment?

The themes expressed above in the other categories covered thus far are repeated as “fears”. They include:

- Rejection/No friends. Prejudice. Mean people. Unfair treatment. People that do not understand. Getting feelings hurt.
- Learning too slowly. Too many expectations. Not being able to learn the new job. Being Embarrassed. Don't know how to handle unexpected situations. Failure/causing problems. Being told I am not ready for work. Getting into trouble. Being confused/nervous. Being too tired. Low self-esteem. Work being too hard. I won't make a good impression. People won't understand what I am trying to say.
- No reasonable accommodations/bad employer
- Not having adequate support. Poor job coaches, poor continuity. No long-term support commitment. Staff turnover means, “I have too many job coaches and they have to keep learning how to help me”. I can't get the help I need.
- New job, new people, new things to do, new expectations.
- Being overwhelmed. Not knowing what to do in an emergency. The unknown.
- Getting hurt.
- Losing my job. What do I do if it doesn't work out? Loss of benefits.

5. What needs to be in place to relieve these fears and help you do a good job in the community?

The participants in the focus groups were never at a loss for suggestions of things that were needed, and were at times quite adamant about what needed to be present to address the question above.

The first, and most frequently mentioned item for this category, is support and effective coordination of the supports.

This includes providing the right intensity of supports, funding for follow-along services on a long term basis, better transition from school to work and from workshop to work, and better training - especially on the job training.

The following suggestions were offered in at least 5 different locations: On demand supports, self-advocacy supports, and more 1:1 work from pre-employment through stable employment.

There was also a concern that the employer receives the supports they needed to be effective in working with employees who have disabilities, regardless of the disability.

Many participants also saw co-worker/employer sensitivity training as being critical, along with business training on how to make reasonable job accommodations.

There was a great deal of concern expressed that people who have disabilities are not really being taught the skills they need to be successful in the workplace.

There are a multitude of ways to teach these skills and many suggested skills training where the skills are actually required (as opposed to training social skills at the workshop or in a classroom setting) and job exploration. Job development, social skills training, job shadowing, work trials, listening skills, problem solving and coping skills were also mentioned as being important. It was frequently expressed that providers needed to teach more important skills, including but not limited to self-advocacy and how to confront prejudice effectively. Finally there was a significant amount of concern about the problems with the school to work interface. Bottom line on that issue: "Better training at the school level and seamless transition to adulthood and employment."

Again the social needs associated with work arise with the request for funding for social/peer networking support and events. Using many different words the message was the same: We must focus on social aspects of work. There was a great deal of concern expressed about resolving the problems of funding and confused public policy. As one person said: "We need funding that makes sense."

**"Policies that make sense are critical.
We must get rid of stupid state rules and disincentives."**

Funding is seen as critical for job coaching staff, which must be increased (in the participant's opinions) to decrease turnover and be able to offer more 1:1 support.

One policy change recommended was to shift DRS focus from short term "quantity of closed cases" to quality of employment to include length of employment.

Multiple concerns regarding DRS needing to follow all the same rules with consistent interpretation (even the counselors) were heard. Finally, many people expressed concerns that we need more incentives for employers, providers and agencies that do a good job.

Quite a few participants expressed a desire to see post-secondary education be offered to people who have cognitive/intellectual/developmental disabilities. Further, reasonable adaptations are perceived as needed to enable these students to successfully attend the schools (especially community colleges). Some participants believed that remedial education should be paid for at the post-secondary level since the public school system failed to educate them appropriately. There were suggestions that some individuals could benefit from e-learning opportunities. Job carving was a clear concept frequently heard.

Many suggested that the state develop insurance programs to remove employer concerns associated with both health benefits and liability. Quite a few participants recommended that parent-to-parent support and education should be facilitated to help parents get more motivated to help their child to achieve more than sheltered services.

The following concepts were mentioned several times during the focus groups as ideas that should be considered to support people in their employment, especially those who have more significant disabilities:

- **Micro-enterprise support – Helping people become self-employed by supporting the start-up of new micro-businesses via an “incubator” model.**
- **Adaptive technology – If people had easy access to adaptive technology, many felt that the numbers of those who could work successfully in the community would increase substantially.**
- **Universal supports – This concept involves helping people attain supports that all people might be able to use to help them attain or maintain employment, or expand their employment opportunities.**

Participants identified good public relations with employers frequently.

The belief is that employers would be more willing to hire people with developmental disabilities if they understood the capabilities that people with disabilities have, what supports were available, they wouldn't lose money by employing people with disabilities, are at no greater liability risk if they hire people with disabilities, etc.

Benefit rule changes and benefit coordination, while directly related to “funding and policy changes” above, required separate attention because of the frequency that it was mentioned and because of the controversy that surrounds this issue.

There is widespread confusion among consumers, their family members, and staff as to what can be done to coordinate benefits and minimize the impact to the loss of public benefits.

As mentioned earlier, transportation was an issue wherever we went. The plea for better transportation, especially safe, inexpensive, and reliable door-to-door transportation was universal.

6. Any other comments or questions?

At the end of each focus group session all participants were asked if they had anything else that they felt needed to be said to communicate their concerns, ideas, etc. to the readers of this Blueprint.

Following are the comments that are not included elsewhere in the narratives of the focus group issues or which are specifically illustrative of key concepts above. The entire list of topics is included in the Appendix A.

- There is a major concern about what people who only work part-time will do since many workshops do not want to accommodate part-time employees.
- The state creates many barriers (such as residential funding, program fees, etc.) Residential placement means you can't work full time or you will lose Medicaid and/or placement
- Enclaves may be a "stepping stone" to more independent work (This is a very controversial topic. Every time it was raised many responded that enclaves as they have historically been done are not a positive step forward). Several people discussed “creative enclaves” but could not describe how they would be different from traditional enclaves.
- There is a need for concerted work on the front end to help people learn how to *be* at work.
- Ticket-to-Work has too many hassles and doesn't work at all for people who can only get, or tolerate, part-time work.
- There is a program for all people who work in IL to be able to get health insurance but very few people know about it. (Health Benefits for Workers with Disabilities)

- **There is a need to create alliances that are stronger than the institutions and workshops. (It is the perception that the institutions take the lion's share of the funding which is why there is no funding available for community employment and that traditional workshops have a vested interest in thwarting community employment.)**

- There is a need to do community public education/PR with the belief that if the community was more supportive of people who have DD then employers would not be afraid of losing customers, co-workers would be nicer, customers would not say mean things, etc.
- The adult provider agencies must be willing to support all people to get employment and not just people that are easy to support.
- The adult provider agencies must develop support for people who have multiple part-time jobs at multiple locations.
- People with disabilities need computer skills - to apply online, e-learning, job duties.
- We must improve quality improvement and assurances monitoring to assure that providers are doing what they are supposed to be doing.
- We should prosecute discrimination when we know it occurs and employers would be less likely to discriminate against people who have DD in hiring.
- We need public policy changes to expect and fund better outcomes
- Residential and employment issues/problems go hand-in-hand.

The final statement of this section captures an important concept that summarizes was heard throughout the focus group series:

“Once people experience a community job that becomes the “real job” standard and anything else is not a real job and therefore not satisfying. Supported Employment has totally changed their lives for the better...they develop self-esteem.”

B. Intensive Interviews Critical Issues Narrative Summary

The topics that resulted from the more intensive interviews follow. Again, none of the comments were significantly different from the issues raised in the focus group sessions, however, because of the more intimate setting, people felt freer to comment about how they personally felt about community employment and what they felt the problems and solutions were for their needs.

It is important to note that a common theme throughout these interviews was that people, regardless of their role, generally did not like day programs/sheltered employment but they were afraid that if they complained they may wind up with nothing or, at the least, be labeled a “trouble maker”.

The general consensus was that the traditional day Programs had poor outcomes, were boring, caused almost as many problems for some people as they solved for others, and that there was “no way out”.

The feeling was evident that they (or their son or daughter) would not be seriously considered for employment in the community due to some barrier (health, transportation, severity of the disabling condition) and that this was unfair.

People paid to support individuals with disabilities felt that providers needed real support to be able to make the transition from a primary emphasis on traditional facility based day services to community based employment focused services. Among the supports they felt they needed were rates that could support the service (that were stable/reliable so that their investments in effort and money would not be “here one week and gone the next”), technical assistance, training (especially for job coaches), and “transition” funding.

They felt that the grants must be realistic with clear outcomes and significant incentives for follow-along/long-term support, innovations in business efforts, and assistance establishing micro-enterprises especially to support people who have more severe disabilities.

It was the general perception that providers do not feel that they have the luxury to really develop the relationships with businesses, especially smaller businesses, to find out what their needs are and how they might be able to collaborate to meet those needs while providing employment for people who have developmental disabilities.

The need for safe and reliable transportation, benefit protection, job exploration programs, funding for peer supports and social events were also expressed as critical elements needed for community employment success. Parents and siblings especially fear the loss of benefits and the friends of the person with a disability who will remain at the day program.

There is also a strong desire to be assured that there is reasonable “protection” for the person who is engaged in community employment from teasing, being hurt/abused, or being taken advantage of.

There was a distinct concern about what to do for people who have developmental disabilities who lose jobs.

Further, there was a concern that no one talks seriously about helping the people who have more significant disabilities. This is made more obvious because of the perceived emphasis by DORS to only work with the people who are identified as “highest functioning” and then, only with short-term support.

The general consensus was that job coach case loads must decrease so that they can “really pay attention” to the needs of the person they are working with – with the assumption that the vast majority of people will need one-to-one support for at least their initial phases of community employment.

Further, to stem turnover and increase the effectiveness of the job coaches (and thus the people who have disabilities that they are working with) it is critical to increase pay rates to a level that will enable them to only work one job (the job coaching job).

Another item related to funding was the need to fund job developers so that they can really work with the employers to determine their needs, customize employment, etc.

Many of the social needs expressed in the focus groups were also repeated in the intensive interviews. They also made it clear that they wanted to work on goals that mattered to them, to be desegregated, and to have legitimately increased options and opportunities.

Failing in social situations (because they don’t know how to interact, poor social skills, don’t know how to respond to prejudice, etc.) and in the workplace (due to task issues) were over-riding themes. The reality that it is hard to learn new skills and to keep up with current employees (confusion, task complexity/multi-tasking, pace, stamina/energy) etc. was seen as a barrier and clearly discouraged some people who have disabilities from attempting community employment.

One interesting comment was that the “staff at the day training center understand people who have disabilities but they don’t understand how to help people with disabilities work in the community”. The converse was also believed to be true in that employers know how to work in the community but do not understand people who have disabilities. Several times participants mentioned the need for job carving (customization) and job exploration opportunities as a solution for this problem.

One individual who has a disability concluded his interview with the following statement:

"I want evening/night shift but staff don't like to help on those shifts, only morning shifts.

I want to be happy, get a job doing what I can and enjoy my life in peace and happiness.

*Maybe that is too much to ask...
Give me a chance to really make a living. Please!"*

Summary Comments Chapter III. The Perceptions of Illinois Stakeholders including 123 Individuals with Developmental Disabilities and 46 Family Members on Advancing Supported Employment

These focus group responses were consistent with the barriers to employment identified in Chapter II. The vast majority of individuals with developmental disabilities who were interviewed want a job but there are many highlighted fears, concerns and issues that need to be addressed. Many of these can be reasonably addressed in policy adoption such as funding for supported employment, increases in wages and benefits for support staff, maintenance of benefits when working, effective collaboration, and seamless transition from school to work and workshop to work. Other issues on implementation of supported employment can be addressed through effective training of both the individual before and after acquisition of employment.

Staff training in delivering effective job development and job supports in a facilitating manner can go far to address individual concerns on how they are treated on the job. Employers can gain increased confidence in the capabilities of individuals with developmental disabilities to effectively perform required duties through successful worker outcomes and experience. Advocacy and support groups can go far to address individual fears, concerns and issues through support of peers who have overcome these challenges. With addressing individual fears, concerns, and issues, individuals with developmental disabilities can thrive as employees of real businesses, with real wages, and real work. Chapters VII and VIII that follow identify some important ways other states and agencies have effectively addressed these concerns and broadly implemented supported employment in rural, suburban and urban areas of the country.

Chapter IV. Effective Systems Change Advancing Supported Employment: Managing at the Speed of Change: How Resilient Managers Succeed and Prosper Where Others Fail

We live in a tumultuous time of rapid change: modes of communication, advanced media technology, growth of information, fragile ecosystems, changes in economic and political forces, advances in health care and related ethical issues, faster modes of transportation, redefinition of male and female, ethnic, and racial roles reshaping our society, global terrorism.

Effective leaders are needed as agents of change who are capable of reframing the thinking of those whom they guide, enabling them to see that significant changes to effectively manage changing expectations and realities are not only imperative but also achievable. They must determine what needs to be done differently and how to execute those decisions to ensure the greatest possibility for success. ²

Prerequisites for Major Organizational Change...involve pain whereby a critical mass of information justifies breaking from the status quo. The following mass of information involving today's developmental disability systems and its relationship to segregated versus integrated/inclusive services is instructive of such pain: ³

Such pain involves dissatisfaction with the status quo and a desire for a change to alleviate the pain. Examples of such pain may be as follows:

- A) The majority of young adults with developmental disabilities do not want segregation residentially, in employment, or related activities after experiencing inclusion in the public schools. **Pain: To be placed in Sheltered employment or group homes; not to have meaningful work; to not have a seamless transition from school to work.**
- B) Contract work typically done in segregated facilities is increasingly being outsourced (often offshore) or has become obsolete. **Pain: There is no meaningful work within sheltered settings and considerable downtime results creating boredom and a less than effective existence.**
- C) Ethical issues of paying individuals with disabilities sub-minimum wages when real wages, in real jobs, and with real employers can be acquired within the mainstream workforce. **Pain: Doing piece rate work which most people**

² Conner, Daryl R. "Managing at the Speed of Change: How Resilient Managers Prosper Where Others Fail" Random House, New York, 2006, pages 3-4.

³ Conner, page 99

would find boring or difficult (fine motor skills) and receiving miniscule payment for the effort.

- D) Shortage of labor in key positions in industry and businesses that can be acquired and capably done by individuals with disabilities. ***Pain: Knowing that jobs exist that I as an individual with a developmental disability could acquire, effectively perform and receive a living wage and benefits and be productive with an enhanced life but the opportunity is not advanced because of policies that do not set this as a priority way to do business.***
- E) Twenty plus years of values training on self-determination and person centered planning creates changing expectations of what can be achieved by the individual who has DD. ***Pain: Not being able to realize one's dreams for a job, a home of one's own and an enhanced life in the community.***
- F) Adults successfully integrated within the community with persons who are not disabled, through innovations in employment and residential services and supports have been demonstrated as doable practice. ***Pain: Public policy and politics keeps the majority of individuals with developmental disabilities in segregated, congregate care even though some states have demonstrated the effective and efficient implementation of community integration and inclusion.***

Remedies for such pain are desirable actions that will solve the problem or take advantage of the opportunity afforded by the current situation ⁴

Such remedies include:

Desirable actions

- A) Establishing an Employment Vision, Mission, Values and Beliefs that are put into action and are not just words and includes each of the following principles below;
- B) Employment is difficult: state and local agencies must collaborate effectively to manage scarce resources and duality of effort to maximize real employment opportunities for individuals with developmental disabilities;
- C) Establishing key leadership with distinct responsibilities, authority, and accountability for clear employment change objectives, from the top down and with a broad range of stakeholders.
- D) Training for all stakeholders in the new and possible, as well as the changing expectations about individuals with developmental disabilities and the agencies that support them – To change the focus from “can’t” to “can”;

⁴ Conner, page 99

- E) Providing financial incentives for employment goals and removing incentives to maintain segregation;
- F) Ensuring that employment supports are properly funded to address the true costs of service and incentives for conversion and achieving outcomes, including social supports, transportation needs, etc. and do not maintain the status quo. This funding shall also address person specific funding needs as opposed to generic service funding;
- G) Change staff roles from “*placers and controllers*” to “*facilitators and community integrators*” whose responsibilities distinctly include employment opportunity development; and
- H) Clearly define what constitutes supported employment so outcomes and expectations are fully realized.

Pain and discomfort with the status quo is a necessary condition for change to occur. As demonstrated above when the pain threshold becomes intolerable, people seek remedies for the pain through desirable actions and changed ways of doing business. In high performing states and agencies advancing supported employment, this elimination of pain through desirable actions has changed the system and the way of doing business away from congregate care to integrated, inclusionary practices yielding enhanced lives.

A systems transformation approach to our traditional ways of doing business within a public policy arena revolves fully around people and their commitment to the above. People that hold the role of being decision makers must decide on policies, practices, involvement, funding, and participation. The following are the roles within this arena that people perform⁵

Sponsors: A sponsor is the individual or group who has the power to sanction or legitimize change. Sponsors consider the potential changes based on strengths, weaknesses, opportunities, and threats, decide what will happen, communicate the new priorities, and provide necessary reinforcement to ensure success, and to create the environment that enables change to be made on time and within budget.

In states transforming to integrated, inclusive employment, there is enthused, coordinated, charismatic leadership by state and local agency officials sharing a common vision, mission, values and beliefs and unwaveringly focused on clear outcomes that are not compromised.

Illinois sponsors would include the Governor, legislators, Divisions of Developmental Disabilities, Mental Health, and Rehabilitation Services, Medicaid, State Board of Education, and the Department of Commerce and Economic Opportunity. Local agencies would include independent service and support

⁵ Conner, pages 107-109.

administration, adult services providers, local public schools, mental health agencies, one stop employment centers, disabilityworks, and employers.

When these sponsors are working together with coordination and affiliations including innovative ways of doing business they will be able to develop effective employment services (real jobs, with real wages, with real employers, and full inclusion in the mainstream workforce) for individuals with developmental disabilities. Sponsors must make many changes themselves, often in the way they think about the work they do, and support the agents in making the necessary changes.

Agents: An agent is the individual or group who is responsible for implementing the changes designed by the Sponsors. Success depends on the ability to diagnose potential problems, develop a plan to deal with these issues, and execute the change effectively. Employment agents are “facilitators and community integrators” and not “placers and controllers”. Their role is to develop opportunities. Agents would include agency and educational staff, state-monitoring officials, support coordinators, families and peer mentors. Agents support the Targets in making the necessary changes.

Targets play a crucial role in the project success because they are the individuals or groups that are the focus of the change effort and will enjoy the primary benefits of the changes. Targets include individuals with developmental disabilities, their families and representatives, employers, and all of the above organizations.

Advocates: An advocate is the individual or group who wants to achieve a change and works toward that end but often lacks the power to demand that it occur. Advocates must have the skill to gain support from the sponsors who must approve their ideas and the targets who will benefit from the effort. Advocates include a variety of organizations like Illinois Arc, Equip for Equality, the Autism Society, Family Support Network, Centers for Independent Living, provider organizations, and unions.

At different times and in the face of different challenges, a person may play the role of sponsor, agent, target, and or advocate. At some times it is possible to actually have multiple roles simultaneously.⁶

Meaningful, sustained change is very difficult, especially in the early stages. To effect change it is essential to work with people in the key roles who are highly resilient.

⁶ Conner, page 109.

People who are resilient are:

Positive - Views life as challenging but opportunity filled;
Focused - Clear vision of what is to be achieved;
Flexible - Pliable when responding to uncertainty;
Organized - Applies structures to help manage ambiguity,
and;
Proactive - Engages change instead of evading it. ⁷

The Chinese express the concept of crisis with two separate symbols. The top character represents potential danger; the lower one conveys hidden opportunity. By combining these two symbols, the Chinese seem to be characterizing change as a paradox. While one tends to see primarily dangerous implications, the other typically focuses on the promise of new opportunities.



People with HIGH resilience who are very positive, flexible, organized, positive and proactive respond to change faster and are able to assimilate change better and restore their functioning quicker in the event of obstacles. They will be oriented to seeing change as an OPPORTUNITY ⁸

⁷ Conner, page 243.

⁸ Conner, page 237.

People with LOW presence of these five factors will be highly dysfunctional when attempting to respond to change, will have much difficulty adapting to change and will take longer to restore their functional levels. They will be oriented to seeing change as DANGER.

The more invested one is in their personal success and comfort and their historic performance the less resilient they tend to be. The more focused someone is in achieving the goals and outcomes of the organization, and the success of others, the more resilient they tend to be.

In high performing states and local agencies related to advancing supported employment for people with developmental disabilities, highly visible, dynamic, and resilient leadership was present.

To make major changes envisioned by advancing supported employment, the governors, legislators, state directors, agency directors and key management staff, employers, as well as individuals with developmental disabilities and their families, advocates must serve as pioneers who are willing to seize the opportunity and risks to mentor the program and see it successfully implemented and sustained.

The barriers identified in Chapter Two all need to be addressed in order to make change happen. Highly resilient people need to be actively engaged in that systems change process.

You can enhance resilience of people in major organizational change if you:

1. Understand the basic mechanisms of human resistance and their respective stages:
 - A. Negative: Immobilization, denial, anger, bargaining, depression, testing, acceptance
 - B. Positive: Uniformed optimism, informed pessimism, checking out, hopeful realism, informed optimism, completion
2. View resistance as a natural and inevitable reaction to the disruption of expectations.
3. Interpret resistance as a deficiency of ability or willingness.
4. Encourage and participate in overt expressions of resistance.
5. Understand that resistance to positive change is just as common as

resistance to negatively perceived change and that both reactions follow their respective sequence of events, which can be anticipated and managed⁹.

Summary Comments Chapter IV. Effective Systems Change Advancing Supported Employment: Managing at the Speed of Change: How Resilient Managers Succeed and Prosper Where Others Fail

We have found that in each state that has been successful in systems change that advances supported employment that it evolves around people. The process of identifying resilient stakeholders is fundamental and critical to successful and sustained implementation of supported employment within this Blueprint.

High performing supported employment states have key leadership from state directors and top level management who embrace supported employment throughout their own principles and have guided such principles enthusiastically within the fabric of their agencies, all of their interrelationships with other state and local agencies, other stakeholders, and the people they support.

It is highly important for the state developmental disability agency to have a top-level executive to oversee and advocate for supported employment, with direct and easy access to the state director. Likewise, it is important that local agencies emulate these actions within their own management structure.

High performing local educational and adult employment services providers similarly have key management personnel that collaborate and implement effective practice methods of ensuring youth with developmental disabilities are gainfully employed upon graduation. This process effects positive systems change advancing supported employment and closing the door on access to segregated systems.

Likewise educational and adult service personnel working on advancing supported employment must be vested in modifying old practices and ways of doing business that effect major changes that will be both less than fully functional at first, but later yield rewards for them and the people they serve thorough supported employment and the enhancements it can produce for the lives of individuals with developmental disabilities.

Effective supported employment is done one person at a time. Pioneering individuals, families, advocates, and employers can also serve as effective and resilient mentors for supported employment with less resilient stakeholders.

⁹ Conner, pages 145-146

Clearly supported employment expansion is predicated upon one success breeding future successes as barriers and dangers are effectively addressed and opportunities are advanced.

It is evident across the United States that supported employment for individuals with developmental disabilities can work if people believe in what can be achieved and have strong resilience: they are focused, flexible, organized, positive, and proactive in moving the system to a new way of doing business.

Chapter V. Promising State Policies Advancing Supported Employment

Several states across the United States have adopted through their legislature public policies related to advancing supported employment as a sole or preferred way of doing employment services for adults with developmental disabilities. These efforts are pioneering the future of such policies, which certainly will be advanced in other states. They are discussed here as key promising state policies.

A. State of Washington

The Washington State supported employment system is based upon the recognition of the state's obligation to provide aid to persons with developmental disabilities *"in a uniform and coordinated system."* The system should enable independence, personal fulfillment and respect for the rights of self-determination consistent with the Constitution of the United States and state of Washington. *"The policy of Washington State has a fundamental premise that an individual with a disability can be gainfully employed with some support from the State."*

This policy allows an individual to pursue their own individual path to work, a career and to shape their own participation in the community. The policy of Washington State transitions individuals from state dependence to self-reliance, lowering the burden upon the state agency and taxpayer.

The supported employment system is made up of county and state employees with caseworkers who provide counseling and support for individuals with disabilities who are entering or in the workforce. Supported employment supports are given to working age individuals (21-62), helping them find a living wage, integrated into a normal job. These services are available to any individual with a disability. The employment services needed are designed in cooperation with each individual and their family by a caseworker. Each individual is supported independently and with his or her unique needs in focus.

This is a state where sheltered workshops and group homes are not now readily available to individuals with disabilities. The clear state priority is for all individuals to be trained and supported to work in the mainstream marketplace.

Individuals with disabilities will be taught how to obtain and maintain a job with other people in the community and doing a job that provides a living wage. This allows for optimal choice by each individual and training can be tailored to the individual's skills, desires and goals. The individual is supported by a job coach and continuing support as needed. These programs are outside a system of workshops and institutional care where individuals with disabilities are grouped

together performing rudimentary jobs. The actual working age policy is in Appendix C.

Pathways to Employment services are unique to each person and are designed to support a participant to pursue employment in the community. Participants and their families work with a contracted service provider to plan their employment services, identify goals, determine support needs and maximize available resources.

While on the Pathway, some participants will need more support than others. Some participants may spend a significant amount of time in activities that will prepare them for future community employment. Participants will be supported in a variety of settings and activities designed to help them achieve their identified community employment goals.

Other important factors that will help Washington to be successful in supporting Employment for working age adults are:

- **Relentless and disciplined pursuit of best practices and new skills;**
- **Clarifying priority and tracking progress;**
- **Building provider capacity;**
- **Continuous development of partnerships with families, schools, providers, counties and other governmental agencies;**
- **Marketing employment for everyone.**

B. State of Vermont

Vermont is a high performing state on advancing supported employment.

Since 2002, it is devoid of sheltered workshops and principally focuses on supported employment and residential supports that primarily are supported living and adult foster care.

Adult foster care is facilitated by extensive matching considerations between the provider and the adult with a developmental disability with heavy emphasis on the adult being included in usual activities of the person or family providing the foster care. This facilitates community inclusionary activities.

Day activities outside of work parallel the State of Washington's Pathways to Employment with a heavy emphasis on attaining skills needed in the world of work, which may lead to gainful employment or employment advancement.

From the Vermont Statutes Online contained in Appendix D are the following excerpts:

In 1996 the following legislation was enacted by the Vermont legislature:

Developmental Disabilities Act 8721. Purpose

It is the policy of the state of Vermont that each citizen with a developmental disability shall have the following opportunities:

- (1) To live in a safe environment with respect and dignity.
- (2) To live with family or in a home of his or her choice.
- (3) To make choices which affect his or her life.
- (4) To attend neighborhood schools, be employed and participate in activities (emphasis added), to the extent that this purpose is not construed to alter or extend rights or responsibilities of federal laws relating to special education.
- (5) To have access to the community support and services that is available to other citizens. (Added 1995, No. 174 (Adj. Sess.), § 1.)

Within this act is a required three year System of Care Plan, which requires the department to adopt a plan for the nature, extent, allocation and timing of services that will be provided to people with developmental disabilities and their families. Each plan includes:

- (1) priorities for continuation of existing programs or development of new programs;
 - (2) criteria for receiving services or funding; and
 - (3) a process for evaluating and assessing the success of programs.
- (b) Each plan shall be based upon information obtained from people with developmental disabilities, their families, guardians and people who provide the services and shall include a comprehensive needs assessment, demographic information about people with developmental disabilities, information about existing services used by individuals and their families, characteristics of unserved and under served individuals and populations and the reasons for these gaps in service and the varying community needs and resources. The commissioner shall determine the priorities of the plan based on funds available to the department.
- (c) No later than 60 days before adopting the plan, the commissioner shall submit the proposed plan to the advisory board, established in section 8732 of this title, for advice and recommendations.

(d) The department shall report annually to the governor and the general assembly regarding implementation of the plan and shall make annual revisions as needed. (Added 1995, No. 174 (Adj. Sess.), § 1.)

The State System of Care Plans, together with the Developmental Disability Services Annual Report, covers all requirements outlined in the developmental disabilities statute. The System of Care plan is developed on a three-year cycle with annual updates and determines criteria for individuals to obtain services and funding, including priorities to develop new, and continue current, services and programs.

Roughly 13,145 of the state's 625,935 citizens have a developmental disability. In 2006, 3,224 individuals were provided services, about 25% of persons eligible. There are a net of 100 individuals added each year to the service rosters from the public schools.

The System of Care Plan is developed with a wide range of input from self-advocates, consumer surveys, quality management reviews, public guardians, local designated agencies, family satisfaction surveys, and the Vermont Developmental Disabilities Council Survey. Each designated agency (DAs) is required to submit a local three year system of care plan to guide local services including identifying priority areas of support and use of resources to meet specific regional needs and to inform the State System of Care Plan and the annual budget process.

The Vermont System of Care plan includes seven chapters. with 1: Introduction, 2: Eligibility for Supports, 3: Plan Development, 4: Accomplishments from the FY 2005-2007 Three-Year Plan, 5: FY 2008-Fy 2010 System Development Activities, 6: Funding Process and Guidelines and 7: Applicant and waiting Lists. Within Chapter Six are "Limitations on the Use of All Developmental Disability Services Funding" as follows:

Division funds cannot be used to increase the availability of the following services:

Congregate residential settings in excess of four beds for adults (age18 and over).

Congregate (defined ad three or more individuals) for children under 18 years old); (Exceptions by DAIL sole approval)

Institutional settings (e.g., nursing facilities) for providing "community supports" other than for people living, working, or volunteering in the setting; (Exceptions by DAIL sole approval)

Additionally, Division funds cannot be used to increase the availability of the following services:

- **Any residential schools/treatment centers, in-state or out-of-state institutional or congregate placements (e.g., out-of-state ICF:MR, nursing facility, public or private training centers or schools; (Exceptions by DAIL sole approval)**
- **Room and board paid for with Medicaid waiver funds, including costs of vacations (Medicaid funds may be used to cover costs incurred by a paid caregiver to support an individual on vacation (e.g., airfare, hotel and food expenses).**
- **Sheltered workshops or enclaves (segregated work environments within an employer’s worksite). No identified exceptions.**

The last exclusion promotes integrated and inclusive employment for individuals with developmental disabilities with supports funded by the division.

In March 2006, the Vermont Division of Disability and Aging developed an action plan for developmental services supported employment. The reason for the plan was as follows: “People with developmental disabilities continue to be underemployed. Families and consumers say they want meaningful employment opportunities and hope to become an integral part of our Vermont work force.

This plan addresses a statewide system approach to decrease existing barriers, increase access to new employment, and enhance career growth opportunities in the developmental service system”. Essentially, the division was seeking to convert community supports to supported employment for all individuals requesting such conversions. The goals for this plan were as follows:

Goal 1: Increase the option for individuals to access employment by converting community supports (CS) to supported employment (SE) services.

Goal 2: Improve understanding of the recent SSA work incentive changes.

Goal 3: Evaluate the status of Supported Employment from a systemic and best practice viewpoint in order to identify new methods and strategies for

advancing employment in the future and to evaluate the current funding model.

Goal 4: Publicize the success of VT SE by gathering accurate data and developing PR tools to highlight SE in Vermont. Expand the type of data collected to better measure the outcomes of Supported Employment.

Goal 5: Assure employment as an option for youth exiting high school.

Goal 6: Develop a direct peer advocacy model for supported employment by recruiting self-advocates as SE staff.

Goal 7: Increase supported employment provider competencies through expanded and targeted training.

According to state officials, community supports and related activities are now provided mainly through foster care providers who are matched with one individual with a developmental disability. It is expected that such providers include the individual in all activities of community life including vacations. The Vermont Medicaid Home and Community based services waiver includes a provision for paying such providers for these activities including even their costs for vacations.

Traditional day services are now converted to supported employment and employment activities to increase employment outcomes for individuals with developmental disabilities. The States of Vermont and Washington have charted nearly the same path to advance supported employment and community inclusion in their best practice public policies.

C. State of Oregon

According to state officials, Oregon used to be a leader in supported employment initiatives in the 1990's but has fallen back having focused on other prevailing issues in the state developmental disabilities system. To reinvigorate efforts on advancing supported employment, the state has put forward the following Blueprint, which is highly instructive of essentials in this initiative.

The State of Oregon developed a blueprint “to enhance the quality of life in Oregon by achieving, maintaining and advancing the competitive and inclusive employment of persons with disabilities.”

The goals are to:

- **Empower people with developmental disabilities to obtain meaningful employment.**
- **Educate and engage employers to develop and market the “business case” for employing people with disabilities.**

- **Enhance the availability and effectiveness of employment supports for persons with disabilities.**
- **Enhance Oregon’s workforce system and expand its availability for persons with disabilities.**

The state then set about creating core values for the Blueprint, which would help guide in policy creation.

The values they chose were:

- **Informed choice and self-determination.**
- **Person-centered planning and decision-making.**
- **Equal opportunity, full participation, and contribution to community.**
- **Empowerment and community inclusion.**
- **Diversity and cultural competency in process, communication, policy and program development.**
- **Self-sufficiency and economic independence.**
- **Access to appropriate training and education to achieve career and employment goals.**
- **Education, training and technical assistance.**
- **Collaborative decision-making.**
- **Evidenced based- practices and measurable outcomes.**
- **Work that is beneficial and enhances the quality of life.**
- **Advocacy and inclusion of people with disabilities in policy and service design**

After setting out its goals and values, Oregon pushed forward with several initiatives. They organized a leadership council of 25 people to address problems in each element of the blueprint and to obtain feedback from stakeholders. A team was organized to develop concept papers addressing specific issues, a planning team found strategic opportunities for partnerships and a team interviewed additional stakeholders to identify additional needs. These activities produced a series of employee and employer supports that would be necessary to successfully launch the program.

The program then went on to outline critical areas where individuals would need assistance in integrated employment settings. These include: transportation, family and child supports, housing, training and technical assistance, resource mapping and guides, and waiver policies. The entire document is contained in Appendix E.

D. State of Tennessee

Employment First! Making Integrated Employment the Preferred Outcome in Tennessee 10¹⁰.

The Tennessee Division of Mental Retardation Services (DMRS) implemented the Employment First! initiative in 2002. The goal of Employment First was to make employment the first day service option for adults receiving supports funded by DMRS, Medicaid, or the state. Employment First set the standard that employment was the preferred service option for adults with mental retardation and developmental disabilities (MR/DD).

Implementation

Prior to the Employment First initiative, Tennessee did not have a specific focus on integrated employment. However, the DMRS vision statement provided a strong foundation to support the Employment First policy. This statement addressed the importance of supporting choice in residence, employment, recreation, and other community activities.

Additionally, data from a late-1990s survey of DMRS consumers indicated that Tennesseans with MR/DD wanted the opportunity to work. The vision statement and consumer survey data were important factors that set the stage for DMRS to focus on integrated employment.

The Employment First policy was a collaborative initiative that grew out of the work of several advocacy groups, including the Tennessee Council on Developmental Disabilities (DD Council) and the Arc of Tennessee as well as stakeholders in the state's settlement of several federal lawsuits.

Individually, each of these groups began to discuss the importance of expanding integrated employment in Tennessee. The Arc and DD Council developed and submitted separate position papers to DMRS to make employment the preferred day service option. Additionally, the DD Council offered a grant to DMRS challenging the agency to increase integrated employment outcomes across the state. The challenge grant, data on consumer desires, and advocacy by stakeholder groups were all factors that led DMRS to implement Employment First. An important feature of the initiative was defining the desired outcome clearly.

¹⁰ Winsor, Jean E. and Huber, Julie. "Employment First! Making Integrated Employment the Preferred Outcome in Tennessee" Institute for Community Inclusion, UMass Boston, January 2007.

Employment First defined "employment" as a job in an integrated community setting that provided the opportunity to earn competitive wages and benefits equal to the job's responsibilities, and that encouraged persons to work to their maximum potential.

The initiative assumed that both formal job supports (employment provider staff, technology, etc.) and natural supports (co-workers, friends, family, etc.) should be available on an ongoing basis to meet individual support needs, and that all jobs should be developed as part of a larger career plan.

An additional notable characteristic of Employment First was its requirement of a periodic community-based work assessment. In Tennessee, Independent Support Coordinators managed services for people with MR/DD. Under the initiative, a piece of this role's responsibilities was to ensure that individuals who were not in integrated employment participated in a community-based work assessment at least every three years.

This requirement aimed to provide an opportunity for individuals who might be hesitant to pursue community employment to experiment without fear of failure. Tennessee struggled with balancing the right of the individual to refuse the assessment and the state's desire to see more people choose integrated employment.

To support Employment First, DMRS reevaluated the rate paid to providers for day services. One important change was to pay a daily rate for all day services. Prior to 2005, the state had paid an hourly rate. The hourly rate was found to discourage providers from expanding integrated employment services because it was not structured to allow people to easily transition between sheltered and integrated employment, or between short- and long-term employment supports. Additionally, to encourage community rehabilitation providers to expand integrated employment activities, DMRS established a higher rate of payment for integrated employment than for other day services.

The Employment First initiative was a pioneering act in Tennessee not only because it made integrated employment the preferred service outcome but because it was developed and implemented in cooperation with multiple stakeholders. This broad coalition of support led to an ongoing commitment across the state to expand integrated employment.

As part of the initiative, the state developed benchmark goals to track state progress in increasing integrated employment placements. Providers were asked to report specific data on the number of people in integrated employment, hours worked, wages earned per hour, and job title. Since 2002, the number of adults in day services employed in competitive jobs in the community has increased by nearly forty percent.

In 2002, the Tennessee Customized Employment Partnership (TCEP) project began in Knoxville. A national demonstration project to develop model strategies for supporting people with significant disabilities to secure and maintain employment, TCEP is a collaborative of Workforce Connections (Knoxville's local workforce investment board), the University of Tennessee's Center on Disability and Employment (CDE), and TransCen, Inc. (a nationally recognized provider of technical assistance). Due to the success of TCEP, the U.S. Department of Labor's Office of Disability & Employment Policy (ODEP) awarded the WorkFORCE Action Grant (Tennessee Olmstead WorkFORCE) to replicate the TCEP model throughout the state. The TCEP model is designed to combine resources of the Career Center and the disability employment system to create model "customized" employment plans for people with significant disabilities. A critical element in the success of this goal is the development and implementation of effective strategies for blending funding and services from multiple sources to provide needed supports details of which are included in Appendix F.

E. State of Florida

The State of Florida, through legislative action, created a policy for individuals with disabilities that incentivizes a supported employment system.

The supported employment model, in law, is the preferred service system of the state, the individual and stakeholders for delivering supports to individuals with disabilities and their families.

These individuals with disabilities are given the opportunity, with support and training from the state of Florida to find a job, which fits their individual skills, needs and goals. The jobs for these individuals are within the mainstream workforce, along side individuals without disabilities. The program has the correct elements of community inclusion and personal responsibility that are essential to sustaining a program of supported employment.

The Florida system acknowledges the inherent advantage of supported employment over previously used systems of institutionalization and sheltered employment.

Florida recognized that this institutional/sheltered system is excessively expensive, ineffective, has poor outcomes that stifle individuals from reaching their full potential and is often demoralizing for individuals.

The state has created mechanisms for localities (city or county generally) to administer the programs and to determine the most appropriate way of providing employment-focused services within clear, state defined parameters. The jobs are in the community in which the individual lives and services will be provided in a manner that is effective for the individual and their family.

State resources are shifted to utilizing caseworkers who will engage with the individual, their families and educators to determine the most appropriate services and determining what resources are necessary for the individual to achieve independence and self-determination.

Support is designed to be ongoing to help ensure job-retention and gaining skills to become increasingly independent, to the extent possible and feasible. It is also now preferable for the State to engage with businesses, non-profit organizations, or others already in the community who are providing services that are more cost-effective than could otherwise be provided by the State and the traditional system.

Finally, institutionalization (including “community” institutionalization via traditional workshops) is to be avoided if at all possible and should only be provided as an exception to a system of supported employment.

To ensure this move to community based-services the Legislature directed, “all persons with developmental disabilities who live in licensed community homes shall have a family living environment comparable to other Floridians.” Individuals are then able to access medical assistance when needed and personal care services to assist them in their daily lives. Further “*supports for continuing employment will be provided as necessary to maintain employment in an integrated setting.*”

Summary Comments Chapter V. Promising State Policies Advancing Supported Employment

These public policies are being implemented in these states as they intend to advance supported employment for working age adults with developmental disabilities. How well these policies work will need to be assessed through outcome analysis of the individuals and their employment outcomes over multiple years in the future. Certainly they are all promising policies that when implemented and acted upon effectively can lead to integrated employment for many individuals with developmental disabilities.

These goals and activities are fundamental to creating the conditions and resources necessary to advance supported employment and related supports in the State of Illinois. They are captured here to provide a reference to them for the Blueprint. Truly, if these goals and activities are fully implemented, the capability of reaching employment outcomes for individuals with developmental disabilities will have a much-improved potential.

Chapter VI. Promising State Practices Advancing Supported Employment

Several states have practices that are highly important in advancing supported employment. They are reviewed here as critical methods for ensuring successful outcomes and continued progress within and among agencies at the state and local levels.

A. The Illinois Medicaid Buy-In Program

The Illinois Medicaid Buy-In program offers Medicaid coverage to people with disabilities who are working, and earning more than the allowable limits for regular Medicaid, the opportunity to retain their health care coverage through Medicaid. This program allows working people with disabilities to earn more income without the risk of losing vital health care coverage.

Because of recent changes in the law and expansion of the eligibility criteria for this program, the Illinois Medicaid Buy-In Program is certainly a promising practice and reduces barriers to individuals with developmental disabilities making wages and benefits while still being able to afford health benefits necessary for a complete life.

Governor Rod R. Blagojevich on August 29, 2007 signed legislation that will help make healthcare more accessible for people with disabilities. The Governor signed into law House Bill 1256, which expands the Health Benefits for Workers with Disabilities (HBWD) program.

“Every day, individuals with disabilities face a number of challenges many of us wouldn’t think twice about. Things most of us take for granted – like shopping, filling our cars with gas, even owning our own homes – are more difficult for them. But accessing quality healthcare at affordable rates should not be one of those challenges,” said Gov. Rod Blagojevich.

“I am happy to sign this bill to help make sure that those who have disabilities in Illinois have equal access to what is a fundamental right.”

HB 1256, sponsored by State Representative Sara Feigenholtz (D-Chicago) and State Senator Don Harmon (D-Oak Park), expands eligibility for the HBWD Program from 200 percent of Federal Poverty Level (FPL) to at least 350 percent of FPL. This legislation will continue the program’s focus on keeping individuals with disabilities working by allowing those individuals to qualify for healthcare while earning a modest income, and by exempting retirement and medical

savings accounts from being counted as assets. HBWD will be further expanded by increasing the limit of non-exempt assets from \$10,000 to \$25,000.

The HBWD program will have new eligibility criteria in 2008. Current incomes limit income eligibility to 200% FPL. The new guidelines provide income eligibility up to 350% FPL.

New *income guidelines* are as follows:

Household size	Current	2008
1 -	\$851	\$2978
2 -	\$2282	\$3993
3 -	\$2862	\$5008
4 -	\$3442	\$6023

The new law also increases the assets threshold from \$10,000 to \$25,000 per household. Retirement accounts that cannot be accessed until age 59 ½ are totally exempt, as well as medical savings accounts established pursuant to 26 U.S.C. 220.

Individuals who participate in the HBWD program and then become ineligible for it, and apply for the Aid to the Aged, Blind and Disabled AABD program, will be able to exempt their retirement accounts (inaccessible until age 59 ½), medical savings accounts pursuant to 26 U.S.C. 220, and up to \$25,000 in other assets, in the AABD eligibility determination.

B. Vermont Seamless Transition From Education Agencies To Adult Agency Providers

The Vermont Division of Aging and Independent Living (DAIL) does a survey through Designated Agency Intake and Supported Employment Coordinators to identify all youth with developmental disabilities who are eligible for and desire to participate in the Vermont Medicaid Home and Community Based services waiver for adults with developmental disabilities and other such supports.

The survey is a best practice since it identifies the youth, their needs, and allows the state to make a budgetary recommendation to the Vermont General Assembly for additional appropriations for the necessary services and support under the waiver for them.

The actual reference documents for this process are contained in Appendix G and the results are in Appendix H. This practice essentially allows the youth to make a seamless transition to adult life with necessary resources and supports.

C. Point of Transition Service Integration Project (San Diego State University)

The last day of school should be no different than the day after.

This project has developed and implemented the Transition Service Integration Model (Pumpian & Certo, 1996) in approximately a dozen communities in California which has resulted in a seamless transition from school to integrated direct-hire employment, Postsecondary education and inclusive access to a wide range of preferred community activities and settings for students with severe disabilities during their last year in public school (i.e., typically students who are 21 years old).

This model utilizes a one-stop workforce investment strategy that unifies the three primary systems responsible through enabling legislation for this transition: the public school system, the rehabilitation system and the developmental disabilities system. It results in students exiting school with a stable job and a scheduled routine for accessing non-work activities in natural community settings when they are not working, and it ensures the continued support needed to maintain these activities after graduation.

POTSIP benefits consumers and systems in many ways

Successful Strategies (Project Level)

- New partnerships among all stakeholders (building trust)
- Holding two sets of regular meetings: funding/policy issues & programming/practice issues
- Different approaches across state: designing new agencies; expanding services of existing agencies
- Fostering collaboration among vendored agencies to share billing approaches, support strategies, other expertise
- Meeting with service coordinators (case managers) as a group each spring
- Meeting with vendors (i.e., Vendor Coalition) to encourage participation by non-project sites; develop partnerships with new school districts and selected agencies
- Building capacity within stakeholders, e.g., buying out a percentage of a DR counselor; supporting a percentage of a teacher's time; subcontracts to agencies to provide a job developer and transition liaison to work exclusively with the targeted students
- Including students, family members, employers, as well as representatives from schools, DR, & DDS in presentations at conferences, workshops, & for visiting professionals (e.g., Denmark, Netherlands, Japan)

Changes in Practice (Program Level)

- **More students are leaving high school with jobs and keeping those jobs.**
- **Students are involved in other non-work activities that are continuing.**
- **Students who are 21 (or in their final year of school) are provided services differently (e.g., no school holidays, different daily hours, located off-campus)**
- **Services are being re-examined for students who are 18-20, in order to support job placement during Point of Transition year.**
- **Families are receiving information early on regarding options for adult supports and services (e.g., meeting with school personnel, service coordinators, representatives from Dept. of Rehab., DDS, vendored agencies)**
- **Families and students are feeling more empowered in making informed choices regarding their future.**

Changes in Policy/Funding

- Split or shared funding to support work and non-work activities (DR & DDS)
- Department of Rehab. providing funding earlier, while students are in last year of school
- DDS providing a 60-day safety net for students who lose a job to support continued job development time
- Using staffing allotments and assignments in more creative ways (funding staff from vendored agency to work with targeted students)
- Sharing assessment & collateral packets among all school partners, adult agencies, DR, and DDS in order to provide consistency, less redundancy, and working toward the use of single planning document that will satisfy all partners' requirements.
- School districts are moving students (18-22) off high school campuses (e.g., Leasing space from vendored agency) ¹¹

¹¹ www.interwork.sdsu.net

D. New York School to Work Transition Collaborative Projects FY 2008

In June 2007, the New York State Board of Education announced a process for requesting proposals ultimately allowing the selection of sixty school districts with three to four affiliated agencies for school-to-work transition programs for individuals with disabilities based upon “evidence-based practices.”

The goal is to assist students with disabilities attending high schools to prepare for adult life. The high schools need the best tools to do this and the program will be implemented in 60 test schools over the course of 3.5 years. The data analysis of “evidence-based practices” will be one of the key factors in the program proposal. How best practices are identified and evaluated must be demonstrated in the proposal for favorable consideration.

The program requires partnerships between the public schools with colleges, independent living centers, community rehabilitation providers, adult vocational training institutions, business and chambers of commerce.

The program should improve the academic and functional achievement of students with disabilities.

The improvements may come in vocational, post-secondary, or supported-employment scenarios. In a highly coordinated setting the program will incorporate activities that reflect an individual’s needs, strengths, preferences, goals and interests. There will also be transition coordination, orientation to vocational rehabilitation and assistance in preparation of job eligibility documentation.

The program will allow school districts to develop these activities and programs for all students with developmental disabilities.

Approved multi-year activities may include workplace exploration, job shadowing, internship and actual work experience (such as summer employment). The program must take into account the need for specific responsibilities for carrying out transition services. The parents must also be trained and prepared for transition just as much as the student.

A needs assessment must be conducted before proposals are submitted regarding the allocation of resources currently at potential program sites. Needs assessments should also be aware of the range of rural and urban/suburban school districts; targets of positive post-secondary placements and establish effective referral practices. The roles of various community partners in any program should also be included in the needs assessment.

Three letters of support should accompany the submittal of the proposal. The letters should be from groups from which a collaborative agreement will be based. Support can be from parents, community rehabilitation providers, colleges, businesses, or ILC's.

Activities which are not included: Diagnostic vocational evaluations, job development, job coaching, or on the job training. Programs shall be divided into a technical proposal document and a separate cost proposal document. This initiative represents a promising practice to re-energize these important collaborative relationships on school to work transition for youth with developmental disabilities and needs to be replicated. The entire request for proposal is contained in Appendix I.

E. Vermont Individual Support Agreement

In Appendix J is the Vermont Individual Support Agreement that is written and directed back to the person whose support plan it is. It contains meaningful comments and directions for the individual to assist in understanding all the components of the agreement. Truly, it embodies the principles of self-determination and a true person centered planning focus.

It is included here as a descriptive model for agencies to evolve from documents and practices that are less focused on the individual and more focused on bureaucracy.

F. Vermont Action Plan for Advancing Supported Employment

Several states have indicated that they believe they have lost ground in advancing supported employment.

Vermont put forward an action plan in March 2006 to explore reasons why people with developmental disabilities continue to be underemployed and solutions for remediating the underemployment.

The plan addresses a statewide system approach to decrease existing barriers, increase access to new employment, and enhance career growth opportunities in the developmental service system.

Goal 1: Increase the option for individuals to access employment by converting community supports (CS) to supported employment (SE) services.

Goal 2: Improve understanding of the recent SSA work incentive changes.

Goal 3: Evaluate the status of Supported Employment from a systemic and best practice viewpoint in order to identify new methods and strategies for advancing employment in the future and to evaluate the current funding model.

Goal 4: Publicize the success of VT SE by gathering accurate data and developing PR tools to highlight SE in Vermont. Expand the type of data collected to better measure the outcomes of Supported Employment.

Goal 5: Assure employment as an option for youth exiting high school.

Goal 7: Develop a direct peer advocacy model for supported employment by recruiting self-advocates as SE staff.

Goal 8: Increase supported employment provider competencies through expanded and targeted training.

The actual action steps for individuals, agencies and the state are displayed in Appendix K. This plan needs to be routinely updated to continue the complicated process of advancing supported employment through coordinated leadership and focused attention on the desired outcome, namely advancing supported employment for all individuals with developmental disabilities who can be employed.

G. New Hampshire Data Collection Survey Methodology

Data collection is critical to knowing the outcomes for individuals with developmental disabilities on supported employment. Regular data collection allows effective evaluation and establishes issues for action planning as referenced previously for Vermont.

The New Hampshire Division of Developmental Disabilities twice a year collects a range of comprehensive data on its longstanding supported employment initiative.

The information is collected for each of the ten area agencies that do support coordination on behalf of the state. This process displays the results for each of the ten areas and creates a competitive environment on the results.

The survey includes total individuals and jobs, age, gender, medical/physical and behavioral challenges, cognitive challenges, language, number of differing jobs and businesses, length of employment, termination reasons, work environment, types of work, ours per week and without paid support, hours restricted due to concerns about benefits or transportation issues, average hours per week and pay per hour, funding for employer, payment method, use of work incentives,

months of vocational rehabilitation, use of adaptive technology, and transportation.

Using this as a model PPIWDC created a spreadsheet for data collection that also incorporated type of residential supports as an important variable for community inclusion and self determination. One of the major outcomes for this data both from New Hampshire and PPIWDC was the number of hours individuals worked per week. Generally, the majority of individuals were working on average less than twenty hours per week, which needs addressed from perspectives of underemployment and community work and non-work activities. The most recent results of the survey are presented in Appendix L.

H. State of New York Options for People through Services (OPTS)

In 2004 the State of New York Office of Mental Retardation and Developmental Disabilities (OMRDD) implemented Options for People through Services or OPTS. This unique initiative utilizes an organized health care approach to promote increased choice and greater individualization of services as well as to expand and create additional opportunities through a unique and flexible funding methodology.

Through this initiative, OMRDD is able to offer individuals as well as the public and nonprofit providers who care for them a wide array of affordable options that promote inclusion and personal choice options that also offer greater flexibility and opportunity for efficient and effective use of the program funding.

Individuals and family members have been and will continue to be involved on the Steering and other OPTS committees. The program has been designed and is being implemented and monitored for success by parents, family members, voluntary providers, local government representatives, state staff and self-advocates, so that it best represents the needs and choices of the individuals who will be receiving services. Voluntary providers are offered the opportunity to participate in OPTS via a contract mechanism.

The Guiding Principles, which were designed with and for the individuals who will live by them, include:

- Maximize opportunities for individual choice through person-centered planning;

- Advance independence, inclusion and individual and family responsibility throughout the system;
- Create funding mechanisms that strengthen capacity to deliver individualized services;
- Preserve oversight systems to ensure the highest quality of services for all individuals;
- Assure that all providers promote the health, safety and protection of individuals through compliance with the highest standards of operation;
- Improve access to needed services and supports for eligible individuals;
- Enhance flexibility within the services system;
- Promote user-friendly efficient and effective operations; and
- Encourage continued participation and open communication among all those involved in the system.

As directed by its Guiding Principles, OPTS creates an appropriate system that supports self advocacy and self determination, promotes personal responsibility, provides services that meet individual needs and provides the oversight and guidelines necessary to assure the highest quality for the consumer.

OPTS essentially operates with the state as the provider of applicable Medicaid Home and Community Based Services and Supports with sub contracts with applicable agencies for the supports needed by individuals with developmental disabilities. It is an important vehicle for the Office of MRDD to assume leadership in fostering supported employment, supported living and other supports in community inclusive, integrated ways.¹²

I. The New Hampshire Model for Measuring Outcomes for Adults with Developmental Disabilities and Self-Determined, Person-Centered, Inclusionary Lives

The State of New Hampshire Division of Developmental Disabilities Services has created an ongoing evaluation process for community inclusion of adults with developmental disabilities.

Jeanne Cusson is the leader behind this initiative with other staff of the division. New Hampshire has a long-standing history of pioneering efforts in self-determination and real person-centered planning truly centering on the person. The lines of questioning in this survey are indicative of the true implementation of these values. The evaluation process is pretty straightforward with key lines of questioning for paid work and volunteer activities as follows:

¹² New York Office of MRDD OPTS at <http://www.omr.state.ny.us/opt/index.jsp>

II. Paid work

- A. Do you have a paid job?
- B. (If "No") Would you like to have a paid job?
- C. Do you like your job?
- D. Would you like to work more hours?
- E. Do you want to make any changes in your job / job supports?
- F. Did you choose or hire _____ (name paid employment staff)?
- G. Is there some kind of work/job that you would like to have someday?

III. Volunteer activities

- A. Do you volunteer?
- B. (If "No") Would you like to volunteer?
- C. If you would like to volunteer (or do not like the activities you are doing, are you being helped to find volunteer activities that you are especially good at or interested in doing?
- D. Do you like this (these) volunteer activity (ies)?
- E. Are there any changes you would like to make in your volunteer activities?
- F. Did you choose or hire _____ (name paid staff who support you during volunteer activities?

The entire adult outcomes survey is located in Appendix M and contains eleven areas for the survey. State and area agency staff get out there and personally interview people who receive services in every region of the state. This survey was put together 11 years ago. While it has been tweaked a bit over time, the basic questions have not changed.

New Hampshire has felt for a long time that you can effect improvements in services by asking the right questions. Just an example: you will find the question, "Did you choose or hire the staff who support you?" repeated several times.

Eleven years ago New Hampshire did not come out with a rule that said people who receive services had to be involved in the selection or hiring of their staff. But by asking the question several times during the interview, and by agencies getting the feedback in the annual reports, the practice has now become widespread. Agencies do not want negative reports so they work to change their practices, knowing that this is the expectation.

J. Illinois Interagency Coordinating Council Transition Programs and Services

The following agencies are members of the Illinois Interagency Coordinating Council Transition Programs and Services, which was authorized by the Illinois General Assembly in 1990 to support School to Work Transition.

Illinois Department of Corrections
Illinois Board of Higher Education
Illinois Community College Board
Illinois State Board of Education
Illinois Department of Employment Security
Illinois Department of Commerce and Economic Opportunity
UIC Division of Specialized Care for Children
Illinois Department of Healthcare and Family Services
Illinois Council on Developmental Disabilities
Division of Rehabilitation Services (Employment, Training & Education)
Division of Developmental Disabilities Services

The agencies are to develop and implement a coordinated, multidisciplinary, interagency service system for youth with disabilities, which will increase collaboration and cooperation among all in providing services to youth with disabilities and their families.

The Agency Compendium:

- Provides clarification of the programs and services offered by each of agency on the Interagency Coordinating Council;
- Identifies and describes the programs and initiatives to be coordinated by the Interagency Coordinating Council; and
- Improves awareness of and ensures transition-related service information is available for use by state and local agencies, local school districts, local service providers, and consumers to improve the transition process and outcomes for young adults with disabilities.

The document will support state, regional and local areas to identify and coordinate services that will enhance successes for young adults with disabilities as they transition to their post-secondary goals for employment, education or training, community participation and independent living.

It represents a promising model to be used not only for school to work transition but also in advancing supported employment for adults with developmental disabilities. There is still a need to evaluate its functionality, which was beyond

the scope of this Systems Analysis. It does contain a viable structure for the systems' interface and collaboration that is needed toward advancing supported employment across agencies serving individuals with developmental disabilities.

Summary Comments Chapter VI. Promising State Practices Advancing Supported Employment

Within this chapter, PPIWDC identified numerous promising practices including the Illinois Medicaid Buy-In program improvements, the seamless transition process from school to work in Vermont, Vermont's individual support agreement written for the individual receiving the supports, Vermont's ways to reinvigorate its supported employment program, the San Diego, California, Illinois and New York State Board of Education multi-agency approaches to school to work transition, New Hampshire employment data collection and outcomes surveys, and a flexible approach to funding from the State of New York Office on MR. These approaches are certainly promising practices to enable states and local agencies to advance supported employment in meaningful and effective ways. They have been provided as instructive methods for system transformation.

Chapter VII Advocating for and Advancing Supported Employment And Related Services

A. An Effective Method For Listening To Individuals And Families: A Promising Practice

Bryan Dague, a professor at the University of Vermont in Burlington, is very supportive and a key resource in advancing supported employment through his university work, his research, and his technical assistance provided to the state and affiliated local agencies.

His dissertation research focused on systems change from the perspective of individuals and their families and is very instructive of the struggles that the older and younger generations go through as they experience yet one more systems change effort with the intended outcome of true inclusion in society; including real jobs, real wages, and real employers. Excerpts from his conclusions are presented here to set the tone for the interface of the state and local agencies with individuals and their families and advocates as we advance supported employment. "The conclusion sections are arranged as: "Letting Go", "On the Road to Inclusion", "The Final Destination", "Summary and Implications", and then some "Final Thoughts". The following excerpts in green italics are totally in the words of Dr. Dague with identified references.

"Letting Go"

As they were renovating the old cavalry stable for the new sheltered workshop, a newspaper article stated,

"The brick stables are solidly built as if the federal government never thought horses would go out of style." Perhaps the founders of Lake Industries felt the same way about their sheltered workshop. In 1894, Fort Daniels was considered a state of the art facility for the military with 1,800 Cavalry horses and kerosene lamps. In 1973, Lake Industries was considered a state of the art facility for the disabled with a segregated facility and sub-contracted work.

Both were state of the art, at the time.

In 1967, when that group of young parents defied the system... they set the ball in motion to change the way society viewed developmental disability. They changed the paradigm so society started to help people labeled mentally retarded, rather than locking them away.

They set the ball in motion that led to increased community involvement and community awareness. The agency mission statements over the years strived for community inclusion as their goal.

Letting go is difficult.

The parents seem to grieve the loss.

Kübler Ross (1969) identified the progressive stages of grief as denial, anger, bargaining, depression, and acceptance.¹³

On the Road to Inclusion

The group that started Lake Industries in 1967 did so to avoid the institutions. In many ways, they appear to be a lost generation caught in between the two conflicting paradigms of facility-based and community-based services for people with disabilities.

The general community would be charitable and raise money for them, and businesses would sub-contract work to them, but nobody would include them.

Margaret Mead defined an ideal human culture, as one in which there is a place for every human gift. Given that definition, one could argue (and the parents have) that Lake Industries cultivated an ideal human culture, within their walls. For the older parents, that was good enough, but for the younger parents, it is not. They strive for an ideal culture in total, not just within the walls.

¹³ Kübler-Ross, E. (1969). *On death and dying*. New York: Touchstone.

*Pancsofar (1993) has done a significant amount of work in the area of community inclusion of people with developmental disabilities.*¹⁴

He identifies three progressive steps to community inclusion as: being present, having presence, and actively participating.

Being present means the person is physically in the community.

Having presence means the person is recognized within his or her community.

Actively participating means that the person is a contributing member of his or her community.

Pancsofar's third step of community inclusion is a little more difficult, but people are now actively participating in community life through their community jobs or volunteer work, singing at a karaoke bar, or cheering for the Red Sox at Fenway Park. Yet, despite their increased community involvement, it is not necessarily community inclusion as they are usually in the company of a paid staff person.

Lutfiyya (1988) reports that there are at least six characteristics that non-disabled people experience in meeting people and developing relationships that are usually not available for people with disabilities. These include opportunity, support, diversity, continuity, freely given and chosen relationships, and intimacy (Lutfiyya).¹⁵

*Several participants from Lake Industries have been involved with the national Best Buddies Program through a local college. Best Buddies was formed by 1987 with the following vision statement:
"People with intellectual disabilities are often excluded from society because of their differences. Best Buddies is determined to end social isolation for people with intellectual disabilities by establishing meaningful, lasting one-to-one*

¹⁴ Pancsofar, E.L. (1993). *Community connections: A resource guide for all people who support the full inclusion of individuals with disabilities*. Manchester, CT: Communitas, Inc.

¹⁵ Lutfiyya, Z.M., (1988, September). Other than clients: Reflections between people with disabilities and typical people. *TASH Newsletter*.

friendships with their non-disabled peers. These friendships help increase self-esteem, confidence and the abilities of people with and without intellectual disabilities.”¹⁶

Through a local college, they are paired up with college student volunteers for one year. They will meet for individual and group outings. Both the parents and participants of Lake Industries have appreciated this program.

Final Destination

The label used for this population was mentally retarded. Looking up the term in the dictionary, I found this definition, “Affected by a condition that limits the ability to learn and to function independently, as a result of congenital causes, brain injury, or disease.” Looking up the word retardant, I found, “Something designed to slow down a particular process or change.”

As a result of this research, it seems that if these people are in fact mentally retarded, then the professional system and community has to take some responsibility for being the retardant.

People labeled as mentally retarded have been institutionalized, segregated in sheltered workshops, denied education, and excluded from society. People with disabilities and their families did not ask to be disenfranchised from society.

The result of this has created a segment of our population that is perhaps seen as mentally retarded because they have been denied access, education, inclusion, and the resulting benefits of being members of the community.

In The Careless Society, McKnight (1996) criticizes the professional service system for adopting the philosophy;

“You will be better, because we know better.”¹⁷

He claims this attitude has professionalized our society and diminished the power of communities to be caring and nurturing. Lorna’s comments reflect this as well when she said her son’s mistreatment came at the hands of

¹⁶ <http://www.bestbuddies.org>

¹⁷ McKnight, John *The Careless Society: Community and its Counterfeits*. Basic Books 1996.

“experts” who claimed to know more than she did. She felt compelled to put her son in the institution at the age of three based on her doctor’s recommendation. One might wonder what their lives would have been like if the professional system offered her the help she needed to raise a disabled child at home, rather than removing him. McKnight asserts that our society has become so used to not seeing people labeled as different, that it is assumed they are not suited for community life.

Summary and Implications

The (older/ parents do miss the set schedule of hours and predictability, as the workshop provided needed respite. Community life and employment does not fit into a neat box, it can be messy and unpredictable, but can also be more fulfilling.

The younger parents I interviewed are happy with the direction of Lake Industries. They welcome more community-based activities and employment, as they could not see their child functioning well in a segregated environment.

Table 1: Viewpoints of the Conversion Process

Older Generation	Younger Generation
<i>Closing doors to workshop</i>	<i>Opening doors to community</i>
<i>Letting go: loss and grieving</i>	<i>Opportunity and dignity of risk</i>
<i>Fearing ridicule and abuse in general community</i>	<i>Preference for community work and social life including non-disabled peers</i>
<i>Taking away old friends and insular community</i>	<i>Desiring a similar aged peer group with community involvement</i>
<i>Concerned about care after elderly parents are gone</i>	<i>Graduating with jobs and learning social and daily living skills for community life</i>
<i>35 years of tradition and culture and exclusion from community</i>	<i>Preference and expectation of community inclusion</i>
<i>Understand rationale for conversion but feel it is too late for their adult children</i>	<i>View sheltered employment as reclusive and stigmatizing</i>

The older generation finds meaning in the past, whereas the younger generation seeks meaning in the future. The challenge has been to reconcile the two. It is difficult to serve both equally as they are in opposition to each other. For over 35 years, the professional systems kept changing their own

paradigms and viewpoints of disability services. It must have been difficult to develop trust with an ever-changing professional system. In many ways they made meaning out of this by avoiding the professional institutions and systems and dealing with the issues as a collective family, taking care of their own.

The younger generation strives for full community inclusion, but does recognize that the community may not be as accepting and inclusive as they hoped.

The safety net is something they hold on to as well. Although wanting full inclusion for their children, they remain protective too, as they realize community life can be difficult.

They make meaning of the conversion by taking advantage of the newfound opportunities, many the result of the work and groundwork laid by the older generation.

As the older parents' greatest concern is care after they are gone, the younger parents remain hopeful for a typical life of inclusion, free from harassment or discrimination, for their children.

The common thread that all of them shared was not so much a label of mental retardation or developmental disability, but the fact that they were not accepted or included in the community.

Vermont can claim to be the first state without sheltered workshops, but they are thriving throughout the rest of the country.

If sheltered workshops are to remain, it will be at the expense of young high school students.

This study indicates that high school students in special education do not want sheltered employment. Their parents do not want sheltered employment or sheltered programs, and the schools are preparing students for life in the community, not sheltered programs.

The students and their families want, and expect, more community inclusion.

There is still a strong national hold on sheltered workshops, but by holding on to sheltered workshops, is that not the equivalent of riding those Cavalry horses into battle today?

Why are we so invested in an outdated model? Why would we want to continue a model that segregates people based on a label? Is not the essence of life essentially the same for all of us? If so, then a mere label of disability should not mean exclusion and isolation from the community.

This also indicates a need for research on the current transition planning for students with disabilities. From my own experience, transition planning needs much improvement. Also, current labor trends forecast a severe labor shortage with an increase in older workers retiring and lower birth rates.

The changing labor force estimates that there will be 13 million more jobs than workers in the year 2020 (Kiernan, 2005).¹⁸

People with disabilities constitute a viable, yet untapped, workforce.

Final Thoughts

My advice to others embarking on a similar systems change is to listen and be kind. Remember there is more to systems change than just the system. Those most affected are the participants and families.

When I conducted the first round of interviews, I was nervous that they would see me as the change agent who was disrupting their lives, but they were genuine and welcomed me into their homes and I think they truly appreciated somebody just listening to them, really listening. Each was able to tell his or her story. I hope I have done justice in telling their collective story.”¹⁹

This ends the excerpts from the dissertation of Dr. Bryan Dague.

PPIWDC incorporated this conclusion to show the importance for those who are sponsoring and advancing supported employment to center on individuals and their families because of the tremendous changes that will individually and collectively reverberate throughout the “developmental disabilities’ system”.

¹⁸ Kiernan, W. E. (2005). *Fourth national organizational change forum*, Charlotte, NC.

¹⁹ Dague, E. Bryan. *Sheltered Employment, Sheltered Lives: Navigating the New Realities of Community Employment*. A Dissertation Presented to The Faculty of the Graduate College of The University of Vermont. In Partial Fulfillment of the Requirements for the Degree of Doctor of Education Specializing in Educational Leadership and Policy Studies May, 2006. Excerpts from ages 74-90 with permission of Dr. Dague.

Other necessary and important parts of advancing supported employment are self-advocacy organizations, parent support groups, and peer mentoring as follows.

B. Green Mountain Self-Advocates: A Promising Practice for Employment Supports Self-Advocacy

Green Mountain Self-Advocates (GMSA) is a statewide self-advocacy network run and operated by people with developmental disabilities in the state of Vermont. The GMSA board includes representatives from 17 local self-advocacy groups. The groups come together to listen to each other, make new friends, learn about people's rights and tell politicians and others why people with disabilities are important.

Green Mountain Self-Advocates is building a movement for self-advocacy through public education and awareness, peer mentoring, support, advocacy and direct action.

The mission of Green Mountain Self-Advocates is for people with developmental disabilities to take control over their own lives, make decisions, solve problems and speak for themselves. We educate and make the public aware of the strengths, rights, wants and needs of people with developmental disabilities.

In 1994, GMSA grew out of a self-advocacy group in Burlington. With the help of allies, they connected with other Vermont self-advocates to create a network. Together they started self-advocacy groups in Barre, Middlebury, Rutland and St. Albans. Today hundreds of self-advocates speak up for themselves as members of local groups. It is funded in part by grants in aid from the Department of Disabilities, Aging, and Independent Living and the Vermont Planning Council on Developmental Disabilities.

GMSA board meetings are held monthly in Randolph. At least twice a year membership meetings are held on interactive television at 10 different sites enabling people from all over the state to participate.

Green Mountain Self-Advocates provide practical “how to” tools necessary for anyone who is interested in being a self-advocate and leader in making choices and decisions about how they live their lives. GMSA also offers a number of advocacy workshops including ones on the following topics:

Knowing Yourself, Being Part of the Community, Communication, Problem Solving, Rights and Responsibilities, How to Be a Strong Self-Advocate, Get On Board and Make a Difference: "Nothing about us, without us!" 7 Habits of Highly Effective Teens and Adults, Disability Awareness Workshops, Our Bill of Rights, How To Stay Safe and Knowing Your Legal Rights and Responsibilities, Voting Rights Workshop, Train-the-Trainer Retreats.

Seven representatives of Green Mountain Self-Advocates participated in a roundtable discussion on Tuesday October 30, 2007 at the Vermont Conversion Institute in Burlington, Vermont. They answered and dialogued on the following questions as presented by their coordinator, Karen Topper.

- 1. What kinds of messages did you get when you were growing up about you working, about getting a job?**
- 2. What kind of negative messages about you working did you hear?**
- 3. How did that make you feel?**
- 4. So how did you respond how did you speak for yourself?**
- 5. Were there or are there people in your life who encourage you to be all you can be?**
- 6. How has having a job enriched your life?**
- 7. How does having a job affect your self-confidence or self-esteem?**
- 8. What kinds of problems have you encountered on the job?**
- 9. Can you tell me some stories about how you advocate for yourself on the job?**
- 10. Can you tell me about any ways that your job has helped you to find friends?**

11. Have you ever been afraid before starting a new job? If so, what kinds of suggestions or advice do you have for self-advocates who want to leave a workshop and get a real job?
12. Then there is the issue of support staff, job coaches etc. What advice do you have for them? Let's begin with what works, what has been helpful?
13. Have support workers ever done things that embarrassed you or were not helpful when you were working?
14. Have you ever been in a situation where people did not believe you could do a certain job you really wanted? What self-advocacy strategies did you use to change people's minds?
15. To support workers or state workers from other states who do not want to close down sheltered workshops- what would you say to them to change their minds?
16. How does working help you get connected-feel apart of your community?
17. A lot of people are afraid of losing benefits-how would you respond to this?
18. When you meet people in other states-like at a national conference who spend their days in a sheltered workshop or day program-what do you think of that?
19. Did you experience any differences with how you were treated in school in comparison to how people treat you at work?
20. Why is it important for government or agencies to have self-advocates on the committees that are working to shut down sheltered workshops?
21. Obviously-it is your choice about telling your employer the details about your disability-but you may need accommodations. So tell me how you have been able to describe your disability and what accommodations you need?

The session was very well done and shows the true involvement of each of the representatives in their employment positions and situations. Each of the representatives also performs peer mentoring for other youth and adults with

developmental disabilities who are considering employment or have issues with their employment.²⁰

The participants demonstrated how useful and important self-advocacy and meetings of self-advocates can be in supporting one another in achieving their outcomes for employment and community life. Agencies desiring to advance supported employment in Illinois need to facilitate the establishment of self-advocacy organizations like the Green Mountain Self-Advocates to provide ways to bolster this important supportive mechanism for individuals with developmental disabilities. One question in particular that stood out is no. 20 “Why is it important for government or agencies to have self-advocates on the committees that are working to shut down sheltered workshops?” The participants, all of whom work, were leading advocates on how to effectively implement supported employment. In one example, they expressed considerable concern over job coaches who talk directly to employers about the individual (employee) without bringing them into the discussion and notifying them of the issue in advance. In these new relationships and as a representative and supporter of the individual, old practices have to go by the wayside. The Green Mountain Self-advocates were able to verbalize multiple concerns like this while advocating for supported employment. It is essential that they become a voice in the structure of these new employment initiatives.

C. Employment Advocacy in the State of Washington: A Promising Practice of the Arc of King County, Washington and A Blueprint for Parent Advocacy and Support

Margaret-Lee Thompson, Coordinator of the King Co. Parent Coalition for Developmental Disabilities of the Arc of King County in the State of Washington, established multiple groups to advocate for employment supports for youth and adults with developmental disabilities.

Here is the blueprint over nearly twenty years for the evolution of parent support on assisting their sons and daughters to acquire and retain their own jobs, with real wages with real employers.

²⁰ Presentation by the Green Mountain Self-Advocates on October 30, 2007 at the Vermont Conversion Institute, Hilton Hotel, Burlington, Vermont. For information about any of the trainings and events listed above contact Green Mountain Self-Advocates phone at (802) 229-2600 or (802)-760-8856, Karen Topper, Coordinator.

1. Local Parent Group Development

- In 1988, Margaret-Lee Thompson started a parent group at the local high school. Single focus: Parents wanted JOBS for their son/daughter with developmental disabilities.
- Buy-in was obtained from teachers and principal for these meetings.
- The Local Parent Group brought in speakers – vendors, county, state government. Started process of building relationships with government employees and vendors of supported employment.

• Mrs. Thompson attended King County Developmental Disabilities Board meetings and stood up during “Public Input” every meeting to say her son wanted to work and would be graduating.

- Parents were taken to legislative hearings.
- Meetings were held at her home with invitations to parents and vendors. Each parent was asked to bring one job idea (someone they were willing to ask about hiring an individual with D.D. – not necessarily for their son/daughter). Parents were asked to bring a resume for their son/daughter:
 - What does my son/ daughter really like to do?
 - What does my son/ daughter do well?
 - What won't work for my son/daughter?

2. King County Parent Coalition for D.D.

- In 1990, Mrs. Thompson organized grassroots parent advocacy, named the King Co. Parent Coalition. This coalition is funded by King Co. Developmental Disabilities Division. They fund salary, benefits, mileage, supplies, copying, postage, room rentals.
- The Coalition is not a newsletter model.
- Systems Advocacy and Information are the goals.

• Mrs. Thompson began by calling each of the Special Ed. Directors of the 19 school districts in King County. She asked if there was a parent who was a strong advocate; a parent who was in their office routinely or wrote letters to them. This process worked like a charm.

- She called every disability support group she could find to create diversity of disabilities, ages, ethnicity, and geography.
- Everywhere she went, she introduced herself and struck up conversations.

- The Parent Coalition staff interviews each person who is added to the “membership” list. Each member’s issues are important to advocacy. Trust is built with these connections.
 - There have been monthly meetings since 1990. In addition, four times a year there are two meetings per month to include south King County families.
 - There is an annual potluck where awards are given to legislators. A good number have received awards concerning their work in employment.
 - The Coalition postal mails a packet of information each month by bulk mail: news; federal, state, county information; legislative and congressional information; school and birth to three information; DD systems information, Sr. Family issues, etc.
 - There are email-only members.
 - Email ACTION ALERTS, NEWS, etc. are sent.
 - There is a RAPID RESPONSE Team in order to develop positions on policy items that have not been discussed in a meeting. This Team is composed of members from each of the 16 legislative districts, with age, disability and ethnicity variety. Majority opinion becomes the Coalition’s position.
 - MEMOS have been written and revised. Transition to adult life: Are You Ready?; Individual Provider Training; DDD Assessment for adults and for children, etc. These are used statewide.
 - Parent Coalition staff attends all county board and committee meetings, regional meetings, statewide advocacy meetings, statewide parent coalition coordinator quarterly meetings, etc.
 - The Parent Coalition feels strongly that they are part of the D.D. team: individuals, parents, state, and county.
 - When there is face to face lobbying, The Arc of King Co. pays salary and mileage.
 - The Parent Coalition is under the umbrella of the national Arc Policy Positions. For the first four years, this was not the case. King Co. is very diverse, including having one of the 5 state institutions. It was stressful. The Arc is a good place to be.
3. Statewide Parent Coalitions
- Presently, there are 18 Parent Coalitions coordinators representing 21 of the 39 counties. Mrs. Thompson mentored many of these coordinators as they came into their job.
4. Legislators’ Forum
- King Co. Parent Coalition is a co-sponsor with the King Co. Board for D.D. for the annual legislators’ forum. The 18th forum was presented in November 2007.

- **At each forum, parents and individuals have presented supported employment. There are “workers” who tell their name, their legislative district, their job, how long. It is a favorite part of the forum for legislators.**

- Some of the parent speakers thank legislators for their son's and daughter's job support services and other parents talk about their hope of this service.
- The Coalition staff is in charge of all speakers, grassroots organizing to invite elected officials, room set-up, etc.
- 500+ people attended Nov. 2007.
- 32 of the 48 legislators from King County attended.
- 5 of the 6 Congressional districts were represented by staff,
- Governor's office, King Co. Executive, Dept. of Social and Health Services Secretary, Director of the Division of Developmental Disabilities.
- Outcome: Legislators and Congressional staff know that Mrs. Thompson knows many of their constituents and can provide unbiased and accurate data. This is very helpful during legislative session.
- Since 2005, the forum has been televised: You can view the 2007 forum on cable TV at:

<http://www.tvw.org/media/mediaplayer.cfm?evid=2007110138&TYPE=V&CFID=1736124&CFTOKEN=10adee59d9912261-6121A002-3048-349E-4E344526AF0CC3F6&bhcp=1>

5. Parent Training

- In 1994, a Parent Training coordinator was added to the Parent Coalition contract. Since then there have been dozens of trainings. The Parent Training coordinator responds to requests and present hot issue topics for parents, with no charge. Again, King County DDD is the funder.
- The Parent Training Coordinator works with King Co. DDD to present annually a “Transition to Adult Life” series of 4 trainings. These are well attended. Each year they are held in a different location in the county. Energy goes into making sure parents know about this training.
- There is a separate mailing list for these trainings, to encompass teachers, and interested parties, as well as parents, who are the main target.
- Annually, there is an open-house type of Vendor Fair where families and individuals can meet vendors of supported employment. These are well attended.
- Specific school districts can request a Transition planning night.
- A number of Memos have been developed, with revisions for families: Are You Ready? Attached.

6. School to Work Pilot

- The Parent Coalition strongly supports a current pilot project in King County: School to Work. This is a program where vendors, parents, high

school Transition teachers and county staff work cooperatively. A certain number of graduates are designated to be in this program with the goal of graduating with a job. Very successful. The state legislature has funded pilots in several counties this past session.

7. Advocacy Day. Washington State has a biennial legislative system. Odd years are the Main Session and even years are Supplemental. The Main Session: middle of January to middle of April. Supplemental year: middle of January to middle of March.
- Advocacy Day is held in Olympia on each Wednesday of session. The Arc of WA and The WA State DD Council fund and organize this. Mrs. Thompson runs the meetings.
 - From 10-11:30 A.M., speakers present on chosen topics of importance to DD.
 - At this meeting, The Arc of WA has available, issue papers on many topics for individuals and parents to use in talking with their legislators.
 - From 11:30 on, visits to legislators or legislative aides are made. Hearings, floor activity, Governor's office are experienced. Goal: to take the mystique out of the legislative process.

• Hundreds of parents and sometimes their child have spent the day with Parent Coalition staff in Olympia. It is always a good experience. Outcome: Parent Coalition staff and members get to know each other better during the carpooling ride. At the end of the day, each person understands how important advocacy can be. They tell their own story to their legislators; Parent Coalition staff is there for the data. There is a heightened response to ACTION ALERTS from the people who are clear about the legislative process. This is time-consuming but invaluable if your goal is grassroots participation, not just participation by a few.

- Parents are invited to give testimony at important hearings, especially budget hearings, where employment funding is considered. An effort is made to invite parents from districts of committee members. Each Coalition member is mentored through the hearing process.
- One third of Washington State's Legislature is from King County. Thus, there are many Committee Chairs and many in leadership of both chambers. Goal: build relationships and trust. Tell the truth. Keep them updated. Develop champions.

8. Parent Groups

The Parent Coalition has cooperated with many grassroots parent groups over the years. One current parent group has a great model that works well. Parents meet in one room with topics of interest while their teen-aged or adult sons/daughters meet in same building. Outcome: teenagers talk to adults with DD who have jobs and have money to spend!

9. Stakeholder Work Group:

- In 1997 Mrs. Thompson was asked to be on the statewide Employment/Day Program task force. This was a two-year process.

• After many difficult discussions, the task force unanimously agreed upon the following statements: "It is the assumption that all individuals with DD can work. This work should be in ordinary places."

- Exceptions to Policy are possible, agreed by a team of people, e.g. over age 62, extreme behaviors, multiple disabilities, etc.
- The process of every person with DD being able to work may take a "Pathway". This Pathway may be short or may be very complex, have many steps and take years. The ultimate focus is employment.

10. Working Age Adult Policy:

In 2004, the Division of Developmental Disabilities presented the Working Age Adult Policy (WAAP), which was based on the stakeholder workgroup outcome.

- This has meant changes to Day Programs.
- This means more volunteer work and no mall walking.
- This means changes to sheltered work, which have concurrently lost most of their contracts to overseas.

• Mrs. Thompson states that this policy would have been a huge help to her son when he graduated from high school in 1990. She spent the first 21 years of his life, advocating for his abilities. Now there is a policy that assumes the ability to work.

• This policy is codified in law and in state policy. Parents now have leverage.

- Changes can be hard: family schedules can be accustomed to daily sheltered work; residential setting schedules are disrupted. These are legitimate problems.

- Families may need more respite or adult day care in order to retain a parent's job.
- Individuals may need more social and recreation activities to fill up extra hours.
- Transportation must be worked out.
- There are many different solutions. Creativity is needed.

11. Testimony by Mrs. Thompson:

Our son Dan, who passed away in January of 2005 worked for 14 ½ years at Microsoft in Seattle, eventually as a mail sorter.

The week before he passed away, he bested his own record: he was the most accurate and fastest mail sorter. His bosses knew it and his co-workers knew this.

His self-esteem was a wonderful part of his life. Never would I have dreamed at his birth that our son would have this opportunity to work 35 hours/week. There were no role models for supported employment. We were fortunate to have good teachers and active parent groups in which we participated (3 states).

I have a passion: our folks should be in ordinary places, doing ordinary things. I believe with all my heart that everyone is welcome in our society. Our son taught me this. ²¹

²¹ Presentation on November 15, 2007 during a informational briefing for PPIWDC sponsored by Linda Rolfe, Director of the Washington Division of Developmental Disabilities in Seattle, Washington and reconstructed by Margaret-Thompson.

D. Anixter Adult Community Transition Program in Chicago, Illinois: A Parent Sponsored Initiative

Anixter, in Chicago, Illinois, has developed...

...the Adult Community Transition Program, which evolved in 1998 out of the efforts of parents working with Anixter's special education cooperative, Northern Suburban Special Education District, NSSED, to explore barriers to and solutions for effective transitioning from formal education to adult life for individuals with developmental disabilities.

From the exploration of the problems and challenges to successful integration, the parents learned that a system of support was necessary to maintain successful functioning in the community. The Parent Advisory Group (PAG) developed and proposed a program that became ACT, which was modeled on the transition program being established by NSSED.

The ACT Program takes place in the community with a 5 to 1 client to staff ratio. Staff work with clients to develop a schedule each week.

Goals for the Program Participants:

- **Meaningful contribution to society: Employment, Volunteering;**
- **Self-Sufficiency: Life Skills Development, Use of Community Supports;**
- **Social relationships: Disabled and Non-Disabled Peer Networks;**
- **Continued Personal Growth: Education, Therapeutic Recreation;**
- **Self-determination and choice for participants;**
- **Realization of participants' dreams and hopes, as can be accomplished;**
- **Access to and integration for participants within the community, as can be achieved;**
- **Collaboration among various community entities; park districts, schools, local businesses and provider agencies;**
- **Belief that all elements of the individual's life - the social, vocational, developmental and life skills competencies -**

- must be addressed to achieve success in transitioning into adult life; and**
- Regular reviews and evaluations of the program to maintain quality and ensure that participants are making progress towards their individual goals**

Customized Employment Initiative:

Anixter Center was the recipient of a T-TAP grant (Training and Technical Assistance for Providers) in 2005. The purpose of T-TAP is to provide customized employment with individuals who are classified as harder to place and who are currently working in a more sheltered setting.

The ACT Program hired a Community Developer who was trained in the principles of customized employment. Program participants were identified and the Community Developer began to work with them on their interests, developing a circle of support and talking with prospective employers or volunteer sites about possible employment/volunteering.

While this process is very labor intensive and also takes longer than more traditional methods of placement, several of the ACT participants started on a vocational path for the first time – either volunteering or part time paid work.

The dynamic forces behind these initiatives and their continuation are Ellen Garber Bronfeld (creator), Alan Bergman, Chief Executive Officer, Cheryl Smith, Vice President for Adult Services and Carol Woodward, Vice President of Programs.

Summary Comments Chapter VII Advocating for and Advancing Supported Employment And Related Services

Advocacy, support groups and peer mentoring were discussed in this chapter with practical approaches. As identified under Chapters II “Barriers” and III “Focus Groups”, youth and adults with developmental disabilities and their families/representatives have serious concerns, issues, and fears when making changes like those envisioned moving from congregate supports to integrated employment with supports in the real world.

The methods described in this chapter, active listening, self-advocacy and peer supports, parent support groups and related advocacy for supported employment, and parent action to cause reforms in adult services activities can be highly assistive in reducing fears, concerns, and issues and allow individuals and their families to make more informed decisions through better information and support with real life examples.

The methods identified in this chapter certainly are way PPIWDC endorses for Illinois adult service agencies to structure advocacy and support initiatives to provide improved acceptance and adoption of supported employment as a priority way of doing business.

Chapter VIII. Examples of Best and Promising Practices on Integrated and Inclusive Supported Employment and Related Supports Among Local Agencies

The criteria for inclusion in this category is that the agency promotes, as its top priority, the employment of individuals with developmental disabilities facilitating the acquisition by such individuals of employment at typical work sites in an integrated and inclusive manner with the mainstream workforce at commensurate wages paid to other workers performing similar responsibilities.

The intention is that individuals work at individualized work sites with non-disabled workers. When more than one individual with a developmental disability is employed by a business that such individuals work in different departments or are dispersed throughout the business.

It is also intended that the individuals are employed by the business and not by the support agency whenever possible. The providing agency is also intended to greatly reduce services that represent congregate care such as sheltered workshops, enclaves, and provider driven residential services. There are many agencies that represent best practice in accordance with these standards throughout the United States. Public Policy Impacts of Washington, D.C. made visits to the following agencies over the past six months and has verified that they meet the above criteria.

The stories and information below are important to gain perspective on the inclusionary fabric of these agencies. Spreadsheets have been developed by PPIWDC to show where adults are working, wages earned and other employment data, the inclusionary and integrated aspects of the employment, especially focusing on individuals working in singular work settings without congregation, transportation methods and types of residential supports. This survey technique and modifications, thereto, is recommended to be used within this Blueprint for outcomes assessments.

A. Common Ground in Littleton, New Hampshire (An Example from a Rural Appalachian area of the Northeast United States)

**Employment Services Transition from TEMPO to Common Ground
1993 – 2007 in the words of Mark Vincent, Chief Executive Officer**

The need for meaningful employment opportunities was one of the major catalysts leading to the reorganization of the service delivery system in the 22-town region served by what was then known as TEMPO.

In 1993, as a new Area Director, I was concerned by the slow progress the agency was making toward bringing people into integrated work environments. There were several enclave settings including a private school, a seasonal amusement park and a natural fiber factory. There was clear resistance to losing these workplace contracts, where the staff had established relationships that allowed them to “place” several individuals under staff supervision. None of these settings utilized natural supports. Only one individual was working in an integrated community setting, and this was an unpaid position with staff support.

Most of the individuals served were viewed by staff as needing extensive “day habilitation” and not being “ready” for employment. Ironically, the organization had closed the sheltered workshop just prior to my arrival and this decision, intended to move more people into the community, had actually moved people away from employment and back to either “crafts” or facility-based recreation.

Several of the individuals who had thrived in the sheltered workshop had been moved into the enclaves, but reported less job satisfaction.

After a five-month dialogue with staff at all levels, it became clear that part of the problem was the way in which our resources were deployed. All staff were based in the building, with only two people viewing their job as primarily community-based. This forced employment into enclaves because there were not enough line staff to facilitate other employment or volunteer options. Another issue was the training of staff.

Most staff were comfortable in a facility but very uncomfortable attempting to establish relationships that would lead to community opportunities. There were several people who had a long history with the agency and were invested in maintaining the status quo.

Meanwhile, both vocational rehabilitation and the State of New Hampshire Bureau of Developmental Services were displeased by the lack of movement toward integrated community-based services.

After a period of angst and confusion, a plan gradually emerged in which all positions were re-advertised: essentially a new service structure was “born”.

The new program was christened “Common Ground” by the newly hired staff. The organization consisted of five self-directed work teams. Each team leader was responsible for hiring, motivating and overseeing line staff who were called “community integration specialists” (a term that is now common, but was totally novel at the time).

In January 1994, the proposed job description for this position included the following:

“The key ingredient for this position will be the ability to aggressively pursue individualized job, recreational and leisure opportunities in the community”.

After further refinement, we decided to hire an employment consultant to work with each team because meaningful employment was one of the core outcomes we hoped to achieve.

As the new system moved forward during the next 12 years,

...we have been repeatedly taught lessons by the individuals we serve: most can work in paid setting, even those persons who had previously been deemed “not ready”.

An array of options has emerged, none of which are in congregate, sheltered or enclave settings.

Many individuals are supported naturally in the workplace, which allows our staff to be “invisible” in their lives.

Community integrators are selected for their local connections and their sense of optimism, which has paid dividends in employment and volunteer opportunities.

At this writing, 35 persons are employed. A sampling of jobs includes: grocery bagging, customer service associate, retail merchandiser/stock person, janitorial work, cook, dishwasher, package handler, and farm help.

For individuals being assisted by our services, a job is key to self-esteem and is often the link to socialization and support. Employment in the community has replaced “day habilitation” in the facility as the core of our service system.

Today, Common Ground, located in rural New Hampshire, serves 39 adults in supported employment, and 38 individuals live in foster care with the balance living on their own or with their family or in supported living.

Adult foster care is emphasized with one or two individuals living with the provider in an inclusive manner. It was found to be much less expensive than was supported living.

Common Ground emphasizes community inclusive activities through the foster care or family provider of residential supports.

Five individuals with severe and challenging conditions own their own businesses and are self-employed.

The SE model is to assist individuals to acquire their own jobs. Transportation is paid at the federal rate for reimbursement. Common Ground also has contracts with school districts on school to work transition especially for hard to serve individuals with the goal to have the students be gainfully employed at the time of graduation.

Common Ground adheres to the following principles: No more than 2 people can work together, sometimes different jobs and different shifts. Employers and their natural supports do not want to say the individual and the job are not working out. We encourage employers to fire the individual if the job is not working out.”

It is quite revealing what an agency can do in a very rural Appalachian area such as Littleton, New Hampshire.

The dynamic force at Common Ground is its chief executive officer, Mark Vincent, who has shepherded the agency's conversion from congregate employment and day services to individualized supported employment over

the last fourteen years. Within Appendix N is the survey of the employment outcomes for 39 adults who have acquired employment through Common Ground.

B. Job Path of New York City, New York (Midtown Manhattan) (An Example from the largest U.S. City)

Job Path was born out of Vera, a non-profit agency that began in the 1970's piloting assistance to criminal justice ex-offenders in gaining supported work.

As part of the Willowbrook consent decree, Vera developed Job Path for deinstitutionalized individuals and Job Path has offered employment services since 1978.

Since then, Job Path has helped people with developmental disabilities find and excel in mainstream jobs. The agency has placed more than 2,000 people in positions such as porter, maintenance, food service, clerical, stock, mailroom and child care.

Job Path graduates work in banks, law firms, and other prestigious organizations including: Saks Fifth Avenue, The Gap, JPMorgan Chase, UPS, Blockbuster Video, Restaurant Associates, Modell's Sporting Goods and Daffy's.

The dynamic force behind Job Path is Fredda Rosen, who is the executive director and has been a Job Path employee since 1980. Within Appendix O is information on the individuals who have acquired employment with the assistance of Job Path.

The Transitional Employment Team works with individuals who have the ability to move into the workplace with intensive but time-limited assistance lasting about 12-18 months. Each person starts with a five-week on the job assessment so that the team can identify his or her strengths, skills and needs. The person receives a stipend while trying out different job tasks.

Following the assessment, the person and their family are brought together to discuss the results and create a job development plan. As part of the job development process the person learns how to complete job applications and prepare for interviews. Once a person acquires a job, Job Path provides support and coaching to help them learn the required tasks and adjust to the workplace.

Job Path follows up with everyone for at least one year after hire. Staff visit regularly, helping employees adapt and giving supervisors tips on how to encourage the employee's best work. After that time, some workers are self-sufficient. Yet even the most independent workers occasionally need assistance to meet increased responsibilities, to adjust to a changing work environment, or to seek a more advanced position elsewhere.

Job Path steps in whenever assistance is needed to provide long-term support but encourages co-workers and employers in providing customary support. Transitional employment serves 100-125 people with average wages that are significantly above minimum wage.

The Customized Employment Team provides services for people who need long-term supports to enable them to work. Job Path worked with Mike Callahan of Mark Gold and Associates to develop customized employment processes. Central to customized employment is the "discovery process" during which employment specialists spend time with individuals, their family and friends, and in their neighborhoods to get to know each person's strengths, abilities and needs.

The information gleaned during the discovery process is used to develop an individualized vocational profile. The profile targets particular types of jobs and skills, along with specific employers that might prove a good match. Using a personalized marketing profile, the Customized Employment Team develops jobs by working closely with employers to customize a job that serves the employer's needs and takes into account the individual's strengths and needs as well.

Job Path provides intensive job coaching as individuals learn their new jobs and continues assistance over the long-term to ensure job retention. Customized employment is provided to 30-35 individuals per year and 40 are provided long-term supports.

Job Path also offers Community Supports to help individuals actively participate in the life of their communities. These services were developed as an alternative to group-oriented day programs and are for people who need long-term supports to enable them to become involved in civic, volunteer and recreational activities in their communities.

Job Path looks for service and religious organizations, social centers, parks, and gyms, where individuals can pursue their specific interests. The goal is to facilitate each person's unique plan. (Some people have also elected to find paid jobs through Job Path's employment programs). Initially, Job Path is the individual's main resource, along with a few close relatives and friends. But as individuals become known in their communities, they develop friendships with the people they encounter from classes, gyms, volunteer work, and other activities, and their support circles expand. Thirty individuals with significant and challenging conditions are offered community supports.

Job Path helps people find **Supported Living** and affordable housing and put in place whatever services they need to live in their own homes under supported living services. Targeted to people with severe disabilities who need around the clock assistance, this program is also available to people who require less intensive help. Approximately forty individuals receive supported living services.

Finally, Job Path offers **Medicaid Service Coordination**, assisting individuals with developmental disabilities to find the services they need to lead healthy and fulfilling lives.

The focus in MSC is on assisting each person to identify his or her goals and desires and to achieve them- from having a home, a job, pursuing interests and hobbies, a "circle of friends" and participating in community life, In addition, the service coordinator ensures, the person has access to medical, clinical, and other services that promote good health and safety.

The service coordinator is a strong advocate who helps each person put together a life plan and makes sure all paid and non-paid supports are working together on that person's behalf. The coordinator, who is involved with the person's family as well, helps locate all the supports and services that person needs. For example, the coordinator may help a person get connected with a doctor, solve a housing problem, straighten out problems with SSI, or other entitlements and find an employment program. Sixty individuals receive service coordination.

Job Path has deliberately tried to remain small in order to offer quality services. It is now implementing a **special pilot program** for ten individuals with Asperger's Syndrome assisting them with development of a Life Plan and supported employment. The challenge here for Job Path is that the individuals, who are cognitively higher functioning, will be competing with a mainstream workforce, also cognitively higher functioning.

Job Path operates on a budget of \$3.5 million per year obtained from federal and state sources and locally raised private monies. Job Path has never operated any congregate services for individuals with developmental disabilities.

Nick Rose of the New York Developmental Disabilities Planning Council participated in a 1990's venture for ten sheltered workshops across New York State to advance supported employment as a prevailing practice and lessen reliance on sheltered employment.

He directed PPIWDC to Riverside Arc, Troy, New York and Westchester Arc, White Plains, New York to see how the agencies have evolved over the course of the past twelve years to provide inclusive and integrated employment services for youth and adults with developmental disabilities. Certainly instructive is the time it takes to make these major transitions.

C. Riverside Enterprises in Troy, New York (A Suburban Supported Employment Example)

Originally named in 1978, Riverside Enterprises first meant a sheltered workshop program. Over the last two decades, Riverside Enterprises has evolved to come to represent a family of day supports and services all focused upon dramatically improving the quality of life for people with developmental disabilities.

Many of the supports are geared towards helping people with developmental disabilities become valued, contributing members of their community.

Community Inclusion Project

Begun in December 1993, the Community Inclusion Project is designed to connect persons with developmental disabilities on an individual basis to local community life based upon their choices.

The Project helps people to become involved in volunteer jobs, associations, churches, recreational groups, and self-development/educational activities. Over the last two years, supported employment services have become more available to people involved in the Project. Medicaid waiver monies as well as NYS Vocational and Educational Services for Individuals with Disabilities VESID resources for supported employment services fund people involved in the project.

The Project is known both statewide and nationally as one of the first successful efforts to provide those supports on an individual basis in the community. Building supports around a person's unique needs, interests, talents and choices in their community is what the staff of the Community Inclusion Project excels at!

Employment Services

Since 1986, Riverside Enterprises employment services have been assisting people with developmental disabilities to become successfully employed in the community. What makes employment services offered through Riverside Enterprises special is the attention staff gives to getting to know each person supported as an individual with his or her own interests, gifts, needs, and dreams. It is clear right from the start when an employment services staff person goes to a person's home to meet and get to know the individual and his/her family that customer service is a priority.

All job placements are done on an individualized basis to provide the best possible match between the person's needs, interests, skills and, the job site. In Appendix P is a chart showing recent job placements, types of work being done and wages.

Group placements or enclaves are not utilized as they detract from a person's ability to build strong social relationships with non-disabled coworkers.

Work Centers/Production Operations

The roots of Riverside Enterprises can be found in the work center that was developed in the late 1970's as a means to provide vocational training to people with developmental disabilities.

The work center expanded in size and numbers of people served through the mid 1980's until supports shifted to helping people learn the necessary employment skills in a paid community job.

Now 50% smaller in numbers from the late 1980's, today's Riverside Enterprises is a sophisticated combination of three product lines and a work force comprised of people with and without disabilities.

A third of the workers with disabilities also spend a portion of their week in community roles, such as volunteering or taking classes, building upon their interests, talents, and choices.

One product line, wire forming, creates wire products for the floral industry and is sold in 48 states, Canada, and Puerto Rico. Intensive development work over

many years has resulted in Riverside Enterprises becoming a serious competitor in this growing market. Check out our on-line catalog at www.wirestore.com.

School to Employment Transition

Riverside Enterprises offers school to employment services for students with developmental disabilities. Recognized as a leader in transition services in New York State, Riverside Enterprises has married their person-centered approach with the concept of developing a working partnership with the school – all in support of the young adult's success in community employment.

Perhaps the flagship of transition programs in New York State, the School to Employment Partnership (S.T.E.P.) was developed with the Enlarged City School District of Troy in 1995. The Partnership is a highly innovative blending of school district staff and Riverside Employment staff to support freshmen through senior students to become employed competitively by graduation and provide post-graduation employment support.

Other transition arrangements have been developed with area districts with as few as a single student, but all sharing the person-centered approach that is the hallmark of Riverside Enterprises. A model contract for such services is contained in Appendix Q. Over 95% of the youth graduating from high school are gainfully employed at the time of graduation and receive employment supports as necessary provided by Riverside.

D. Westchester Arc in White Plains, New York (A Suburban Supported Employment Example)

Westchester Arc is the largest organization in New York's Westchester County serving children and adults with intellectual or developmental disabilities. We are a family-focused agency offering opportunities to individuals with disabilities such as autistic spectrum disorders, Down syndrome, mental retardation, cerebral palsy and learning disabilities. The agency supports social inclusion for people with disabilities because of its benefits to the entire community.

Westchester Arc is committed to achieving the highest degree of self-reliance consistent with the personal abilities and choices of individuals with developmental and learning disabilities. Acquiring and retaining gainful employment is critical to such independence in adult life.

Career services offers personalized career planning, training, job placements and employment-site coaching. We explore the interests and aptitudes of the people we serve, then match them to work opportunities. We emphasize community-based employment but also operate work centers in Mount Kisco, White Plains and Yonkers for individuals who require additional supports.

Career planning should begin in high school, and our S.T.A.R. (Students in Transition Accessing Resources) program partners with public schools to begin preparing students, 15 and older, for the adult work world.

S.T.A.R. (Students in Transition Accessing Resources) works closely with students (15 and older), families and teachers to prepare young adults for satisfying careers and lives as contributing members of their communities.

- **We begin by building a Person-Centered Plan for each student, identifying career, recreational and residential options.**
- **We then work with special education instructors to teach young people about work ethic, team-building, interview techniques and other career skills.**
- **We identify internships so that students can gain firsthand experience before making important career choices.**
- **We locate post-graduation jobs that match student interests and abilities.**
- **We coach on the job to reinforce classroom discussion and to ensure a satisfying work experience.**

The goal for school to work transition is to assist students to acquire employment before they graduate so they can make a seamless transition to adult life.

Pre-vocational services are designed for adults who need training in preparation for employment. The curriculum focuses on general knowledge rather than specific skills, including:

- Following directions and adapting to a work routine
- Work ethic
- Socially appropriate behavior
- Employer expectations
- Travel training

Services are provided individually or in small groups in one of Westchester Arc's training facilities (Mount Kisco, White Plains and Yonkers), businesses (micrographics, mailroom, cleaning service, recycling/redemption), or community sites throughout Westchester County.

Based upon personal preferences and skills, adults with developmental disabilities are matched to in-community career opportunities with one of over

250 business partners. Explore jobs in office, retail, food service, maintenance and other settings. Job coaches provide initial onsite training, and then continue to monitor progress for the duration of the work relationship. Within Appendix R is an impressive survey of the current employment services for adults with developmental disabilities who are provided support in part by Westchester Arc.

Westchester Arc strives to meet this goal by providing a continuum of day services to individuals depending upon need and personal preference.

Services

- Without Walls - Without Walls gives individuals with developmental disabilities the tools to function in society on a daily basis. Activities are delivered entirely in the community and include bowling, movies, museums, library visits and community service work. Participants gain self-confidence, improve social skills and achieve stronger ties with the community.
- Choices - Choices is a new program for young adults with developmental disabilities. It combines day habilitation with supported employment services. Unlike typical supported employment, individuals work and volunteer at community sites and are supervised by staff at all times. The experience helps young adults build job and life skills, provides the opportunity to make friends and helps students transition into the adult world. As the program's title suggests, activities are based on the skills and interests of each participant.

As one of several agencies originally vested in advancing supported employment services in the 1990's as part of the New York Planning Council for Developmental Disabilities, Westchester Arc is now at the threshold of closing the final door on its sheltered workshop through a new initiative for around thirty adults with significant developmental disabilities.

Through this OPTS Pilot project, Gateway to the Community, Westchester Arc proposes to offer meaningful opportunities for community inclusion, community day habilitation, community prevocational activities, and community employment to 32 individuals with developmental disabilities.

These individuals currently receive prevocational services in a sheltered workshop setting at either 121 or 39 Westmoreland Ave in White Plains, NY.

These individuals present significant service challenges and have not been able to obtain or sustain community employment. On a systems-basis, approval of this proposal will contribute to the closing of what was once the largest sheltered workshop in Westchester County. In December of 2007, Westchester Arc plans to close its 121 Westmoreland Ave facility and move to a new multi-purpose site in Hawthorne NY. As currently planned the new site will not provide sheltered workshop services.

More importantly, on an individual basis, Westchester Arc proposes to offer ongoing person centered supports and community based services to the 32 individuals with the conviction that these individually chosen and community focused supports and services will maximize their potential for vocational/community involvement and their growth in independence and self advocacy.

Examples of services to be provided include mobility training, instruction in the appropriate use of job related facilities (e.g. lunch rooms; rest rooms); assessment, training, and assistance in developing appropriate social behaviors in such community places as restaurants; recreational facilities; and stores; communication skills; patterns and routines appropriate to the practices of the local community; basic safety skills; personal care skills; health care skills; money management skills; meaningful leisure and fitness skills; self advocacy skills; and other skills related to an individual's successful participation in community activities.

With the consultation and participation of Dr. Beth Mount, Westchester Arc staff have met with and worked with these 32 persons for many months on the new opportunities that this proposal would provide. Each of the 32 persons and their families has expressed interest in participation in this *Gateway to the Community* proposal. It is envisioned that the intensive staff and transportation supports and services to be provided by this project will more effectively make possible community based employment and other community activities to each participant based on their individual interests, talents, and choices.

While it is envisioned that most activities for these 32 individuals will be provided in the community, the agency's new site will provide several other services and opportunities to complement their community and employment activities, e.g. career planning, vocational assessments, classes in occupational fields such as office work, commercial photography, the arts, physical fitness assessments and planning, and self advocacy training and meetings. The new site will also offer new internships, part time and full time employment opportunities for these consumers.

Westchester Arc uses pre and post consumer and family satisfaction surveys as a measure of effectiveness. Semi-annual meetings will be arranged individually and collectively for the consumers and families to discuss and document their respective levels and satisfaction with individualized services. Quality Assurance department staff will conduct annual surveys to ensure regulatory compliance.

An Evaluation Committee will be established to oversee the evaluation process, which will review satisfaction survey results, QA surveys, and personal outcomes for the individuals served. The entire OPTS proposal is referenced in Appendix S.

E. Project SEARCH: a collaborative effort among the Division of Disability Services at Cincinnati Children’s Hospital Medical Center, Great Oaks Institute of Technology and Career Development and the Ohio Rehabilitation Services Commission. (Cincinnati, Ohio)

In 1995, the American College of Healthcare Executives adopted a policy statement, which encourages healthcare organizations “to take the lead in their organizations and their communities in creating working environments that enhance the opportunities of persons with disabilities to gain and maintain employment.”

Project SEARCH is a collaborative effort among the Division of Disability Services at Cincinnati Children’s Hospital Medical Center, Great Oaks Institute of Technology and Career Development and the Ohio Rehabilitation Services Commission. Project SEARCH provides employment and education opportunities for individuals with significant disabilities.

The program is dedicated to maximizing the potential of people with disabilities through competitive employment in non-traditional jobs. The dynamic force behind Project SEARCH from its inception in 1999 has been Erin Riehle who is the director and is employed by Cincinnati Children’s Hospital Medical Center.

Ms. Riehle, a registered nurse by profession, created Project SEARCH to meet shortages of staff at the hospital and to essentially have the hospital give back to individuals with disabilities who have paid so much into the hospital over the years for their care.

Project SEARCH has adopted this policy statement as a guiding principle and actively works to create innovative solutions for workforce and career development for people with disabilities. Although our initial expertise was

focused in the healthcare setting, we have since expanded our program to other businesses, such as banking and retail.

Project Transition Clinic

The purpose of the Vocational Educational Transition Clinic is to work with youth (ages 14 and older) with chronic illnesses, traumatic injuries, rehabilitation issues, or other disabilities to generate a plan that addresses their vocational, educational, training and employment goals.

The program is individualized to meet the specific needs of clients and may include services such as coordination of GED programs, researching appropriate career and technical or college choices, and encouraging the adoption of appropriate assistive technologies in schools. The process that the Vocational-Educational Coordinator uses for plan development includes:

- **A family interview to determine vocational interests, abilities, aptitudes and needs.**
- **Coordination of evaluations to provide information related to individual career goals.**
- **Provision of eligibility and referral services to community service agencies, including state and community rehabilitation agencies, as needed.**
- **Development of the vocational components of an Individual Education Plan (IEP) for school-aged children.**
- **Coordination of services and information exchange between the school, the medical team and other service providers.**
- **Provision of long-term follow-up and support, especially during key transition times and after high school/employment (when appropriate).**

Eligibility Criteria:

- Age 14 years or older (with focus on last two years of high school)
- Must have a chronic illness or disability
- Must be referred by a Children's Hospital Medical Center staff

High School Transition Program

The High School Transition Program is a one-year program for students with disabilities in their last year of high school. It is targeted for students whose main goal is competitive employment.

The program takes place in a healthcare or business setting where total immersion in the workplace facilitates the teaching and learning process through continuous feedback and application of new skills.

A typical school day includes classroom instruction in employability skills, participation at one or more worksite rotations, lunch with peers, and feedback from the instructor. The rotations are designed to complement each student's interests, skills, and strengths. Individualized job development and placement begins after the rotations are completed. Students are given support through on-the-job coaching and work site accommodations with the ultimate goal of independence.

Eligibility Criteria:

- 18-22 years old
- In last year of high school (may have participated in deferred graduation)
- Desires to work in the community
- Willing to access independent transportation options
- Has met all academic requirements for graduation
- Has basic communication skills
- Has appropriate social, grooming and hygiene skills
- Has independent toileting and feeding skills
- Can pass drug screen and felony check
- Has updated immunizations
- Has achieved 2nd or 3rd grade reading and math levels (preferred)

Adult Employment Program

Project SEARCH provides a comprehensive approach to employment, job retention, and career advancement for individuals with disabilities. Serving as a single point of entry, the Adult Employment Program coordinates job development and agency referrals with human resource needs. Our goal is to match qualified employees with open positions, primarily in healthcare. We provide on-the-job support, such as job coaching, adaptations and accommodations, final task definitions, and travel training. Our on-site job retention staff creates a unique support system where people with disabilities can successfully maintain employment and advance in their chosen careers.

Program Steps:

- Identify open healthcare position(s)
- Perform job analysis/identification of essential functions
- Research possibility of job clusters
- Match job to qualified candidate
- Identify and implement accommodations and adaptations
- Coordinate job coaching during initial phases of employment
- Adapt orientation for new employees, co-workers and supervisors
- Provide retention and career advancement opportunities

Eligibility Criteria:

- A minimum of 18 years old
- Desire to work in a healthcare setting
- Willingness to access independent transportation options
- Has basic communication skills
- Has appropriate social, grooming and hygiene skills
- Has independent toileting and feeding skills
- Can pass drug screen and felony check
- Updated immunization

Project SEARCH employs approximately seventy individuals with disabilities within a mainstream workforce of over six thousand employees.

F. Cuyahoga County Collaboration on School to Work Transition (Collaboration between an adult services provider, schools, and the Cleveland Clinic)

The Cuyahoga County Board of MR/DD and the Mayfield City Schools representing Cuyahoga East Vocational Education Center have an interagency agreement for the implementation of school to work transition planning and supported employment services.

The purpose of the agreement is to provide for meaningful post-school employment outcomes for youth with developmental disabilities graduating from the public school system.

It is understood that the students targeted for services in this agreement will meet the eligibility criteria for enrollment in the Cuyahoga County Board of Mental Retardation and Developmental Disabilities. These students will become the responsibility of CCBMR/DD upon completion of transitional programming and graduation.

The agreement covers:

- 1) Schedule of Interaction of Cooperating Agency Liaisons;
- 2) Individual Transition Meetings;
- 3) School Services;
- 4) CCBMR/DD Services;

- 5) The Transition process;
- 6) Exchange of Information; and
- 7) Expected Outcomes.

This agreement has resulted in nearly thirty individuals acquiring jobs at the Cleveland Clinic. The jobs have largely been carved and customized from parts of jobs from other employees. One transitioned worker, now an adult, has a position in the Transplant Department that involves document copying, running errands, taking specimens to the laboratory, retrieving X-Rays, assembling new patient charts, and assembling laboratory kits. The worker is paid slightly above the minimum wage for the work.

A complete analysis of the positions is located in Appendix T. The contract between the Cuyahoga County Board of MR/DD and the Eastern Cuyahoga Public Schools is located in Appendix U as a promising practice model. The dynamic forces behind this initiative are Terry Ryan, Superintendent and Joe DeCapite, Director of Employment Services with Joseph Marino, Program Coordinator of the Cleveland Clinic Internship program on behalf of the Cuyahoga East Vocational Educational Consortium.

G. Individual Advocacy Group, Romeoville, Illinois (An agency serving individuals with dual diagnoses of severe mental illness and developmental disabilities.)

Individual Advocacy Group was founded in 1995 essentially a program without walls. It has never operated congregate services including adult workshop services. It serves some of the most difficult individuals with developmental disabilities including a large group of individuals with dual diagnoses of mental retardation and mental illness as well as individuals involved in the criminal justice system.

The dynamic force behind IAG is Charlene Bennett, Chief Executive Director and David Brooks, Chief Operations Officer, who both founded IAG. Individual Advocacy Group's underlying principles for community living have been a holistic approach to community involvement blurring the lines between what has been traditional residential and day services.

To live in the community one should have a home. All individuals at IAG rent or lease a house or apartment. Up to 3-4 people share the cost of rent for a 3-4 bedroom house in a single-family neighborhood or 1-2 people rent 1-2 bedroom

house or apartments. IAG provides supports and assistance to the individuals residing in their own home, specific to the type and intensity developed with the person's input and direction.

Similarly, the focus of the CEC program is to support people in the participation in and enjoyment of community living. Participation in community living includes work and participation in activities the individual finds interesting and fun. The CEC program was developed to provide a systematic approach for providing opportunities and seek out personal interests. The CEC program is not static, but rather adjusts with new ideas, new opportunities and new interests.

Finally, the IAG programs have been focused toward individuals with severe developmental disabilities and for people who are dually diagnosed with mental retardation and severe mental illness.

For the present project, all 141 people in the program for people with a developmental disability funded through the State's MR authority were reviewed.

Of the 141 people, 110 (78%) participated in paid work (minimum wage or more) as part of the CEC program or in jobs at community businesses. Of the 141 individuals, 60% are dually diagnosed with mental retardation and severe mental illness, 20% Autism, 10% Cerebral Palsy, 10% MR plus Other (dementia, spina bifida, Parkinson). Nearly all individuals in the program have a history of institutional placement, incarceration and/or psychiatric hospitalization. For a majority of the individuals, renting a home or apartment (typically 3-4 people) is the first time they have had their own bedroom. Previous work experience is rare.

In addition all 22 people in IAG's program for 18-21 year old young adults funded through the State's Child Welfare agency were presented. All 22 individuals have a diagnosis of PTSD or Borderline Personality Disorder with diagnoses of Mental Retardation and/or Severe Mental Illness.

IAG Creating A Day In The Life Of: Introduction

Each individual has a personalized "Day In the Life Of" plan that they and/or their guardian have developed with the input from the people that provide them with support.

Individuals can choose to work, enroll in a class, participate in the Community Without Walls program and/or volunteer their services in a community.

Schedules are developed to be flexible so that an individual can work as well as take classes, volunteer, and participate in the Community Without Walls program. Participation in one program does not exclude the person from another nor does it mean that an individual must choose to participate in each option. Information about each opportunity is described below.

IAG Continuing Education: Life Long Learning

All individuals have the opportunity to enroll in IAG's Continuing Education Center. Each individual enrolls in the courses of their choice using course catalogs. Each course lasts 10 weeks targeting skills and personal goals within the context of the curriculum that each individual can be an active participant. (See Addendum for listing of the courses.)

The purpose of each course is to encourage skill development in the areas of employment, activities of daily living, independence, community integration, recreation, social development, life long learning and personal growth and development and personal interest.

Professional instructors teach the courses with either a Bachelors or Masters degree in the content area that they teach. In addition, trained peer mentors assist the instructors as needed to provide specialized assistance to individuals that need additional support for active participation. The classes often occur in the natural setting in the community. For example, if an individual is learning a fitness skill in the Health and Fitness course the training occurs in the gym. An individual who has written a song could spend time in a music studio making a recording of his/her creation.

Upon successful completion of each course, individuals receive achievement awards.

Individuals are also provided the opportunity to continue their education at the local Community College if there is an interest.

Examples of classes that individuals have taken include culinary arts, child development, and general education classes.

There are a number of classes that are geared toward future employment. For example,

...the Helping Hands is a course whereby individuals volunteer their services in a neighborhood nursing home.

They are taught skills of companionship, empathy, gratitude and charity. The individuals mentor a senior citizen who requires a “friend”. They are taught a variety of activities that can be chosen by the senior to spend time with the volunteer engaging in while they are spending time together. There have been individuals who have been hired at the end of the course to continue as Activity Aides.

Man as Best Friend is another example of course that is geared toward long-term community employment focused on animal care. Individuals volunteer their time in an animal shelter feeding, walking, playing and generally caring for the cats and dogs that need a friend.

Individuals often have been asked to continue volunteering their services after the course has ended. There have been instances of individuals working at the shelter long after the course ended.

Community As A Classroom

Individuals that desire and require more active involvement in the community can enroll in the Community Without Walls program.

This program is specifically designed for those individuals that have challenging behaviors and need specialized learning environments to achieve outcomes.

The courses are designed to promote active involvement in neighborhoods through community based learning experiences. Specifically trained “Clinical Mentors” are the life coaches that provide the real life training in a variety of neighborhood settings. This program is oriented for groups no larger than three but often for an individual that requires very specialized assistance.

Employment Options

A major emphasis for all individuals is employment with wages paid at least at minimum wage. The employment options vary according to the specialized needs of the individual. (Please refer to the survey in Appendix V for specific details about the various jobs).

Other characteristics include:

- The hours worked vary according to the stamina and capability of the individual as well as the nature of employment. For instance, the individuals who are employed as instructors may only work when the classes are being taught rather than on a daily basis.
- Each individual gets paid no less than minimum wage regardless of the job.
- Natural supports are utilized whenever possible.
- Self-employment options are encouraged and supported. (i.e. Car wash, dog walking, lawn care, baby-sitting, public speaking and advocacy, can recycling)
- Transportation is provided whenever public transportation is unavailable.
- Individuals are integrated with other paid non-disabled employees.

A future project for the next two years is to develop a customized employment model project for twenty-five individuals who have significant and challenging developmental disabilities so they can move from their internships with the Individual Advocacy Group to acquire and retain employment with community businesses. Once this customized employment model has been successfully implemented, it will be advanced to others desiring to be so employed.

H. Ray Graham Association, Downers Grove, Illinois (Division of Rehabilitation Services Milestone to Outcome – DRS and Other Supported Employment Initiatives)

Each year, Ray Graham Association (RGA) serves nearly 250 people in the community employment services division of the organization. RGA offers person-centered customized supports that assist people to find and keep employment. Each year, nearly 100 people find employment.

The retention rate for employment opportunities found is 85%. All individuals are hired by the employer and work at an hourly rate at or above the minimum wage. Based on fiscal year to date data, the average hourly wage is \$7.87.

Many people secure fulltime employment, while others secure part-time employment. Data for FY 2007 indicates that the average hours worked per week is 22. Additional data is contained within Appendix W along with a Community Milestone program. The dynamic forces behind these initiatives at Ray Graham Association are Cathy Ficker-Terrill, Chief Executive Officer and Kim Zoeller, Director of Adult Services

Each year, approximately 40 people become completely independent from job coaching. Natural support facilitation is a primary focus.

The employer hires all people employed. All employment situations are individualized, thus there are no crews or enclaves supported through RGA's community employment services.

The department consists of eleven Employment Specialists, two Job Coaches, one Marketing Specialist, one Vocational Specialist, and two Employment Services Coordinators. Employment Specialists support people to find jobs (job develop), maintain employment (job coaching and follow up supports), and serves as the support coordinator for people served.

The Marketing Specialist position assists with the development of partnerships and relationships with area employers through various networking activities. This position targets specific corporations or companies that may require much effort in the development of a productive relationship.

RGA receives funding for employment services through the Division of Rehabilitation Services and the Department of Human Services (Division of Developmental Disabilities). Services are offered to people through five different types of grants or funding sources. The following are the various funding sources:

Milestone to Outcome – DRS

Partnering with the Illinois Division of Rehabilitation Services (DRS), Ray Graham Association (RGA) redesigned a traditional performance based job placement program to a more innovative model of service delivery. In July 2005, Ray Graham Association launched a pilot program called Milestone to Outcome, which is essentially a menu of supports and services that people with disabilities seeking employment can select to assist them in their pursuit of employment.

RGA decided to continue with this model of service following evaluation of the pilot. In Appendix X is a document showing the Community Employment Services Milestone Outcomes Model for reference.

Benefits

- The structure allows for a menu of services for individuals with disabilities, as well as a step-by-step payment process for the organization.

- Although the initiation of the new system required much up front communication with DRS, the outcome has been productive. There is open dialogue and discussion pertaining to each case.
- RGA experienced an increase in referrals. DRS now considers this a cost effective option.
- Ability to provide more customized services for transition students exiting high schools in need of some additional job coaching or other customized assistance.
- Overall, RGA has served more individuals compared to years past.
- Successful employment outcomes have increased by nearly 30%.
- Flexibility when determining the level of supports people need.
- The menu provides an additional 20 hours of job coaching supports post 90-day employment is needed. RGA has the ability to provide longer-term job coaching on the DHS Grant program through an extended services program,

Challenges

- The data management and billing process is much more detailed.
- Requires more communication (which may also be a positive).
- More detailed month-to-month monitoring, since total revue is based on several different services versus one outcome.
- DRS will not allow a person post 90 days on their job to transition to a DRS funded SEP program.

Title 6B Supported Employment - DRS

This is a Supported Employment Grant that typically supports people that will require more intensive services and supports to find and maintain employment. Services can be provided up to 18 months on this grant. Extensions can typically be easily obtained or if a person is employed for more than 90 days, services can be transitioned to an Extended Services DRS grant. (outlined separately in this summary)

This is a service agreement with DRS where RGA agrees to provide 2,247 hours of direct billable services (refer to the DRS CRP Manual).

RFP 110 Grant - DRS

This is a Supported Employment Grant that typically supports people that will require more intensive services and supports to find and maintain employment. This particular grant originated from an RFP designed to provide additional supported employment services to transitioning youth. However, over the years, DRS has allowed for any person in need of supported employment to access services on this grant. RGA continues to provide services to mostly transitioning

youth to assure a successful transition from school to work. Extensions can typically be easily obtained or if a person is employed for more than 90 days, services can be transitioned to an Extended Services DRS grant (outlined separately in this summary). This is a service agreement with DRS where RGA agrees to provide 985 hours of direct billable services (refer to the DRS CRP Manual).

Extended Services - DRS

The Extended Services grant provides long-term intensive job coaching supports and services to people with more significant support needs. People access Extended Services after they have found employment with services funded by another DRS SEP grant. They must reach a point of 90 days stability on their job and have no other need for services beyond job coaching to be funded by DRS prior to transitioning to Extended Services.

This is a service agreement with DRS where RGA agrees to provide 3,390 hours of direct billable services (refer to the DRS CRP Manual). People can receive services on the Extended Services grant for as long as they need them. RGA does not provide long term 1:1 job coaching, so the end goal is always establishing some level of natural supports and minimizes the amount paid supports a person requires.

Department of Human Services Grant in Aid Program

This is a grant in aid program that provides all services needed to secure and maintain employment. Services are not time limited and people can receive support to find and maintain employment.

This is a more flexible program; however, the intended population is persons with developmental disabilities. This grant is monitored through “service reporting”, which is a combination of direct support hours and the work hours of the people served on the grant. For RGA, the targeted amount is \$2,550 per month. This program is funded entirely by state funds.

Please note that Ray Graham Association is the only adult developmental disabilities program implementing the Milestone program, as a demonstration at this time.

I. Eastside Employment Services, Bellevue, Washington (Replication of Project SEARCH within Seattle Children's Hospital)

Established in 1984, Eastside Employment Services (EES) was one of the first agencies to offer individualized job placement and support services for people with developmental disabilities in King County.

A non-profit organization funded by state and local government, EES currently supports over 100 participants each month and works with over 60 local employers.

In addition to maintaining a highly regarded Individual Employment program, EES continues to look for innovative ways to effectively meet the needs of the developmental disabilities community. In response to community input, in 1999 EES created the Pathways to Employment program to offer expanded employment options to individuals with more significant challenges. These are individuals who may need more intensive or extended support in order to participate in employment or related activities.

EES is recognized as one of the most successful supported employment agencies in the area – recognition that is largely attributable to its clear focus, consistently strong outcomes, committed relationships with participants, their families and advocates, ties to its network of employers, and its commitment to delivering quality services.

An experienced executive director and an active and committed board of directors provide effective leadership. EES is especially proud of its resourceful and dedicated staff, most of whom have been with the organization and supporting people with disabilities for many years. With their diverse backgrounds and abilities, they bring a history of success to job matching and an understanding of what it takes to establish long-term placements that result in positive working experiences for both the employee and the employer.

EES remains committed to delivering positive results for its participants, employers and the broader community.

There are a wide range of employers in King County who have hired individuals with developmental disabilities from Eastside Employment services to work for them including: ADIC, Adobe, Atrium Café, Barnes and Noble, Bank of America, The Bellevue Club, BioControl, Bucky's, Cherry Valley Family Grocer, Children's Hospital, City of Seattle, Embassy Suites, Emerald Heights, ETMA, Evergreen Surgical Center, The Foss Home, Fred Hutchinson, The Gap, Greater Seattle

Chamber, Home Depot, Honeybear Bakery, Ikon Office Solutions, Immunex, Issaquah care, King County Airport, King County Auditor's Office, King County Solid Waste Division, King County Superior Court, The Learning Garden, Lake Washington School District, Linen-N-Things, Little Aviators Day Care, Meydenbauer Conference Center, Pacific Circuits/TTM Technologies, Pacific Iron and Metal, Pediatric Associates, Perkins Coie, The Perkins School, Petco, Providence Marionwood, Rabanco, Ross Dress 4 Less, U.S. Bancorp, Piper Jaffray, Safeco, Safeway, Sheraton Hotel, State of Washington DCS, State of Washington DDD, Seattle Municipal Court, Squak Mt. Greenhouses and Nursery, Starbucks, Thriftway, Tube Art, Ummelina International Day Spa, Union Bay Day Care, WRQ and The Bellevue YMCA.

Eastside Employment Services has also replicated Project SEARCH from Cincinnati Children's Hospital Medical Center at Children's Hospital in Seattle. The program at Children's won a state award for its program that employs adults with developmental disabilities.

The press release is as follows:

On Oct. 15, during National Disability Employment Awareness Month, the Washington State Governor's Committee on Disability Issues and Employment named Children's Large Non-profit Employer of the Year.

This award recognizes the success of Project SEARCH, a program committed to recruiting and placing individuals with developmental disabilities in entry-level positions throughout the hospital since 2004. Currently there are 20 permanent positions and seven student internships filled by Project SEARCH participants.

"The program is grounded in making great hires by ensuring a good fit between the work and the employee,"

says **Debra Gumbardo**, MS, RN director Child Psychiatry and Rehabilitation Programs. "Project SEARCH underscores our commitment to diversity by hiring staff members who reflect the community we serve."

Lisa Fox, program manager, also emphasizes the importance of a diverse workforce at Children's. She says,

"When parents see Project SEARCH employees working here, they see the possibility of a future for their child as an employable adult. And our coworkers see their patients as future employees".

In some cases, employees who came to Children's through this program first learned about Children's when they were patients here. Support Technician **Heather Farrell** was a patient at Children's, where doctors and speech therapists worked to help her improve her hearing and speech.

"Now, I am giving back to the place that gave me so much," she says. Heather works in the Environmental Services Department and has given presentations at an employment conference about her experience with Project SEARCH.

Karen Wheatley also works in Environmental Services cleaning rooms in the Seattle Cancer Care Alliance (SCCA) unit. She has been at Children's for almost a year and loves the interaction she has with our patients. She says, "When I'm cleaning the rooms, I always go in and say, 'Hi! How ya doin'?' This is the best job I've ever had."

It's not just the patients that make this job "the best." Co-workers are also a positive aspect of working at Children's. "The people I work with are nice and really helpful," says **Stevan Dozier**, whose position in Dietary Services fulfills his lifelong dream to work at a hospital like his grandmother, who retired from a 20-year career at Swedish.

Nathan Zeidman, an administrative assistant in Rheumatology, enjoys his co-workers, too. "My favorite thing about this job is working with diverse people," he says.

The work itself is also appreciated by Project SEARCH participants like **Scott Nelson**, who says, "I like doing all the parts of my job." Scott started as a student intern and was then offered a permanent position as the 3rd floor surgical unit coordinator's assistant.

"Job satisfaction among Project SEARCH employees is almost 100%," says Lisa. "They are doing complex, yet systematic work that is challenging and rewarding."

Children's partners with Lisa's employer, Eastside Employment Services, as well as with King County Developmental Disabilities Division, Northshore School District and the employment agency O'Neill and Associates on Project SEARCH.

"The partnerships have been key to our success," she says. "Several other west coast hospitals have come to tour Children's, so that they can replicate the Project SEARCH program at their facilities the way we modeled our program after the one at Cincinnati Children's Hospital. We are now a resource for the Northwest region."

A survey of the jobs held by ninety-eight individuals from Eastside Employment Services is contained in Appendix Y. The dynamic force behind Eastside is David Schlessinger, Chief Executive Officer.

J. Vadis, Sumner, Washington (A supported employment agency in a small suburban town away from Seattle)

Vadis, a non-profit organization located in Sumner, Washington, serves and supports people with disabilities and the businesses and community in which they live. Human Services is a field with challenge and change. Vadis views those changes as opportunities, and works to build lives of independence and healthy interdependence.

The vision of Vadis is for people with disabilities to have the opportunity to define what is meaningful, to choose their own life path, to be supported and accepted in doing so, and to belong. The mission of Vadis is to provide people with disabilities opportunities and experiences to fulfill their economic and human potential.

Vadis opened as a private, non-profit organization in October of 1979. In 1985 we moved into our current headquarters in Sumner. It became "Vadis Northwest" because it was thought it better represented the increased regional responsibilities. Today, it's simply Vadis and operates primarily in King and Pierce Counties, supports over 400 people annually, have about 60 staff, and have established substantial partnerships with businesses, government agencies, the community, people with disabilities and their families.

For some individuals and their families, Vadis provides the first real opportunity to find a life path that leads to employment, independent living, and new skills for full community participation. What Vadis likes to say is "What do you want?" It is a fundamental shift in the way services for people with disabilities have been offered for years.

So, as individuals go through Supports and Services, it tries to remember that no one solution will fit every situation. Vadis strives to tailor the supports offered to fit the need and choice of each individual and family.

Many Kinds of People. Many Kinds of Disabilities.

Individual needs vary based on their life circumstance and disability. Vadis offers two programs for people with all kinds of disabilities ~ One for Adults and one for youth.

Vadis' Careers team offers an in-depth job search approach to adults with disabilities and provides a free two-day seminar, which teaches vital skills needed to get and keep a job. It supports the person in their self-directed job search by offering job-search counseling and by coordinating and negotiating with the businesses that he or she contacts and provides job leads. Vadis

encourages each person to include family, friends and others within their community in the planning and job search process.

For at least a year after a person becomes employed, Vadis provide career counseling and technical assistance to the person and his or her employer to assure advancement, satisfaction and long-term job retention.

Pathways is a program Vadis created to fill the void in services for young people with disabilities. Through this program, youth between the ages of 17 and 21 discover what opportunities are open to them. They discover options beyond being dependent upon public assistance. They are encouraged to choose their own career path based on their abilities and to make a meaningful contribution to the community in which they will work and live.

This Vadis program provides school-to-work transition services to youth with disabilities such as learning disabilities or physical disabilities. Young people with disabilities often have little to no work experience. Schools have traditionally lacked the tools to assist youth who have challenges with employment.

Pathways is designed to help youth develop the tools that they need to move successfully into the adult world. Vadis also provides the free two-day seminar, which teaches the skills needed to get and keep a job. Vadis supports these young people in their self-directed job search by offering advice and by coordinating and negotiating with the businesses that he or she contacts. Follow up services are also provided once the young person becomes employed.

Since 1979, Vadis has helped businesses to successfully hire people with disabilities and work to provide companies with the right employee in the right position. Vadis begin by planning around people's choices and interests. We assess skills and interests. Then, we match this to business needs. We offer our business partners full training and support in the employment process. We call it Positive Supports.

Businesses win when they partner with Vadis. Rewards include a full range of diversity, skilled and productive employees, support from an expert service organization like Vadis and, often, a noticeable increase in morale and contribution of everyone involved.

Vadis puts forward the following challenges and benefits to businesses which include:

- **Recruit with Vision: Incorporating diversity and innovation are easy when partnering with Vadis. Candidates are matched to specific employer needs. Costs associated with hiring are reduced.**

- **Job Candidate Referral: Increase Production and Sales.** Vadis offers creative ideas to enable skilled employees to concentrate their expertise on production, sales, and customer service. Businesses benefit by learning more about the candidate before hiring.
- **Reduce Labor Costs:** The work of more skilled employees is optimized through creative reassignment. Payroll expenses, overtime, and temporary labor costs are lowered.
- **Decrease Employee Turnover:** Diversity increases morale and enhances teamwork. It feels good to be a part of changing the life of a co-worker. Happy employees are enthusiastic, long-term employees.
- **Enhance your Community Image:** Competitive businesses understand the value of cause-related marketing. Your customers will appreciate your efforts to contribute to the community.

Within Appendix Z is a detailed survey of the employment for 83 individuals and approximately 40 individuals who are doing volunteer work within the auspices of Vadis.

K. Illinois Department of Transportation/Illinois Division of Rehabilitation Services Internship Program for Youth and Integrated Employment Program for Adults With Disabilities

Since 2005, the Illinois Department of Transportation (IDOT) in collaboration with the Illinois Division of Rehabilitation Services has created a partnership for a training internship for youth with disabilities and an integrated employment program for adults with disabilities.

The Student Professionals with Disabilities Program is a unique and creative approach to Supported Employment, which allows individuals who have the most severe physical and cognitive challenges to go through a jobs training program sponsored by the Illinois Department of Transportation (IDOT).

The IDOT initiative is working with people with autism, cerebral palsy, blindness, deafness, psychological and emotional disorders, and learning disabilities. The program started in a more traditional venue – food service and support in the IDOT cafeteria. It was originally done in conjunction with the Bureau of Blind Services through Division of Rehabilitation Services. It then expanded to include office/clerical as well as some technical engineering-type work, which is exclusive to IDOT.

IDOT has provided an in-house training site with computers, telephones and other resources to be used in day-to-day training of these individuals. United Cerebral Palsy Land of Lincoln has worked closely to provide on-going supports in the form of job coaches, technology, vocational, personal living, human relations, gender appropriateness and any other needed supports to make candidates work ready. The Illinois Division of Rehabilitation Services makes referrals to IDOT and United Cerebral Palsy Land of Lincoln as supports warrant and they both continued to develop funding resources throughout the life of the project. The School District 186 Transition Specialist has provided appropriate referrals and on-going supports as well as vital linkages between IDOT and United Cerebral Palsy Land of Lincoln. The program has continued to expand and is currently in the process of moving to other offices in districts throughout the state of Illinois.

Since 1991, the adult program has created over fifteen jobs for individuals with disabilities within the 1,100 person mainstream workforce at the S. Dirksen Parkway, Springfield, Illinois headquarters.

Individuals are employed at a variety of jobs including account clerks, civil rights trainee, janitorial, microfilm operators, winter technology and word correspondence technology. Most individuals are employed 37.5 hours per week. All are paid at least minimum wage with an average of over \$11.00 per hour and are entitled to all IDOT employee benefits such as health benefits and retirement.

A complete look at the data is in Appendix AA. The average tenure of these individuals is approaching five years. The leading force behind this program is David Dailey, the IDOT ADA compliance officer.

IDOT plans to expand this program to a maximum capacity throughout IDOT district offices across Illinois, which creates many opportunities for youth and adults to be trained and integrated into the mainstream workforce.

Summary Comments Chapter VIII. Examples of Best and Promising Practices Amongst Local Agencies on Integrated and Inclusive Supported Employment and Related Supports

The identified agencies in this chapter all place a high priority on advancing supported employment.

Job Path in New York City has been a supported employment agency for over thirty years and never was anything else.

Most of the other agencies transformed their agencies to provide supported employment services as a preferred way of doing business.

Usually, there is high connectedness with other entities like schools for school to work transition. There are also long standing relationships with key employers in the community.

The locations of the agencies run from high urban areas like New York City, Chicago, Cincinnati, Cleveland and Seattle, to suburban locations like Troy and Westchester, New York, Downer's Grove and Romeoville, Illinois, and Sumner, Washington to very rural, poor areas like Littleton, New Hampshire.

All of these agencies are successful in advancing supported employment because...

...they have dynamic leadership, have an uncompromising mission to advance supported employment as the priority way of doing business, have effective

collaboration with other entities, and have nurtured other stakeholders including individuals with developmental disabilities and their staff to be a part of their pioneering efforts to eliminate segregation and support integrated employment.

While many other fine supported employment agencies exist across the country, these agencies were selected as representatives of the larger class and also representative of the demographics present in Illinois.

Chapter IX. Best Practice on Support Agencies, Technical Assistance and Training On Supported Employment

PPIWDC has found a wide range of promising practices that support the employment of individuals with developmental disabilities in their quest for employment. Among the identified organizations in Illinois and other states are ones oriented to important business connections, affiliated technical assistance on supported employment initiatives, individual and workplace accommodations, professional training approaches, and federal benefits management and coordination with wages earned. These identified agencies provide effective models of such technical support models and should be replicated or utilized within this Blueprint.

A. Chicagoland Business Leadership Network and disabilityworks

Chicagoland Business Leadership Network (CBLN) membership is open to Chicagoland businesses who are interested in employing (or already employ) qualified people with disabilities. Representatives of for-profit businesses are invited to join.

CBLN nonprofit exceptions include: Chambers of Commerce, healthcare institutions, and educational attractions (i.e. zoos and museums) engaged/interested in hiring people with disabilities. Membership is open to Human Resource representatives and/or Executives of such organizations.

Prospective representatives from nonprofit organizations that provide job development, job placement, job training, or advocacy are invited to join the Chicagoland Provider Leadership Network (CPLN). This enables them to:

- Network with other employers who will share information and education about employing qualified people with disabilities.
- Gain free access to qualified candidates with disabilities through the Chicagoland Provider Leadership Network (CPLN). This includes free job postings and pre-screening of candidates to your requirements.
- Learn more about disability-related employment law and reasonable accommodations and share experiences with others.
- Hear how employing people with disabilities can enhance customer service and public relations and increase business outreach to a larger customer base.
- In other words, learn how hiring people with disabilities can improve the bottom line!

The CBLN mission is to allow employers to understand and benefit from people with disabilities in both the labor and consumer markets. CBLN is a business-to-business consortium dedicated to helping businesses learn from each other how disability can enhance diversity initiatives.

The CBLN vision is to become Chicagoland's number one resource for businesses that want to benefit from hiring people with disabilities.

In pursuit of this mission and vision, CBLN has identified four core organizational values. As such, all activities will be: ethical, business-oriented, educational and place an importance on open, honest communication. CBLN provides a forum, model and structure for employers to share experience regarding employing people with disabilities.

In May 2006, a group of key stakeholders participated in a CBLN strategic planning retreat. Here, the commitment to the above mission, vision and values as well as identified several goals for the near future was reconfirmed.

Among other things, the CBLN leadership is committed to:

- **Identifying resources, tools, and partners to develop educational pieces to address information businesses want to know.**
- **Recognize and reward businesses exhibiting best practices.**
- **Work with other BLNs to build best practices and other resources.**
- **Enhance membership.**
- **Continued growth and improvement of our services.**
- **Partnering with businesses, agencies, non-profits and the community to increase business and career opportunities for people with disabilities.**

Illinois workNet

Illinois' Virtual Employment One-Stop, Illinois workNet is the State's online initiative to increase employment opportunities for all state residents, including people with disabilities. Illinois workNet allows businesses to post job openings throughout the state as well as to look for qualified applicants.

AbilityLinks

On Marianjoy Rehabilitation Hospital/AbilityLinks, employers can post specific job openings for people with disabilities as well as view resumes of qualified applicants who are ready to start working.

disabilityworks, an exciting initiative from the Chicagoland Chamber of Commerce, the Illinois Department of Commerce and Economic Opportunity and the City of Chicago, is designed to increase employment opportunities for people with disabilities throughout Illinois. Through *disabilityworks*, employers, people with disabilities, and disability/employment service providers are strategically linked:

- 1) Employers will understand the business benefits of hiring qualified people with disabilities and will gain access to a large pool of productive and diverse employees.
- 2) People with disabilities will have access to job opportunities and choices for full inclusion and specialized services. This includes accessing CPLN's list of Job Placement & Occupational Training Providers.
- 3) Providers will operate as a resource to employers and people with disabilities, training people with disabilities and referring them to the right jobs. The term "providers" in this site refers to organizations that offer job readiness, job training, job placement, and educational services to people with disabilities.

disabilityworks, under the leadership of Karen McCulloh, Executive Director, provides coordination of the business and employment sector with people with disabilities and the employment services providers.

While supported employment is done one individual at a time, disabilityworks can offer extended linkages, connections and possibilities for gainful employment by such individuals with disabilities and provide for an inclusionary diverse workforce. disabilityworks has recently extended its services and supports to the entire State of Illinois.

disabilityworks can link employers, people with disabilities and employment services providers to the following economic opportunities:

- 1) Employers can join a network of business leaders that have expanded their bottom lines through the hiring of people with disabilities (CBLN), and learn about tax incentives for hiring people with disabilities.
- 2) Find small business development opportunities or centers (SBDC)
- 3) Find jobs in the non-profit sector.
- 4) Colleges, universities and job placement/training organizations can join a network of disability/employment service providers (CPLN).
- 5) Find work incentives and supports for people with disabilities.
- 6) Gain access to employment services. Note that *disabilityworks* does not do direct job placement. Rather, we refer to the CPLN service providers in our network.

7) Gain access to transition information from K-20 educational programs.

disabilityworks encourages people with disabilities, employers and service providers to submit relevant events for posting on the www.disabilityworks.org website. Appropriate calendar postings include the following:

- * Career or employment related events
- * Training events
- * Disability related events with an emphasis on workforce issues.

Other events may be considered on a case-by-case basis.

disabilityworks is designed to connect employers to a qualified workforce of people with disabilities and break down the barriers that keep people with disabilities from finding work in Illinois. Businesses looking for a qualified pool of productive, enthusiastic, job-ready candidates have access to the resources below.²²

B. Chicago Mayor's Office for People with Disabilities (MOPD)

The City of Chicago Mayor's Office for People with Disabilities promotes total access, participation and equal opportunity for all people with disabilities. The MOPD uses education, training, advocacy and direct services to bring about systemic change in the lives of people with disabilities and allow them to achieve their goals.

Programs Include:

Disability Resources: Information & Referral, Independent Living Programs, Case Management Services, Assistive Technology, Homemaker and Personal Assistance and Residential Parking.

Employment Services: Available for job seekers and employers, MOPD is also a partner with *disabilityworks*. Services for Job seekers include: readiness and skills assessment, resume writing and job interviewing skills, career counseling, job placement and referral assistance and benefits planning assistance available for SSI/SSDI beneficiaries. Services for employers include: Access to qualified job candidates, disability awareness training for the workplace, workplace site evaluation, evaluation and recommendations for job-related reasonable accommodations at the workplace. Training is also offered on independent living skills, etiquette, teletypewriter training, amplified phone program and recreational programs.

²² www.disabilityworks.org.

Architectural Services for accessibility include Site Surveys, Technical Assistance, consultation and plan review, information about accessibility laws, home mod program.

Public Information and Education: Disability awareness, special events, workshops and seminars, publications, and community outreach. **Youth programs** include substance abuse and AIDS prevention, mentoring, job shadowing, internships and transition services.

The Chicago Mayor's Office for People with Disabilities is a full service disability agency who is working at the cutting edge of providing individuals with disabilities the services aligning with national best practices.

Karen Tamley, Executive Director is the force behind this support agency.²³

C. Vermont DDAS/DVR contract for Supported Employment Technical Assistance with the University of Vermont Center on Disability and Community Inclusion

This contract is a collaborative effort between the Vermont Department of Disabilities, Aging & Independent Living: Division of Disability & Aging Services and Division of Vocational Rehabilitation Services for Supported Employment Technical Assistance with the University of Vermont Center on Disability and Community Inclusion.

Accordingly, the **University of Vermont Center on Disability and Community Inclusion** performs the following services:

Provide training and technical assistance to supported employment programs serving individuals with developmental disabilities and other severe disabilities including traumatic brain injury, funded by the State performing the following:

1. Assist in the development and implementation of vocational programs and initiatives, including but not limited to the following:
 - (a) Provide intensive technical assistance and consultation to supported employment service providers and State staff for the purpose of increasing the qualitative and quantitative capacity for supported employment outcomes. Training and technical assistance will be provided as a way to meet the needs of current supported employment customers and develop

²³http://egov.cityofchicago.org/city/webportal/portalEntityHomeAction.do?BV_SessionID=@@@@0952372766.1199565961@@@@&BV_EngineID=ccccaddmmhijeecefecelldffhfl.0&entityName=Disabilities&entityNameEnumValue=11

- the capacity of projects and organizations to independently meet the ongoing needs of customers. The Center will develop mutual agreements with each provider who has requested specific on-site technical assistance services that include: specific goals; provider's responsibility and expected action; Center's responsibility and expected action; and evaluation measures and activities.
- (b) Develop at least four (4) to six (6) site-specific training projects that will be prioritized. This training will generally occur on a one-to-one basis with the provider and may often occur on a job site. The Center and State will jointly identify the priority projects.
 - (c) *Assist in the development of new approaches for employment of people with severe disabilities who currently receive State-funded community services or people who are waiting for employment services.*
 - (d) Conduct training needs survey of supported employment providers
 - (e) Develop and Implement a supported employment annual training plan
 - (f) Coordinate and provide a three-day statewide supported employment introductory training series at least three (3) times per year.
 - (g) Conduct four to five (4-5) specialized trainings per year in response to needs identified in the needs survey or in response to requests from supported employment providers and State.
 - (h) Facilitate the development of local/regional forums for the purposes of (a) problem solving and practical application of supported employment practices; and (b) developing regional capacity for supported employment expertise.
 - (i) Provide consultation to Champlain Vocational Services (CVS) to assist in achieving the goals as outlined in CVS's "Community Services to Employment Conversion initiative," funded by a Medicaid Infrastructure Grant (MIG).
 - (j) Submit quarterly reports of progress and activities each year.
2. The Center meets quarterly with State staff to review progress; identify and assist in problem solving on supported employment issues and unmet needs; review the implementation of the training plan; and review technical assistance activities.
 3. The Center has a yearly evaluation of its activities developed by the State Employment Specialist and the Supported Employment Coordinator.

The entire agreement and scope of work is located in Appendix BB.

This agreement is carried out in all of Vermont and represents exceptional technical assistance for a high performing state in supported employment. It represents a model for adult employment agencies to contract with applicable universities in Illinois for necessary technical assistance.

D. University of Illinois at Chicago Technical Assistance For Students and Adults with Developmental Disabilities on Assistive Technology

The University of Illinois at Chicago's Assistive Technology Unit (ATU) is an interdisciplinary clinic at the UIC Department of Disability and Human development. (DHD). ATU clinicians include occupational therapists, physical therapists, rehabilitation engineers, speech-language pathologists, and special educators, each having assistive technology as their area of concentration.

The ATU is a community-based service delivery program, serving over 90% of its clients in the individual's home, school, work, or recreation setting. A fleet of 7 mobile units is used to achieve this, making the ATU the largest mobile AT program in the country. These accommodations are particularly important for youth and adults with developmental disabilities who are attempting to acquire paid employment and need these accommodations to be competitive with the mainstream workforce. The leadership behind this program is Dr. Tamar Heller.

Evaluation and Consultation Services

- Educational Consultation
Services include:
 - Identifying ways to integrate assistive technology into the classroom
 - Adaptation of curricula and educational materials
 - Expansion of technologies currently in place to enhance learning and functionality
- Augmentative Communication
- Computer Access
- Rehabilitation Engineering
- Site Modification
- Team Training Opportunities/Staff
- Inservices
- Technology and Fabrication Labs: fabrication labs can be provided on adapted art-making materials and classroom tools.
- Hands-on training can be provided at the school or at the new ATU computer lab on specific software, AAC devices, and adaptive equipment.
- Continuing Education

The services of The University of Illinois at Chicago's Assistive Technology Unit are nationally recognized and represent a best practice in advancing supported employment for youth and adults who need assistive technology in order to acquire employment.²⁴

E. Virginia Commonwealth University Staff Training Standards on Supported Employment: Web-based Certificate Series

The purpose of the Virginia Commonwealth University RRTC on Workplace Supports and Job Retention is to study those supports that are most effective for assisting individuals with disabilities to maintain employment and advance their careers. The leadership behind the work on supported employment at VCU is long-time professor Paul Wehman. The primary stakeholders for this project are persons with disabilities, with an emphasis on those who are unemployed, underemployed or at risk of losing employment. They are specifically targeting individuals from traditionally underrepresented populations with diverse racial and ethnic backgrounds, since this group is most at risk in America. The secondary stakeholders include rehabilitation professionals, families, and persons working in business and industry.

VCU's online course provides an extensive overview of supported employment and how to facilitate competitive jobs for individuals with significant disabilities. The course also provides access to nationally known trainers within the convenience of your home.

This web based training is a promising practice for advancing supported employment. The contents of this training and the learning objectives are essential learning for employment supports personnel. As can be visualized by the content, this learning is considerably different than that of traditional day and sheltered supports.

A broader description of the web based training program can be referenced in accordance with this website.²⁵

Sessions include information on these important employment strategies:

- **assistive technology evaluation and application,**
- **developing business partnerships,**

²⁴ www.ahs.uic.edu/dhd.

²⁵ http://www.worksupport.com/about_us/index.cfm.

- **career development,**
- **compensatory strategies,**
- **customer choice,**
- **instruction in the workplace,**
- **marketing and job development,**
- **job restructuring,**
- **person-centered planning,**
- **positive behavior supports,**
- **self-employment,**
- **social security work incentives, and**
- **workplace / coworker supports.**

Learning Objectives: After taking this certificate series, participants will be able to:

- Discuss the federal policy and historical overview of supported employment.
- Define the components of a customer profile to include situational assessments, vocational evaluations, and functional resumes.
- Illustrate an understanding of job development for career paths by developing a job search plan for a potential supported employment customer.
- Match a customer's strengths with the prospective employer's business needs.
- Discuss the various job-site training strategies (e.g., natural cues, workplace supports, compensatory strategies, instructional strategies, assistive technology) and their applications.
- Define the features of a high quality long-term support plan.
- Describe the various alternative funding sources for supported employment.

F. Illinois Assistive Technology Program

The Illinois Assistive Technology Program (IATP) seeks to promote independent living through technology for all people with disabilities in Illinois.

IATP' believes that disability is a natural part of the human experience and in no way diminishes a person's right to:

- **live independently**
- **enjoy self-determination and make choices**
- **benefit from an education**
- **pursue meaningful careers and**

- **enjoy full inclusion and integration in the economic, political, social, cultural,**
- **and educational mainstream of society in the United States.**

IATP's primary focus is on education, employment, community living, information technology and telecommunications. IATP's mission is to enable people with disabilities so they can fully participate in all aspects of life. Services include:

- State Financing for:
 - Device Reutilization
 - Device Loans
 - Device Demonstration
 - State Leadership Activities include:
 - Public Awareness and Information and Assistance.
 - Training and Technical Assistance
 - Coordination

The Illinois Assistive Technology Program (IATP) is a statewide, not-for-profit agency, in its seventeenth year of service. It was one of the first nine states funded under the Technology-Related Assistance for Individuals with Disabilities Act of 1988, as amended. Behind this assistive technology program is Wilhelmina Gunther, Executive Director and a more comprehensive discussion of the program is located at this website.²⁶

G. Federal Benefits Management

Most adults with developmental disabilities are recipients of some federal benefits such as Social Security Income (SSI), Medicaid, and vocational rehabilitation funding, among others. It is important to coordinate such federal monies with other assets and especially income earned by such individuals within supported and other employment initiatives.

Agencies need to have under employment or contract a person who is up to date on all the applicable federal requirements and can routinely counsel and advise individuals with developmental disabilities on how to maximize benefits and income in a way that benefits the individuals.

As previously described in Chapter III, a prevailing concern of many individuals and their families is gaining employment and losing benefits. With a possible loss

²⁶ www.iltech.org.

or reduction in employment, individuals want to be assured of an appropriate safety net and not be devoid of a job and benefits too.

Tennessee has done an effective model for blending a variety of federal funding as referenced in Appendix F. This model is very instructive of what possibilities exist.

An important resource which is in its tenth edition is “Benefits Management for Working People With Disabilities: An Advocate's Manual - a reference book for advocates, rehabilitation professionals, attorneys, persons with disabilities and others concerned with how work affects benefits”.

This book guides those interested in federal benefits management effectively through the maize of federal regulations without heavy emphasis on legal jargon. It has a focus on the State of New York but is easily adapted to other states as well and the differences in their regulations.

An overall description of the contents of this book “**Benefits Management for Working People With Disabilities**” is as follows:

“Changing attitudes about workers with disabilities, new technology, new supported employment models and knowledge of the Americans with Disabilities Act all contribute to more employment opportunities for persons with disabilities. Additionally, the Ticket to Work and Work Incentives Improvement Act of 1999 (the "Act"), passed both houses of Congress in November 1999 and was signed by President Clinton on December 17, 1999.

The long-awaited Ticket to Work regulations finally arrived in December 2001. Then, the first week of February 2002, SSA sent Tickets to approximately 10 percent of the Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) recipients in 13 states including New York. With the issuance of Tickets, people with disabilities who receive SSI and/or SSDI are being put in control more than ever before of when, where, what and how they access vocational rehabilitation, employment services and other support services.

New opportunities, however, bring new concerns. Will work result in a loss of SSDI, SSI, Medicare or Medicaid? How will work affect a pending application or appeal?

One goal of the Manual is to provide information on how work activity and wages will affect benefits.

A second, equally important goal is to provide information to the person with a disability and assisting professionals who work with him or her, to enable them to take a proactive approach in their dealings with SSA.

The Manual contains 11 chapters. Nine chapters cover a full range of Social Security, SSI, Medicaid and Medicare issues related to work activity. Chapter 10 covers the benefits available through state vocational rehabilitation agencies. Chapter 11 provides a summary of the Ticket regulations' more important provisions. Each chapter contains up-to-date references to relevant laws (including the recently passed Act), regulations, agency policy and selected citations to case law.

Nearly every Social Security and SSI rule is the same in every state. In fact, the Social Security rules are uniform nationwide. SSI and Medicaid differ from state to state in three significant ways.

- First, SSI benefit amounts differ as states may opt to supplement the federal benefit rate (FBR) at whatever amount they choose. Some states have no state supplement and the FBR is the SSI rate.
- Second, in 39 states and the District of Columbia, Medicaid eligibility is automatic if a person qualifies for SSI. In the other states, known as section 209(b) states, eligibility is determined separately.
- Third, the income test for section 1619(b) Medicaid eligibility (see Chapter 3) is different in each state, as the income "threshold" is determined by looking at the state's unique annual SSI and Medicaid expenditures.

The Manual uses New York's SSI rates (FBR plus state supplement) and section 1619(b) income thresholds in some of its examples. In other examples, it uses the FBR with no state supplement. To see how an example works out in a particular state, simply substitute the applicable SSI rate or section 1619(b) threshold for that state.

Work can affect benefits in many ways. Increased wages can reduce the SSI check. If not reported promptly, wages can also result in an SSI overpayment. Accordingly, sections in the Manual cover SSI budgeting and overpayments. Work can also result, in some cases, in the outright termination of benefits - generally, only when Social Security is involved.

These issues are discussed in Chapter 3, which deals with work incentives and in Chapter 9, which covers continuing disability reviews. Throughout the Manual, Social Security and SSI are contrasted and the differing impact that work activity and wages can have on each form of benefit.

There are many things one can do proactively. Most agencies, which employ persons with disabilities, must periodically send information and reports to SSA. A chapter is devoted to this subject, which shares various approaches for communicating with SSA on a person's behalf.

A chapter is devoted to SSI's Plan for Achieving Self Support (PASS). The PASS allows an individual to take income and/or resources that would otherwise be counted by the SSI program and use them to cover expenses, such as a vehicle purchase or training expenses, if the expense is connected to a vocational goal. This chapter has been extensively revised to reflect the 2001 policy changes.”²⁷

Summary Comments for Chapter IX Promising Practices on Support Agencies, Technical Assistance, Benefits Management and Training On Supported Employment

Within this chapter, important linkages were identified of resources that exist in or outside Illinois that can support agencies and the individuals they assist in seeking to advance supported employment. Several of the agencies, namely the Chicagoland Business Leadership Network, *disabilityworks*, the Chicago Mayor's Office for People with Disabilities represent effective linkages between employers, agencies and individuals with disabilities seeking employment. Other support agencies like the University of Illinois at Chicago Technical Assistance for Students and Adults with Developmental Disabilities on Assistive Technology and the Illinois Assistive Technology Program provide accommodations and devices necessary for youth and adults to be gainfully employed. The University of Vermont technical assistance contract for supported employment is an effective model for the interface between Illinois universities and state and local agencies in the advancement of supported employment. The Virginia Commonwealth University's web based training program is an important vehicle for continuing professional development and advancement for staff transitioning to and involved in supported employment activities. Finally, the book on federal benefits management is important for agencies and personnel assisting individuals who are gainfully employed to coordinate benefits with wages earned so as to maximize the results for the individuals. All of these types of organizations are assistive for individuals with developmental disabilities who desire to acquire gainful employment.

²⁷ Edwin Lopez-Soto, Esq. and James R. Sheldon, Jr. "Benefits Management Manual for Working People with Disabilities" Greater Upstate Law Project, Inc. Rochester, New York.

Chapter X. Lessons Learned

Through the travels and contacts of Public Policy Impacts of Washington, D.C. across the country as well as in Illinois, many lessons were learned concerning advancing supported employment. They are enumerated as follows:

1. Illinois stakeholders are enthusiastically ready to advance supported employment as a top priority and new way of doing business when barriers and sustainability are effectively addressed.

In discussions in Illinois with appointed officials of state and local governmental agencies, individuals, family representatives, individual support agencies, adult services provider and management staff, advocacy and professional organizations, statewide independent living centers, and other interested parties, PPIWDC discovered that there is substantial and enthused interest in this project by Illinois stakeholders.

There is enormous interest of individuals and their families in becoming employed if barriers can be addressed. Noteworthy, there is enormous interest in the adult services provider organizations in advancing supported employment within their organization as a top priority, again, if barriers can be addressed. This level of enthusiasm in spite of the complexities and obstacles that certainly lie ahead has extraordinarily impressed PPIWDC.

The vast majority see this project as a key opportunity toward positive systems change within Illinois' developmental disability system. There is strong concern, especially among the consumers and their families, that there will not be a concerted and sustained effort to make supported employment a reality in Illinois.

2. There are many complexities in assisting an individual with developmental disabilities to acquire supported employment. These include:
 - a. Employment assessments that must be conducted;
 - b. Learning particular new job skills and job behaviors/relationships;
 - c. Ongoing marketing with employers, networking with employment contacts;
 - d. Identification of potential positions and merging employer needs with individual interests and preferences;
 - e. Task analysis and accommodations, customizing employment and job carving;
 - f. Ongoing intensive job coaching, fading of job coaching when possible with the building of natural supports;
 - g. Developing collaborative relationships with other state and local entities on supported employment;

- h. Ongoing analysis and counseling/advising individuals of the interaction of federal and state benefits with employment wages and benefits received, and;
- i. Ensuring ongoing job development when positions may be lost.

Advancing supported employment has many facets and complexities and is therefore more difficult than traditional congregate, facility based care.

However, the results and enhancement of the lives of individuals with developmental disabilities in being able to live the “American Dream” of a job, a home, and community relationships is realizable for any individual desiring to participate.

- 3. Several states that historically were identified as being high performing in supported employment indicated not to come there right now because they had lost ground because of lost focus. The lesson is...

...supported employment must be actively and continually engaged and improved upon if it is to continue to thrive.

4. Staff evaluation of, and expectations of, the performance of individuals with developmental disabilities within sheltered workshops are often a very poor indicator of success in the mainstream workplace.

Much of the work in the workplace is gross motor skills while a lot of the work in sheltered employment uses fine motor skills which even typical workers would find difficult. Many of the skills necessary for success in workshops are actually counter-productive in their application within community employment settings. Some examples include sitting for long periods of time in a single location with a similar focus, which is typical in a workshop vs. the expectation for fast action and multi-tasking response ability in many workplaces.

Another example is that people with developmental disabilities are not typically taught how to appropriately engage customers (as is required in many public jobs). Through on-the-job-training, appropriate supports, job carving, and customized employment the vast majority of individuals with developmental disabilities can be accommodated in the mainstream workplace as has been clearly demonstrated in other states.

5. There needs to be sufficient rates in Medicaid Home and Community based services waivers that provide extended services after DORS funding is terminated and to allow continuity of and follow along supports for employment and related services.

States and local agencies that are high performing in supported employment have waivers that provide from a low of \$48,000 to over \$75,000 per individual that include all of their residential, employment and related supports.

Concomitantly, job supports personnel are employed by the supported employment agency at \$25,000 or more per year plus benefits of around 25 percent or more. The average job coach with three years of experience is paid approximately \$31,000/yr. This contributes to continuity of supports by these personnel and the significant retention of the on the job training, learning and relationship building that has taken place by these personnel.

6. High performing states ensure that there is a seamless transition from the education environment to adult life by ensuring access to resources especially rehabilitation services funding and Medicaid home and community-based services waivers.

There is much collaboration required between all involved in school to work transition at the state and local levels. This collaboration results in students graduating and being employed at that time. Successful transition is a non-negotiable expectation.

7. Supported employment requires different skill sets and requires refined training for employment personnel wishing to make the transition from sheltered to supported employment.

Supported employment agencies understand that there are differing skills and abilities of the personnel working within sheltered workshops with those working within supported employment. There is a need for specialized training in supported employment for personnel making this transition. Sometimes, personnel will find this transition unacceptable and may vacate their positions. This was repeatedly emphasized as a critical element to success.

8. There is a need for sufficient monetary support for advancing supported employment for individuals with developmental disabilities and an effort to utilize natural supports whenever possible.

The Illinois Division of Rehabilitation Services provides funding for job supports from \$17 per hour to over \$40 per hour. When the case is closed and “stabilized”, there is usually an ongoing need for continuing job supports and follow-along. The Illinois Division of Developmental Disabilities under its adult Medicaid HCBS waiver offers \$13 per hour and limits the total hours to around 540 hours on average per year. Since the waiver is not easily accessible to all individuals needing such services, agencies may have to find other resources to accommodate them or leave them to fend for themselves.

High performing states provide about \$40 per hour for supported employment services and have individualized such supports based on actual required needs. There is also a strong emphasis on individuals with developmental disabilities gaining natural supports as traditionally provided by employers to their mainstream workforce. The adult employment services provider fades its service intensity level for some but maintains an on-call presence when needed.

This practice results in allocating resources as long as necessary and then fading out when natural supports can take over with the reallocation to individuals needing more intensive supports. This practice was widely seen in high performing agencies on supported employment services.

9. Businesses want employees who can support their mission of profitability and service in the marketplace and such businesses, therefore, are not human service agencies.

Businesses may fire individuals with developmental disabilities like any other employee for lack of performance or other job related conditions and that is simply a fact. The vast majority of employers that have involuntarily terminated (fired) a person with a developmental disability, it was not because they couldn’t do the work or were otherwise a sub-standard employee relative to the tasks but rather due to poor social skills (they couldn’t get along with other employees and/or customers).

10. The safety net that the high performing agencies have developed for individuals who may lose jobs is direct and immediate activities and training to address the reasons that the job was lost (if involuntary) or skills development related to acquiring a new paid position and active job seeking.

Other community non-work activities like shopping, recreation, and other socialization activities need a lesser priority so they do not become the incentive for losing a job and not acquiring a new one. It has become obvious that they must help the individual to meet these needs so that they do not compete with the individual's motivation to keep their jobs.

Often, community non-work activities are facilitated by the adult provider agency who fades as generic and regular social relations are realized by the individual and the circle of support as a direct result of their efforts to facilitate these relationships.

11. High performing states on supported employment fully implement self-determination and person-centered planning in both action and word.

Individuals are truly at the center of the process with significant control - especially regarding the type of work they want to do and when/how much they want to work. Implementation and evaluation documents of state and local agencies reflect this action.

Self-advocacy is also foundational for effective supported employment to occur and assists to move the program effectively through peer mentoring. Individuals who are working at real jobs should also be employed as peer mentors as it aids in building understanding and support.

12. High performing states on supported employment have clearly laid out policy expectations through actions and words.

Supported employment standards are clearly enunciated and understood so there can be no misconception of direction or expected outcomes. Very high performing states and agencies on supported employment *work for an individual* to acquire a job integrated within the mainstream workforce and actively minimizing clustering with other individuals with developmental disabilities at the worksite.

13. When high performing states and local agencies have embarked on advancing supported employment through policy and practice, there is an identified and dynamic leader in the state or local agency who is in charge of the conduct of all aspects of the new way of doing business.

Such leaders are the driving force and system motivator for creating, implementing and sustaining changes to supported employment. They embody the principles of self-determination, person-centered planning, integrated employment with supports and teaching mechanisms to move organizations, personnel and individuals with developmental disabilities into the world of employment.

They overcome barriers, obstacles, complexities and other issues to create the policy parameters that make supported employment the preferred if not the sole way of doing business within adult services. They are also energizing of others and have high resilience that is contagious as others seek to emulate their enthusiasm for systems change. They are able to create the resources that enable this changed way of doing business to be effectively and efficiently implemented.

Summary Comments Chapter X. Lessons Learned

These thirteen lessons learned are instructive for any entity that seeks to advance supported employment as an effective policy, practice and as a preferred way of doing business for all stakeholders within the Illinois developmental disability system.

Concluding Comments on Systems Change

“At nine thirty on a July evening in 1988, a disastrous explosion and fire occurred on an oil-drilling platform in the North Sea off the coast of Scotland. One hundred and sixty-six crew members and two rescuers lost their lives in the worst catastrophe in the twenty-five year history of North Sea oil exploration. One of the sixty-three crew members, who survived was a superintendent on the rig, Andy Mochan.

From his hospital bed, he told of being awakened by the explosions and alarms. He said that he ran from his quarters to the platform edge and jumped fifteen stories from the platform to the water. Because of the water’s temperature, he knew that he could live a maximum of only twenty minutes if he were not rescued. Also, oil had surfaced and ignited. Yet Andy jumped 150 feet in the middle of the night into an ocean of burning oil and debris.

When asked why he took that potentially fatal leap, he did not hesitate. He said, “It was either jump or fry.” He chose possible death over certain death. Consider this:

- He didn’t jump because he felt confident that he would survive.
- He didn’t jump because it seemed like a good idea.
- He didn’t jump because he thought it would be intellectually intriguing.
- He didn’t jump because it was a personal growth experience.

He jumped because he had no choice- the price of staying on the platform, of maintaining the status quo, was too high. This is the same type of situation in which many business, social, and political leaders find themselves every day.

We sometimes have to make some changes, no matter how uncertain and frightening they are. We, like Andy Mochan, would face a price too high for not doing so.

An organizational burning platform exists when maintaining the status quo becomes prohibitively expensive. Major change is always costly, but when the present course of action is even more expensive, a burning platform situation erupts.

The key characteristic that distinguishes a decision made in a burning-platform situation from all other decisions is not the degree of reason or emotion involved, but the level of resolve. When an organization is on a burning platform, the

decision to make a major change is not just a good idea-it is a business imperative.”²⁸

Throughout the many chapters of this document, many representatives of organizations including a vast array of stakeholders, who have advanced supported employment, have spoken of their trials and their successes.

They are champions and dynamic forces, who have taken the leap from the platform. They are demonstrating how successful outcomes can be achieved for adults with developmental disabilities. In meeting them in their professional venues, it was discovered that each understands and is operating under the notion of a business imperative. They operate no longer as human service agents but as a business that facilitates the acquisition of real jobs, with real wages with real employers by adults with developmental disabilities. They have transformed the very fabric of their organization and who they are.

Unfortunately, as Houtenville’s statistic’s demonstrated in Chapter 1, these high performing supported employment agencies and the states that lead them are few and far between.

Most individuals with developmental disabilities have yet to experience integration and inclusion even though self-determination and person-centered planning have been “practiced” for over twenty years. To break out of the chains of segregation and congregate care, bold action must be taken and....a burning platform mentality must exist. The cost in human lives and the lost opportunities for them and employers is too great not to take this approach.

Pioneering Illinois agencies and their affiliated stakeholders, when given the essential policy foundations that exist in other states, will jump from the platform, to make dreams reality and show the way for this advancement of supported employment to be the way of doing business in Illinois within the next five years.

Success breeds success

Urgency sustains change

²⁸ Connor, pages 94-95.

and the efforts of a few can spread to a much broader group of stakeholders in the State of Illinois, greatly advancing supported employment for youth and adults with developmental disabilities.

This systems change, advancing supported employment as a principle way of doing business, has happened in high performing states like New Hampshire, Tennessee, Vermont and Washington. This change has occurred in high performing agencies like Job Path, Common Ground, Riverside Arc, Westchester Arc, Vadis and Eastside Employment Services. This change has occurred with employers like Cleveland Clinic, Seattle Children's Hospital and Cincinnati Children's Hospital Medical Center. The change is occurring at the Individual Advocacy Group, Ray Graham Association, and Anixter Center here in Illinois.

When this project is implemented and supported employment is advanced as the primary way of doing business in ten pioneering agencies, and when the Illinois policy makers see this work and the outcomes anticipated are realized, there will be momentum and policy incentives that will be assistive for other stakeholders to "jump from the platform".

Illinois operates with an enthusiastic group of stakeholders who are willing to support this venture and make it a bona fide and replicable success.

Appendices

These appendices which contain significant documents of volume are available on disc or at the Council's website

- Appendix A Illinois Focus Group Attendance
- Appendix B Illinois Focus Group Complete List of Topics
- Appendix C Washington SE policy
- Appendix D Vermont Statutes SE
- Appendix E Oregon blueprint-full
- Appendix F Tennessee Blended Funding Excerpts Advancing Supported Employment
- Appendix G Vermont School to work transition
- Appendix H Vermont 06 report for general public
- Appendix I NY Schools RFP
- Appendix J Vermont Individual Supports Agreement
- Appendix K Vermont SE action plan
- Appendix L New Hampshire employment summary
- Appendix M NH Adult Outcomes interview form
- Appendix N Common Ground Employment Services Survey
- Appendix O Job Path Employment Services Survey
- Appendix P Riverside Arc job log10-31-07
- Appendix Q Riverside Arc High School Contract 2007-2008
- Appendix R Westchester Employment Services Survey
- Appendix S Westchester OPTS Final Appendix
- Appendix T Cleveland Clinic Employment Services Survey
- Appendix U Cuyahoga Interagency Transition Agreement
- Appendix V IAG Employment Services Survey
- Appendix W Ray Graham Employment Outcomes
- Appendix X Ray Graham Milestone menu
- Appendix Y Eastside Employment Bellevue WA Survey
- Appendix Z Vadis Survey Sorted
- Appendix AA IDOT/DORS Youth Training and Adult Employment Program
- Appendix BB The University of Vermont Center on Disability and Community Inclusion
- Appendix CC Medicaid HCBS Waiver State D Value Charts
- Appendix DD SSI Calculation Model King County DDD, and the Arc of King County, Seattle, Washington