
A Review of State- and Organizational Level Barriers and Strategies When Considering the Transition to an Integrated Employment Service Model

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Executive Summary

Substantial research has shown that the majority of community rehabilitation programs (CRPs) funded to provide employment and day services to individuals with disabilities support segregation as the model of choice for their clients. Yet many CRPs have successfully expanded competitive employment options, overcoming substantial barriers along the way.

The U.S. Department of Labor's Office of Disability Employment Policy (ODEP) funded Economic Systems Incorporated (EconSys) and its subcontractors, the Rehabilitation Research and Training Center at Virginia Commonwealth University (VCU-RRTC) and ICF International, to conduct research and assemble products and materials for a training and technical assistance (TA) Toolkit as part of broader efforts to increase employment for persons with disabilities. The project will support CRP and state efforts in reducing reliance on sub-minimum wage, segregated employment and day support services.

This paper provides the result of a research study, commissioned as part of the Toolkit development to investigate the issues and barriers that affect the transition of CRPs to integrated services and to identify replicable strategies for addressing those issues and barriers at the state- or systems-level and at the organizational level.

Findings

The literature review found that the most pervasive policy barrier to transition was financial. In many states, CRPs are funded equally for both segregated and integrated services. Other barriers identified in the review included staff, client, and family resistance, local economic and labor force characteristics, and lack of transportation.

The CRP survey collected rich qualitative data from representatives of CRPs that were successful in transitioning much or all of their client base and resources from facility-based, subminimum wage services to community-based competitive jobs. Each organization experienced significant barriers from without and within, including resistance from staff and funding sources, family disapproval, and difficulties with transportation and other logistics. Because of these barriers, the process was slower than anticipated. Still, they found ways to move their organizations forward. One overriding theme through all of the interviews was that the leadership of the agency persevered toward the agency's goals despite the obstacles.

The interviews with state policy makers and review of SELN documents showed that these states used a variety of strategies for promoting employment for youth and adults with disabilities, strategies that can be replicated in other states. Some of the most commonly reported strategies included:

- Modifications to state disability service policies defining "employment" as only referring to community-based employment either at minimum wage or commensurate with other employees;
- Specifying in policy documents and vendor agreements that community-based employment as the first priority for funded clients;

- Adjusting fee-for-service rates and other contractual agreements to provide incentives to CRPs to expand service capacity in community-based employment;
- Developing interagency councils and agreements, including the state Vocational Rehabilitation agency, intellectual and developmental disability agency, Medicaid agency, etc.;
- Developing new reporting systems to monitor progress in transition;
- Modifying their Home and Community Based Waivers to add career planning and exploration services under habilitative services; and
- Providing access to consultation and technical assistance to CRPs in aspects of supported and customized employment, such as job development, assessment of client skills and interests, job coaching, etc.

Recommendations

The findings from this investigation indicate that the following state- and organizational level strategies would be effective in furthering transition efforts:

State-Level

- Cross-agency implementation of "employment first" policy;
- Conversion grants to support organizational change;
- Start-up grants for new provider agencies;
- Funding mechanisms reward community-integrated employment outcomes achieved;
- Licensing of quality programs;
- Development and use of a mentoring process to effect organizational change;
- Development of an evidence base of effective state and local practices.

Organizational Level

- Alignment of the organizational mission to employment first;
- Sharing of successful transition stories among employers, families, clients, and the general community;
- Staff role assignments supportive of competitive employment;
- Creation of innovative transportation programs in areas with transportation needs.

I. Introduction

A large body of evidence accumulated over the past three decades has consistently found that individuals with disabilities, including those with significant and multiple disabilities, can be successfully employed in competitive, integrated positions and can substantially increase earnings in comparison to segregated work or day support programs (Rusch, Connis, & Sowers, 1978; Rusch & Mithaug, 1980; Sowers, Rusch, Connis, & Cummings, 1980). Moreover, the evidence indicates that the majority of individuals with disabilities and their families prefer integrated employment to segregated employment or day services (Migliori, Mank, Grossi, & Rogan, 2007; Murphy & Rogan, 1995).

Significant policy changes and initiatives over the past two decades have been implemented to further integrated employment opportunities for individuals with severe disabilities. The 1986 Amendments to the Rehabilitation Act added community-integrated supported employment as a service option for Vocational Rehabilitation (VR) clients with the most severe disabilities. The Amendments also provided for Supported Employment Systems Change grants for every state to develop model programs of integrated employment. Following the Balanced Budget Act of 1997, which removed the institutionalization requirement for use of Medicaid Home and Community Based (HCB) Waiver funds for supported employment services, spending from that source for employment services grew from virtually zero dollars in 1988 to \$108 million in 2002 (Rusch & Braddock, 2004). In 2001, the Rehabilitation Services Administration which administers the VR program amended its regulations to redefine the term employment outcome to mean an individual with a disability working in an integrated setting (State Vocational Rehabilitation Services Program Final Rule, January 22, 2001), thus excluding sheltered employment as an approved potential employment outcome for VR services and encouraging integrated employment as the preferred outcome for all VR clients. Finally, from 2001 to 2003, the Office of Disability Employment Policy (ODEP) funded 20 demonstration projects to advance customized employment, a flexible, consumer-driven blend of funding, strategies and supports for the employment of individuals with disabilities.

Use of the supported employment model grew rapidly during its initial years, from approximately 8 percent of all intellectual and developmental disabilities (ID/DD) employment service participants in 1988 to approximately 24 percent in 2002 (Mank & Braddock, 2004). Since then, however, the percentage of ID/DD clients in integrated employment has since declined to under 22 percent in 2009 (Butterworth, Smith, Hall, Migliori, & Winsor, 2010).

While evidence abounds that community rehabilitation programs (CRPs) can and do transition from predominantly segregated services to predominantly (and sometimes fully) community-integrated services for clients across the range of disabilities (i.e., Becker et al., 2001; Brooks-Lane, Hutcheson, & Revell, 2005; Fesko & Butterworth, 2001; Murphy & Rogan, 1995; Oldman et al., 2005), the majority of CRPs opt for segregated employment as the model of choice for the majority of their clients (Inge, Wehman, Revell, Erickson, Butterworth, & Gilmore, 2009). For those that wish to expand competitive employment options, the journey can be long and full of challenges (West, Revell, & Wehman, 1998).

The U.S. Department of Labor's Office of Disability Employment Policy (ODEP) funded EconSys and its subcontractors, the Rehabilitation Research and Training Center at Virginia Commonwealth University (VCU-RRTC) and ICF International, to conduct research and assemble products and materials for a training and technical assistance (TA) Toolkit as part of broader efforts to increase employment for persons with disabilities. The project will support CRP and state efforts in reducing reliance on sub-minimum wage employment.

As part of the Toolkit project, ODEP asked the experts at VCU-RRTC to investigate the issues and barriers that impede the transition of CRPs from segregated to integrated services and to identify replicable strategies for addressing those issues and barriers at the state- or systems-level and at the organizational level. To this end, VCU-RRTC conducted (a) a review of relevant literature, (b) a small-sample study of CRPs that have been engaged in transition from segregated services to integrated employment, (c) a small-sample study of states with Employment First Initiatives, and (d) a review of state policy initiatives from the State Employment Leadership Network. This paper presents the results of this study.

II. Literature Review

System-Level Barriers and Challenges

Perhaps the greatest barrier to expansion of integrated employment opportunities is related to funding streams and methods. To better understand this barrier, it is first advantageous to discuss how employment services are typically funded.

Employment funding agencies such as state VR agencies, mental health agencies, and intellectual and developmental disabilities (ID/DD) agencies use a variety of approaches to purchase services from vendors. All approaches to funding services have three common elements: defining the specific services to be purchased, defining the unit of service, and establishing a cost for the defined service unit. Funding methods currently used by state agencies to fund time-limited services fall into three broad categories:

- Fee-for-service agreements;
- Contract or slot-based funding;
- Performance- or outcome-based approaches.

Fee-for-service agreements

In a fee-for-service agreement, the vendor receives payment of an agreed upon fee amount for the *specific intervention time* during which a vendor is engaged in providing services to a specified individual. This method breaks down the unit of service into small increments, typically an hour, and tracks the length/intensity of service provided to each participant. Three fee-for-service alternatives are used by funding agencies. In the first, a statewide fixed hourly rate, the funding agency assigns a rate for a service to all vendors. The second alternative, a negotiated hourly rate based on overall program costs, establishes a vendor-specific rate with probable variations in the assigned rate from vendor to vendor based on differences in program costs and/or community level cost standards. The third alternative is a negotiated hourly rate typically designed to encourage vendors to respond to the needs of underserved individuals who have more complex service needs.

Contract or slot-based funding

Contract or slot-based agreements define a unit of service on a daily, weekly, monthly, or annual basis and make payments to the vendor based on participation by the individual with a disability in the service for that defined unit. In contrast to the hourly fee for service agreements, units of service in contract/slot-based funding are not designed to specifically track intensity of services provided at an individual participant level. The contract/slot based approach funds services through agreements for services to a specified number of individuals in contrast to the individual participant service authorizations used with the hourly fee method. In addition, contract or slot-based funding is typically not based on achieving specific levels of service or service outcomes. For example, in many states using this method of funding, vendors receive the same rate for individuals in integrated employment as for those in segregated day

services. As with fee-for-service agreements, contract/slot-based service funding agencies choose to offer either fixed or negotiated rates to vendors.

Performance- or outcome-based approaches

In performance- or outcome-based approaches, key service milestones are established with a payment level identified for each achieved milestone. Payments are made to the service vendor when the participant achieves each milestone. For example, a funding agency might establish a series of payment steps starting with assessment and goal setting and continuing through job placement, job retention for specified time periods, and finally successful movement to extended supported employment services for purposes of long-term job maintenance. A series of payments would then be made to the vendor as the individual with a disability completes each of the defined outcome steps. As with the other funding methods, milestone rates can be either fixed for all vendors across the state, or negotiated with individual vendors based on their local service costs or client needs.

How funding method affects service capacities

A growing body of research indicates that the method of employment service funding used by state agencies and their funding rates affect the willingness and capability of vendors to expand integrated employment opportunities. Revell, West, and Cheng (1998) conducted a survey of a randomly selected, nationally representative sample of community rehabilitation programs (n=385) that were vendored by their state VR agency to provide supported employment. The overwhelming majority of those vendors also provided in-house segregated employment and/or day treatment. Survey items included (a) the type of fee-for-service agreement for VR-funded supported employment and (b) the perceived effects of the funding on various aspects of service delivery.

The findings consistently pointed to significantly more positive response of vendors to funding methods that incorporate negotiated rates at the individual provider level as compared to statewide fixed rates for all vendors. Statewide fixed hourly rates were found to discourage transition of staff and other resources to community integrated employment options. The same response pattern held true for respondents' perceptions of reimbursements covering the costs of services. Statewide rates for specified outcomes or for daily, weekly, or monthly service units were found to cover the cost of services at levels significantly lower than the other funding methods. When asked to make recommendations for improving their current funding system, the most frequently reported suggestions included increased service rates and change in the state funding method. Remarkably similar findings were reported by West, Johnson, Cone, Hernandez, and Revell (1998) regarding funding of extended services from state mental health and ID/DD agencies.

Together, these two studies underscore the economic realities of employment services funding. As Revell et al. (1998) write:

Vendors are unlikely to voluntarily expand a service which they believe is underfunded and requires them to operate at a loss, regardless of benefits to consumers. Thus, supported employment staffing and consumers remain small

in comparison to segregated, facility-based services where costs can be more readily controlled...When service access is limited in this manner, the right of consumers to choose supported employment as their service option is abrogated and efforts at systems change are impeded. (p. 73)

More recent research has confirmed the role that funding strategies have in provider buy-in to integrated employment. Hall, Butterworth, Winsor, Gilmore, and Metzel (2007) conducted case studies in three states that had the highest proportion of individuals funded by ID/DD agencies in community-integrated employment. They found that these states tended to have flexible funding systems that included such options as block funding, which allowed the local communities and CRPs to direct service dollars as needed for each individual client, and individualized budgeting, where case service funds follow the client in his or her preferred service options. Other funding strategies included blending of funds from a variety of sources to support individuals in integrated employment and financial incentives to those agencies that increased the number of clients in integrated employment and maintained them there successfully. Additionally, Novak, Rogan, Mank, and Dileo (2003) conducted a survey of representatives in state VR agencies in all 50 states and the District of Columbia. Only 11 respondents (22%) indicated that their state had higher rate structures for providing integrated employment services than for segregated services. In addition, respondents strongly associated specific funding policies, such as “money follows the person,” with encouraging integrated employment.

Additional evidence was developed from the Training and Technical Assistance to Providers (T-TAP) project at VCU-RRTC in partnership with the Institute on Community Inclusion (ICI) at the University of Massachusetts Boston, funded by ODEP from September 30, 2002 through September 29, 2007. T-TAP provided training and resources to support CRPs in transitioning to customized employment approaches. T-TAP sponsored a “think tank” meeting in Washington, DC, on October 16 and 17, 2006 (T-TAP, 2006). The focus of the meeting was to discuss the best practices that promote customized employment outcomes for individuals with disabilities as well as the barriers in transitioning from to community-integrated employment. Participants included T-TAP staff from VCU-RRTC and ICI, ODEP staff, individuals who serve as mentors to transitioning CRPs, and other invited guests.

There was a general consensus among the think tank participants that the source and type of funding that CRPs receive for service delivery can preclude integrated employment. For example, if an individual desires to move from facility-based services to competitive employment, funding restrictions, such as in Medicaid, restrict use of those dollars for employment. As a result the person will lose his or her funding if an employment goal is pursued. Also, it was reported that some programs view service dollars as belonging to the program, not the individual. Investment is in the program and maintaining those services and not in increasing integrated employment outcomes.

Think tank participants also identified these additional state-level barriers to increasing integrated employment opportunities:

- (1) A lack of funds, such as incentive grants, to institute organizational change;

- (2) Terminology and practices that are not clearly understood across funding agencies;
- (3) Limited and inconsistent statewide dissemination of information and resources.

Organizational-Level Barriers and Challenges

This section addresses barriers and challenges to the transition from segregated services to integrated employment from the organizational perspective, including (a) staffing issues, (b) consumer concerns, (c) family concerns, and (d) community and economic issues.

Staffing issues

Having staff engaged in the change process is critical to the success of the transition to community-integrated programs. An inherent aspect of organizational change is the feelings of insecurity and a lack of control experienced by staff (Marrone, Hoff, & Gold, 1999). As evidenced in the literature, facility staff can be a major barrier to organizational change (Brooks-Lane et al., 2005; Hagner & Murphy, 1989; Migliore et al., 2007; West, Revell, & Wehman, 1998). Some of the opposition to change is based on personal factors, such as uncertainty of employment status and career implications (Migliore et al., 2007; West et al., 1998), fear of the outcome of conversion (Migliore et al., 2007), perceived scheduling inconveniences and loss of the routine schedule typical with segregated employment (Parent, Hill, & Wehman, 1989), evident increase in responsibilities associated with placement and training in an employment setting (Parent et al., 1989), and an overall sense of feeling threatened (Brooks-Lane et al., 2005). Other concerns are focused on the consumer, such as the feeling that employment in the community might be a threat to the consumer (West et al., 1998) or that the consumer is not capable of handling the conversion process (Marrone et al., 1999).

Consumer issues

Service consumers (i.e., individuals with disabilities) are strongly supportive and rarely resistant to the idea of transitioning from segregated programs to community-integrated programs (Migliore et al., 2007, 2008; Murphy et al., 2002). Migliore et al. (2007) report that only 14 percent of the adults with intellectual disabilities surveyed in their study would not favor employment outside segregated settings and that 82 percent of the adults surveyed believe they can perform tasks in a community employment setting given the appropriate supports. In reflections from transition experiences, Brooks-Lane et al. (2005) and Marrone et al. (1999) state that the individuals with disabilities positively responded to the change experiences. In fact, Brooks-Lane et al. report:

Consumer desire for employment was never an issue. Given the opportunity to experience their community in a positive way, employment is the natural next step. (p. 131)

Similarly, in a reflection eight years after transition, consumers remember that they wanted to work in the community, were unchallenged in the segregated setting, and were apprehensive

initially about employment in the community. Following the transition, most consumers were positive about their experience in community-integrated employment (Murphy et al., 2002).

While individuals with disabilities are typically supportive of the transition to competitive employment, they also share some of the concerns expressed above by families (Migliore et al., 2008). Hsu et al. (2009) state that the top concern for young adults with disabilities in the transition process is interpersonal relationships, followed by low self-confidence, negative prior work experiences, disinterest in jobs chosen, and lack of physical ability to do the job. In a recent study, Migliore et al. (2008) found that among individuals with intellectual disabilities surveyed, the top considerations in deciding whether to be in segregated or community-integrated employment are: transportation (69%), long-term placement (68%), disability benefits (67%), safety (59%), and work skills issues (59%). These same adults indicated that family, friends, and staff rarely encouraged them to pursue community-integrated employment.

Family issues

Families of consumers are key stakeholders in the transition process and can motivate and advocate for change in services for people with disabilities. Studies indicate that parents and consumers have mixed thoughts about transitioning from segregated to community-integrated employment (Migliore et al., 2007; Parent et al., 1989). Some families feel that the segregated setting corresponds with the abilities of the consumer and are satisfied with the segregated programs while others are interested in programs with more independence for the consumer (Parent et al., 1989; Brooks-Lane et al., 2005). Migliore et al. (2007) states that some families question the decision-making abilities of the person with intellectual disability and discourage consumers from entering integrated employment programs. Families have been reported as the top barrier to organizational change (West et al., 1998), moderately resistant yet not supportive of change (Fesko & Butterworth, 2001), as well as supportive but less excited about the change in comparison to the consumer (Migliore et al., 2007).

When families report resistance to the transition to community-integrated employment, they provide a number of concerns. Families consider segregated programs safe and express growing concern over the safety of the individual with a disability in the seemingly unsafe community (Brooks-Lane et al., 2005; Marrone et al., 1999; Migliore et al., 2008; Parent et al., 1989; Tsu-Hsuan, Ososkie, & Ying-Ting, 2009). They fear that employment will negatively impact disability cash and medical benefits (Marrone et al., 1999; Migliore et al., 2008; Parent et al., 1989). Parents also indicate that they are afraid that their children will be teased or harmed by others in the community/workplace (Hsu et al., 2009; Migliore et al., 2008; Parent et al., 1989) and that their children will have no program to return to if they lose their job (Parent et al., 1989; West et al., 1998). Families are concerned that community-integrated employment will cause a fluctuation in the daily routine to which consumers are accustomed as well as cause the loss of the support network of peers and staff at the segregated program (Marrone et al., 1999; Migliore et al., 2008). Families worry the services traditionally connected with the segregated programs will be lost if they transition to community-integrated programs (Butterworth, Fesko, & Ma, 2000; Migliore et al., 2008). A study of transition in Taiwan revealed that parents also

worry about the jobs chosen for their children and do not want their children to feel economic demands (Hsu et al., 2009).

Community and economic issues

Additional challenges from society and the economy arise when thinking about competitive employment in the community. In a national survey of day support providers, respondents stated that community attitudes (local business, leaders, and general public) were a barrier (West et al., 1998). Similarly, Block (1997) states that society is unaccustomed to, and sometimes uncomfortable with, seeing people with disabilities living full lives in the community, such as working in local businesses.

Finally, in communities in which segregated services are prevalent, employers may not be aware of the employment potential of individuals with disabilities (T-TAP, 2006). Block suggests that policies have shielded the general public from encountering people with disabilities and that a long-standing attitude is that people with disabilities need to be protected from a harsh society. Hsu et al. (2009) report that community members are concerned about the possible behavior problems and appearance of adults with disabilities. From an economic perspective, Butterworth et al. (2000) found that adequate work hours and wages are a challenge in the transition and that service providers realized that they need to improve the quality of work options for people with disabilities.

III. Interviews with Community Rehabilitation Provider Representatives

To assist in identification of exemplary practices, the Rehabilitation Research and Training Center at Virginia Commonwealth University (VCU-RRTC) conducted two rounds of semi-structured interviews. One round focused on state-level systems change efforts to facilitate organizational change within the provider network and advance community integrated employment; the second focused on the provider community. For the provider surveys, CRP representatives were solicited that have had or currently have organizational change efforts to increase the number of consumers in community-based employment and decrease those in segregated options. These agencies were identified by the VCU-RRTC staff based on prior experience, such as the ODEP-funded T-TAP. This section reports findings from the provider survey.

Sample

The respondents for this survey were a sample of convenience of representatives from CRPs that had served as mentor agencies under the T-TAP program. Eight CRP representatives agreed to be interviewed.

Procedures

Respondents were provided with the survey items to review prior to the interview and a date and time scheduled for the interview. The surveys were semi-structured, with the interviewer free to ask additional questions as needed based on responses. Each interview was recorded and transcribed for analysis. The survey items included the following:

1. When you were planning for organizational change, did you establish goals? What were they?
2. What barriers did you encounter as you began implementing your plan? Funding issues? Resistance from consumers, families, communities?
3. Did you have to revise your goals or processes? How?
4. How did you address those barriers?
5. How successful have you been in achieving your goals?
6. Have you experienced any unexpected consequences, positive or negative?
7. If you had the chance to initiate this process again, from the beginning, what would you do differently?

The data analysis consisted of a review of the transcripts to identify common themes and experiences, as well as reporting innovative or unique approaches to organizational change at the provider and local community levels.

Findings

Goal Setting and Attainment. Summaries of responses related to goal-setting and attainment are presented in Table 1. Half of the respondents (4) indicated that their agencies had initially established specific goals for transition, such as:

- Complete closure of segregated facilities within a specified timeframe (typically three to five years);
- Strategic planning activities to change the philosophy of the organization, such as bringing in trainers or consultants;
- Increasing the amount of time that each client was engaged in community-based training;
- Specifying the number of individuals who would be transitioned from segregated services to community-based employment on an annual basis; and
- Creating new staff positions, such as job developers or job coaches.

Three other agencies established goals, but the goals were not specific, such as “increasing competitive employment opportunities” for their clients.

All but one of the agencies that had set preliminary goals indicated that they had to revise their goals based on progress. Most frequently, respondents indicated that the transition process was slower and more arduous than anticipated, or that they encountered unforeseen barriers that delayed progress, such as local economic conditions, resistance from funding agencies to community-based employment, and funding policies that provided disincentives to transition. However, two respondents indicated that they had achieved their ultimate goal of terminating facility-based services, and all considered their efforts to be successful even if the agency continued to provide segregated services for some clients.

“I tell people today that we are in the 20-something year of a three-year conversion plan...Obviously, the plans changed. [W]e found as we started to move into an employment focus that there were just so many issues that we had not even thought of.”

“We revise them each year based on progress -- what was changing, funding, staff training, you know.”

“You do have to be willing to change your strategies based upon what knowledge you have at a point in time or the other factors that might change, like the economy.”

“We thought that we could start little by little by taking a few people out. One of our goals was just to decrease the size until there were so few people left we just said, let’s shut the lights off. But there were so many people who wouldn’t budge.”

Table 1. Goal Setting and Attainment

Goals Set	CRP Respondent Number							
	1	2	3	4	5	6	7	8
Established goals during planning	No	Specific	No	Specific	Specific	Non-Specific	Specific	Non-Specific
Revised goals along the way	N/A	Yes	N/A	Yes	Yes	Yes	No	Yes
Eventually terminated facility-based services	Yes	No	No	Yes	No	No	No	No
Considered transition efforts to be successful	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Barriers Encountered and Strategies Employed. Each respondent indicated that his or her CRP encountered resistance and obstacles to transition but to varying degrees (see Table 2). The majority of respondents stated that they had encountered resistance from their agency staff, families of clients, community partner agencies, and funding sources.

With regard to staff, frequently reported problems included lack of training in community-based employment practices, resistance to working with consumers in the community, and high turnover rates. These problems were addressed via increased attention to staff development. Several respondents stated that they had brought in nationally-recognized experts such as Paul Wehman and Karen Flippo, or groups such as Griffin-Hammis, Inc. to provide training and TA. Several of the organizations had also received training and technical assistance through the ODEP-funded T-TAP project. In some cases where resistance impeded transition efforts, disciplinary actions were taken, or staff were encouraged to seek employment elsewhere. One respondent noted that high staff turnover at her agency actually helped the transition effort because replacement staff didn't have the attachment to facility-based services of their predecessors.

“Somebody once said to me you’re going to lose about 30 percent of your staff. And I would say when we had the center we had staff resistant to meeting people at their jobs. Because they wanted to come in, put their pocketbooks down, get a cup of coffee, talk to their friends. When you go to a job you start your job the minute you get there because you’re in the community.”

“The way to get around that barrier is, again, through educating people, having people either read articles that they may never have been exposed to in the past, or visit and see with their own eyes that people who are significantly disabled can work. And in some cases you can’t overcome that barrier because people just don’t believe, in which case you have to have a change in personnel.”

“We really did have some saboteurs among the staff. What basically we kind of went through was folks who did not want change -- they were threatened by change -- did some behind the scenes sabotaging by talking with families that they knew and were close to, to talk about how -- what a bad idea this is, how people are going to die or get hurt or you know, just horrible things like that. And so what we started doing was really an HR disciplinary process.”

Table 2. Barriers and Resistance to Transition Encountered

Barriers	CRP Respondent Number							
	1	2	3	4	5	6	7	8
Agency staff	✓			✓		✓	✓	✓
Agency Board			✓					
Families		✓	✓	✓	✓		✓	✓
Consumers			✓	✓				
Other community partners, services	✓	✓	✓	✓		✓		
Funding sources	✓	✓	✓		✓	✓		✓

With regard to families of clients (and to a lesser extent, clients themselves), resistance often came from those who had lengthy association with center-based services. A commonly used strategy for dealing with client and family resistance was to use a parent-to-parent or client-to-client approach to illustrate examples of successful community-based employment.

“Clearly you don't want to alienate people. You want to bring people along. We've had a lot of examples of family members who just really had no interest in an individual working or being in the community or living on their own or anything like that, and if you just give up or you ignore them that doesn't work. You just need to somehow kind of gently keep in on their agenda and show the assets and also show the abilities of the person. It can be a long struggle. I think we've gotten better with it. We've had more success and so we've had more practice with it. But I think initially we were really not very good at bringing families along.”

“One [strategy] is that we try to put parents in touch with parents so they can talk directly with somebody who has already been placed. We also changed the way we displayed our organization. For example, when people came in to see about our services we didn't give tours.”

“Instead of having a United Way agency tour we would take people to the different workplaces. And that really worked well. And we would include parents with that, too. We tried to make the parents as much a star in the whole thing as everybody else. We tried to make them feel that they were actually probably the most important part of the team.”

“One of the things that happened I think also is that as people were successful and people we supported were successful they became then the best marketers for a different way of doing things. So somebody would get a job and other people who knew that person said well, I want to get a job like him or her.”

“We planned [a parent dinner] and we had over 100 people come. And what we did the second year was feature some job seekers telling their story. So we had a couple of folks telling their story about going to work and some other folks telling their stories about this is what I'd like to do, this is what I'm trying to get to right now. And so it was real people stories instead of presentation kind of stuff.”

Several respondents indicated that they had difficulties with other community partners and funding agencies. A common theme was that, though these entities supported community integration, there were systemic barriers (i.e., funding, regulatory) that prevented implementation or expansion of community-based services. As examples:

“I applied for a waiver to not have this building, and DDA, well, they kept saying they wanted this community, community, community, they were not going to let us run this program without a building. So I spent probably three, three-and-a-half years on trying to get a license that would allow us to operate in the community with no building. So I think that that was a really huge obstacle but I never quit. I absolutely knew that this was the right way to go.”

“There were some advocates that had then become providers -- so they rallied against us too in kind of a competitive way saying that they would continue to provide the traditional services.”

“It causes us great problems trying to fit what we do into rules, the regulations, and the funding even when you can talk to people and they say yeah, we really like what you're doing but the rules, the regulations don't necessarily flow in that way.”

“There are various barriers in terms of people accepting people with disabilities in the community. I think initially it became, “Wait a minute, you're the organization that takes people and you take them away and you do something all day long with them -- we don't know what you do but that, you know, it's wonderful, and now you're saying no, that they can be employees in the community and we don't get it.”

“We have Medicaid funding issues and we also have voc rehab issues. That one's a different one because we're not on a benchmark kind of system. We're on an hourly system so the faster we get people jobs the more money we lose, which is just whacked. It just is very frustrating.”

“My frustration on the supported employment side... was that people gave lip service to wanting these things to happen but rarely, if ever, did anything to make them happen.”

“And there were some barriers from people who were in political positions who've heard from the families who wanted, you know, the safety and security

of the sheltered program who didn't really understand best practices. Some of those who are able to sit down and kind of help them see that this made more sense. Others, you know, couldn't be moved."

"We decided we were going to let our values drive us so what we did at the time the funding streams were all disincentives to do community-based work with customers and what we started doing is heavily write for grants -- and so that's when we got our customized employment grants and that was what enabled us to have the flexibility to do the change."

"We have presented numerous times at the state conference throughout the year. We continue to talk to our local service, human service centers of sharing our visions and goals so they're on the same page, which they're all State employees and report to the Department of Human Services."

Only one respondent reported resistance from CRP Board members and that opposition was limited to only a few members of the Board.

Lessons Learned. The closing questions of the interviews asked respondents to reflect upon their experiences and consider what they would have done differently and what lessons they had learned that could be useful to other CRPs in their own transition efforts. The following are samples of their responses.

"One would be to work a little differently with families. I think that we would continue to be advocates on behalf of the individuals who are saying I want to work and Mom and Dad are saying he can't work."

"We want to continue to do that but we want to not shut out families. We want to bring them along better as best we can for as many people as we can. I think we could do a better job with that. I think that we could and if we were doing it again today I think we could communicate more clearly and more broadly where we're going and why we're going there."

"I would never bring together a group of folks who may oppose the change. No more of those damn mass meetings. I would meet individually with folks and, again, with a very systematic process in place to address their concerns so that it's very productive -- not just to gripe, not just to complain but to address the concerns in a productive way where you can measure the outcomes of what you've agreed or what you've promised that you could do and to not make promises that are impossible because then, your credibility is ruined."

"It was just this whole thing about figuring out that this isn't an issue of disability; it's an issue of economic development. We started partnering with diverse funding sources [state Developmental Disability Council grants, private and corporate foundations] and seeing it as an issue of, you know, people needing better outcomes and were really getting into self-employment, and being excited when people actually were worth some money, and had some stuff, and how much work it was, and how much commitment it took, and how lot of people will never have the stomach for it"

“I think the overall general acceptance from business was a positive surprise for us -- because we were accepted. We thought we were going to have to go in and really pound down the door. And I can’t remember who really beat it into us that you don’t sell disability, you know, this is not a – and probably all of the people we worked with. This is, you know, this is not a program to help a person with a disability, this is a program to help business find good, solid employees who can do the job.”

“I think from a negative to us standpoint – we helped our competition grow, because one of the things that I would say we probably did wrong upfront is we really focused on employment, employment, employment, employment as opposed to helping people become part of their community, helping people, you know, there’s more to life than employment. But we focused very narrowly on employment.”

“I probably lost some friends along the way. Or friends and colleagues, because I would get from a number of people, now, Suzy, you know everybody can’t work. And I would go, no, everybody can work it just depends on how much resource – we’re willing to provide that person to work. But, no, I do believe everybody could work. Do I think we should? You know, so those kinds of conversations had some people, you know, I had the reputation of I was going to burn down the workshops. And I would always say, not when anybody is there.”

“Focus on the full community piece of it. On the fact that it’s not just about work, it’s about life. And I would do a lot more work from an advocacy standpoint with legislators and with community leaders, focusing on, again, the worth, the ability, the diversity of the people that we serve, and what a resource we are.”

Summary

This review collected rich qualitative data from representatives of CRPs that were successful in transitioning much or all of their client base and resources from facility-based, subminimum wage services to community-based competitive jobs. While their experiences have not always been positive, many experienced significant barriers from without and within, and the process was slower than anticipated, they found ways to move their organizations forward. One overriding theme through each of the interviews was that the leadership of the agency persevered toward the agency’s goals despite the obstacles.

IV. Interviews with State Employment First Representatives

This section reports on the surveys focused on state-level systems change efforts to facilitate organizational change within the provider network and advance community integrated employment.

Sample

The respondents for this survey were a sample of convenience of representatives from seven states that have initiated a statewide Employment First Initiative (EFI). EFIs center on holding individuals with disabilities to the same employment standards, responsibilities, and sets of expectations as any working-age adult. EFIs typically advance this goal through policy modifications to promote supported and customized employment approaches to clients of state Vocational Rehabilitation, intellectual and developmental disability, mental health, and special education agencies, and reduction in the numbers of clients who receive facility-based services.

Procedures

Respondents were provided with the survey items to review prior to the interview. The surveys were semi-structured, with the interviewer free to ask additional questions as needed based on responses. The survey items included items related to:

- Specific modifications to statewide disability service policies and procedures to advance community-based employment;
- Outcomes achieved to date; and
- Responses to the EFI from the CRP provider community and from families and consumers.

The analysis consisted of a review of the transcripts to identify common themes and experiences, as well as reporting innovative approaches to organizational change at the state level.

Findings

Policy Modifications. The EFIs had either implemented or were in the process of implementing a variety of policy and procedural changes to promote community-based employment. These are presented in Table 3 and included:

- **Established clear priorities and definitions.** In five of the seven EFIs, state funding agencies modified their policies to establish community-based employment as the expected outcome for all individuals receiving funded services. In addition, “employment” was redefined to exclude group employment options and positions

paying less than the Federal minimum wage or less than others performing comparable jobs, and to include self-employment as a viable option.

- **Provided access to training for staff.** Two state EFIs provided training and technical assistance in supported and competitive employment for provider agency staff. Training opportunities were made available in such areas as job development, job coaching, workability, and other areas.
- **Modified service planning process.** Two states modified their individual client service planning process, including requiring the use of person-centered planning approaches, and modifying the Individual Service Plan (ISP) form and standards to ensure that community-based employment was considered as the priority for day services. For example, one respondent noted that the standard ISP form had been revised to include new state definitions of competitive employment and to address community-based employment needs first in the planning process.
- **Initiated tracking of employment data.** Two state representatives reported that they had initiated systems for tracking placements and outcomes of individuals receiving employment-focused services.
- **Adjusted reimbursement rates for CRPs.** Three state representatives reported that they had increased their reimbursement rates paid to CRPs for community-based employment, thereby providing incentives for transitioning clients, staff, and resources to community-based employment and making corresponding reductions in facility-based services.
- **Made other contractual modifications for CRPs.** Other than adjusting fees for services, two EFI states made other modifications to their contractual agreements with CRPs, including adding requirements for job development activities, requiring planning for transitioning the client from facility-based services to employment, and placing time limits on participation in group employment models.
- **Developed interagency cooperative agreements.** Three state EFIs reported development of interagency agreements to promote community-based employment for adults and youth with disabilities. These agreements were made between state departments of education, vocational rehabilitation, intellectual and developmental disability, mental health, state workforce development agencies, Medicaid, among others, and were ratified by the state agency directors. In at least one state, an interagency committee was established to periodically review progress on the EFI and recommend future directions.
- **Revised state Medicaid Waiver.** Two state EFI representatives reported that they had modified their Medicaid Home and Community-Based (HCB) Waiver, such as adding career planning and career exploration under the category of habilitative services,

- **Developed marketing materials.** One state EFI developed marketing materials directed toward families, providers, and other constituencies to advertise stories of successful transition from facility-based to community-based employment.

Table 3. Statewide Policy or Procedural Changes Completed or in Process

Policies	EFI State Number						
	1	2	3	4	5	6	7
Established clear priorities and definitions	✓			✓	✓	✓	✓
Provided training and TA to CRP staff	✓						✓
Modified service planning process		✓			✓		
Reassessed employment service waiting lists				✓			
Initiated tracking of employment data	✓			✓			
Adjusted reimbursement rates for CRPs	✓	✓	✓				
Other contractual modifications for CRPs	✓				✓		
Developed interagency cooperative agreements	✓			✓			✓
Revised state Medicaid Waiver		✓	✓				
Developed marketing materials				✓			

Positive Outcomes. Although several of the EFIs were still in the early stages of implementation, a number of positive outcomes had already been achieved. These are presented in Table 4. Most notably, two states had already seen substantial increases in the number and percentage of disability service consumers engaged in community-based employment and corresponding decreases in facility-based services.

Respondents reported that initial reactions of CRP providers and families to the EFI ranged from negative and resistant to mixed. As shown in Table 4, all states reported that support from the provider community is growing as agencies become more involved in the effort and with the state EFI teams. Three states reported that families are also becoming more accepting of the focus on employment.

Four state EFI representatives reported that consumers have become more engaged in the service delivery system, such as through participation on advisory panels, self-advocacy groups, peer support groups, and other activities. Two respondents reported that they had experienced more individuals with disabilities accessing benefits counseling services in anticipation of employment, and two reported that their state had increased the level and quality of interagency cooperation on disability and employment issues.

Summary

The state EFIs used a variety of strategies for promoting employment for youth and adults with disabilities, strategies that can be replicated in other states. Some of the most commonly reported strategies included:

- Modifications to state disability service policies defining “employment” as only referring to community-based employment either at minimum wage or commensurate with other employees, and specifying community-based employment as the first priority;
- Adjusting fee-for-service rates to provide incentives to CRPs to expand service capacity in community-based employment, and making other modifications to provider contracts related to the service planning process;
- Developing interagency councils and agreements, including the state vocational rehabilitation agency, intellectual and developmental disability agency, Medicaid agency, and others;
- Modifying HCB Waivers to add career planning and exploration under habilitative services; and
- Providing access to training and technical assistance to CRPs in supported and customized employment via national experts such as Griffin-Hammis, VCU-RRTC, and others.

To date, only two of the seven EFI states have documented shifts in service delivery from segregated services to community-based employment. However, all respondents provided indications that their states are moving toward that goal.

Table 4. Positive Outcomes of Employment First Initiatives

Outcome	EFI State Number						
	1	2	3	4	5	6	7
Increased proportion of clients in employment	✓						✓
Increased provider support for employment	✓	✓	✓	✓	✓	✓	✓
Increased family support for employment	✓		✓		✓		
Increased use of benefits counseling services	✓			✓			
Increased interagency cooperation		✓		✓			
Increased engagement of consumers			✓	✓		✓	✓

V. Review of State Policy Initiatives of the State Employment Leadership Network

The State Employment Leadership Network (SELN) was launched in 2006 as a joint initiative of the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Institute for Community Inclusion (ICI) at the University of Massachusetts Boston. It is a membership-based network of state developmental disability (DD) agencies committed to state systems change to improve employment outcomes for individuals receiving DD services. SELN offers states the opportunity to connect, collaborate, and share information and lessons learned and build cross-community support for pressing employment-related issues and policies at state and federal levels. States commit to work together and engage in a series of activities to analyze key elements in their systems to improve the integrated employment outcomes for their citizens with developmental disabilities. There are currently 17 state members of SELN. Those states included: California, Connecticut, District of Columbia, Hawaii, Iowa, Louisiana, Maryland, Massachusetts, Michigan, Missouri, New Mexico, Nevada, Oregon, Pennsylvania, Texas, Virginia, and Washington.

SELN recently published a report for 2009-2010 citing policy strategies and accomplishments and within its 17 member states (SELN, 2010). Policy strategies were summarized as the following (p. 4):

- **Leadership.** States demonstrate clear and unambiguous commitment to employment in individual community jobs from top leadership through all levels in the system. Local and state level administrators are identifiable as “champions” for employment.
- **Strategic goals and operating policies.** Employment is identified as the preferred outcome in state developmental disabilities policy and supported by program goals and operating practices that are clearly designed to achieve that objective. For example, the District of Columbia Developmental Disabilities Administration (DDA) requested providers to submit strategic plans for assisting consumers in transitioning from day programs to a path to employment. The DDA also held a Day Provider Forum to support their efforts to move to employment first strategies.
- **Financing and contracting methods.** The outcome of employment in integrated community jobs is emphasized and supported through the state’s resource allocation formulas, reimbursement methods and rate setting practices. For example, California’s Department of Developmental Services increased its reimbursement rates for competitive employment, decreased rates for segregated services, and also provided a rate enhancement for agencies that had at least 50 percent of their clients in competitive employment.
- **Training and technical assistance.** High performing employment systems invest in the development and maintenance of a strong, competent workforce, building the skills of job coaches and developers, first line supervisors and key employment

staff. As examples, Hawaii contracted with the University of Hawaii's Center on Disability Services to provide training to case managers on the value of competitive employment for individuals with developmental disabilities; and New Mexico is developing a statewide curriculum for enhancing provider competencies that will include classroom training, web-based learning, and mentorships.

- **Interagency collaboration and partnership.** Building relationships with key state and local agency partners such as vocational rehabilitation, education, mental health and the state Medicaid agency removes barriers that may hamper the ability to provide employment supports as people transition from one funding stream to another. For example, the Maryland DDA formed a new partnership with Maryland Medical Assistance Program (Medicaid) that led to the creation of a seamless system which allows simultaneous access to Home and Community-Based Services Waivers and to the Employed Individuals with Disabilities Program. A renewed partnership with the Division of Rehabilitation Services (DRS) resulted in regularly scheduled meetings between key staff of the administrations to create a clear business flow for people receiving services, including transitioning youth.
- **Services and service innovation.** Service definitions and support strategies are structured and aligned to facilitate the delivery of employment supports to all individuals with developmental disabilities regardless of the intensity of their needs. For example, several of the states have ensured that criteria for competitive employment are consistent across all funding streams (i.e., vocational rehabilitation, DD agencies, Medicaid Waiver, etc.). In addition, both California and Hawaii have added self-employment options (microenterprises) as viable support strategies for individuals with developmental disabilities.
- **Performance measurement and data management.** Comprehensive data systems are used to measure progress, benchmark performance, and document outcomes. Information is gathered on key indicators (i.e., employment status, earnings, work hours) across employment and other related systems and used to evaluate and track results, inform policy, and improve provider contracts and service agreements.

Table 5 presents a summary of the SELN states' use of each of these policy initiatives. As the table shows, all of the states developed leadership roles throughout their state DD service systems to champion individual competitive employment for service consumers. The majority also provided training and technical assistance to their provider agencies, developed statewide performance and data management systems, and developed interagency partnerships and collaborations. Fewer than half of the states either (a) developed policy directives that established individual competitive employment as the preferred outcome for service consumers, (b) altered their financing and contracting methods to provide incentives to providers, or (c) restructured their service definitions or designs to all individuals with DD.

Table 5. SELN State Policy Initiatives and Strategies

Initiative/Strategy	States
Leadership role	17
Strategic goals and operating policies	5
Financing and contracting methods	7
Training and technical assistance	12
Interagency collaboration and partnership	14
Services and service innovation	8
Performance measurement and data management	9

VI. Recommendations for Facilitating Transition from Segregated to Integrated Services

The findings from this review have many implications for states and CRPs. First, systems change from segregated services to community-based employment may be, in the words of West et al. (1998) “a war of attrition rather than a revolution.” Many families, CRPs, and communities have invested deeply, financially and emotionally, in segregated programs and resist efforts to substantially downsize or eliminate them. True systems change may come about, not from changeover of existing facilities, but from new consumers coming into the system who, along with their families, want and expect more than a slot in the workshop or day support program.

Additionally, the findings suggest that new methods for increasing employment systems capacity may be needed. Systems change efforts have resulted in some changes within the SELN/EFI states, but in order to reach the next plateau new initiatives will be required. The following strategies are recommended for states and individual CRPs to press the transition process.

State-Level Strategies

- **Implement cross-agency "employment first" policies.** State funding systems, including VR, ID/DD, mental health, and Medicaid agencies, need to establish a clear message that community-integrated employment is the expected outcome for receipt of employment/day treatment services, align policies accordingly, and establish accountability measures. Niemiec, Lavin, and Owens (2009) present a blueprint of establishing an employment first initiative in state and local service delivery systems.
- **Use conversion grants to support organizational change.** Federal and state grants can serve as conversion support to help programs redirect staff and resources to support customized employment, obtain consultation and technical assistance, and improve staff competencies. Such activities are currently being funded in several states through the Medicaid Infrastructure Grants (Sulewski, Gilmore, & Foley, 2006) which provides grants to states to support development of employment-related Medicaid assistance.
- **Develop start-up grants for new provider agencies.** State grants can also be directed toward start-up for new CRPs that are focused exclusively on community-integrated employment at or above minimum wage. These vendors, unlike existing facilities, would be unencumbered by histories of segregated services and values. These grants can be targeted to provide access to community-based employment in areas where existing CRPs have failed to do so to any substantive degree and possibly prompt change in those facilities as well through competition.
- **Reward community-integrated employment through funding mechanisms.** A clear finding from this review is that funding incentives to achieve specified employment

outcomes can be effective. Funding mechanisms can and should be implemented that are flexible and that provide incentives to CRPs to expand their service capacities for integrated employment. These funding mechanisms could include flexible and negotiable fees-for-services based on the complexities of the clients served and competitive employment outcomes achieved.

- **License quality programs.** Organizations that meet quality standards in providing customized employment should receive credit for that accomplishment. One approach would be a licensing program where licensed agencies have public documentation of their accomplishments. Another would be to use staff from exemplary programs as mentors to other CRPs in the transition process. The T-TAP project described previously developed a manual (Butterworth, Gandolfo, Revell, & Inge, 2007) that describes the development and use of a mentoring process to effect organizational change.
- **Develop an evidence base of effective state and local practices.** While much research has been conducted on strategies for promoting transition from segregated to integrated services, the evidence is largely anecdotal. One experimental study (McGrew et al., 2005) was identified that measured the impact of a results-based funding system on client employment outcomes as compared to traditional fee-for-service agreements. Clients experienced higher rates of employment and earnings; however, the study did not include an assessment of impacts on CRP capacity-building through increased resources and staffing being devoted to integrated employment.

Organizational Level Strategies

- **Align the organizational mission to employment first.** CRPs need to clearly establish integrated employment as their priority mission. Then, they must begin to organize their resources to support that mission, such as adjustments to staffing levels, budget modifications, adding or expanding employment-related funding sources, etc.
- **Market success.** CRPs should use multiple approaches to marketing their priority mission of integrated employment, such as newsletters, banners, and websites, and publicize success stories of people moving into competitive employment. Families and consumers can be involved in the marketing success, both as a target audience and as storytellers.
- **Ensure staff role assignments support competitive employment.** CRPs should focus on employment outcome in its staff design and assignments, and provide needed resources, training, and support to staff.
- **Explore and create innovative programs in areas with limited public transportation options.** Examples may include ride-sharing, volunteer driver programs, and local

transportation coalitions. Descriptions of these and other options can be found on the Easter Seals Project ACTION website (www.projectaction.easterseals.org).

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