Beating the Odds

People with Severe and Profound Disabilities as a Resource in the Development of Supported Employment

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Effective supported employment agencies promote organizational learning. **Learning organizations** use their power to search for situations that challenge their settled ways of thinking and stretch them to discover new competencies. They thoughtfully choose challenging partners and risk collaboration with them, even, or especially, when the collaboration causes them uncertainty and maybe even anxiety. They do this because they believe that they can achieve more meaningful results for everyone who relies on them by prospecting for new possibilities. **Stagnating organizations** use their power to avoid re-thinking their assumptions and to keep demands comfortably predictable. They seek to work only with those who reinforce their current mechanisms for control and leave their current mental models undisturbed. They do this because they see no reward in risking the familiar. (Normann,2001).

People with severe and profound disabilities are a prized resource to supported employment programs that want to be learning organizations and a dire threat to supported employment organizations that just want to get by comfortably. They are a resource for the same four reasons that they are a threat. First, re-

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This paper is partly based on visits to four RSA CHOICE Demonstration Projects, sponsored by The Presidential Task Force on Employment of Adults with Disabilities (no endorsement by the Task force should be assumed for anything in this paper), on discussions with the staff of Community Work Services, Madison, WI, and on agency planning retreats that we have facilitated for five supported employment agencies seeking to improve their capacity to serve people with severe and profound disabilities. We appreciate the thoughtfulness and candor of those who shared their experiences and the lessons they have learned. Preparation of this publication was partially supported through a subcontract to Responsive Systems Associates from the Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through a cooperative agreement (number H133B031116) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

sponding to their potential as workers means inventing new ways to develop jobs and new ways to enroll and support all those who make people with severe and profound disabilities successful at work. Second, learning new ways in collaboration takes time and requires flexibility that many agency managers don't think they can find without jeopardizing the performance required by their funders. Third, imagining people with severe and profound disabilities finding success and meaning at work shakes many people's common sense views about disability and workplace openness. Fourth, for many agencies, making progress means accepting responsibility for contradictions between the agency's stated missions and values and its actual performance. Stated values often include a commitment to individualization and flexibility; actual practice often displays a narrow repertoire of methods for assisting people to work successfully and the lack of a systematic process for inventing new methods to adapt to changing needs. Stated values often include a priority on those most severely disabled; actual practice often ignores or rejects people with severe and profound disabilities. Labeling some of the people whose needs fit current practice as "most severely disabled" covers this uncomfortable contradiction. One parent of a person with profound disabilities observed,

> *For them, 'most severely disabled' means 'these are the most disabled people we can imagine serving'. My daughter doesn't register on their radar screens at all.*

Strategic decisions

Learning organizations recognize that developing the capacity to assist people with severe and profound disabilities is more than adding on some skills. The change is systemic and challenges and strengthens their organizations culture: its ways of relating, its ways of working, its ways of understanding. The first shift comes in recognizing that this kind of organizational learning requires partners, not clients or customers. Negotiations, agreements, and actions that generate trust and joint effort between agency staff and people with severe and profound disabilities and their allies build partnerships. These partnerships take staff outside their usual boundaries to invent new ways to work and

discover new ways to think about people with disabilities as workers. Leaders can improve the performance of supported employment agencies by generating thoughtful discussion of two compound questions.

- **What would it take for us to be a learning organization and do we want to make a way to do what it takes?**
- **What could we learn by increasing our capacity to assist people with severe and profound disabilities and do we want to create ways to learn these things?**

A learning organization could reasonably choose to learn things from partners other than people with severe and profound disabilities. However, we think that every supported employment agency should consider collaborating with people with severe and profound disabilities because of the great organizational learning potential and because people with more severe disabilities are very likely to be left out of employment unless supported employment agencies learn to assist them.

This doesn't mean that supported employment agencies control the only route to work for people with severe and profound disabilities. In fact, one important benefit of individual funding in some disabilities service systems has been the number of people it has allowed to overcome provider reluctance by creating their own opportunities and supports. However, we think that self-managed employment supports should be a choice among real alternatives, not an imposition on people who want to pursue their own vision of employment but can find no agency willing to learn how to assist them.

While it is possible for supported employment agencies to make progress on assisting people with severe and profound disabilities to work within the constraints of block-funded, professional-bureaucratically controlled service systems, system level reforms of the sort demonstrated by the CHOICE projects offer more space for learning. A service system that wants the capacity to offer opportunities for employment to all disabled people will find ways to regard learning partnerships with people with severe and profound disabilities as a vital form of research and development. Its leaders will assure that a growing number of supported employ-

ment agencies include a growing number of people with severe and profound disabilities as they implement policies demonstrated effective in the CHOICE projects. The policies that have the best chance of supporting necessary learning include: providing sufficient funding through individual budgets that offer participants the option of paying directly for needed services; offering the flexibility to negotiate modifications when generally effective system policies don't fit individual circumstances; investing in training and person-centered planning processes that support people with severe and profound disabilities and the people who know and care about them to explore what it will take for a person to move into the workforce; making it easy to locate and pay new providers if people with a reasonable plan can't find what they need from existing agencies; and investing in the kind of critical reflection on practice that will encourage agencies to get better at inventing individualized supports to match unique circumstances (O'Brien, 2001).

These system level reforms open the space for organizational learning, but the decision to learn rests with supported employment agencies themselves. Thoughtful consideration of the decision to partner with people with severe and profound disabilities engages three questions: Is it possible for people with severe and profound disabilities to work? Is it relevant to our agency for us to learn with them? Is it worth the effort?

Is it possible?

People with both paychecks from community employers and labels of severe or profound disability have beaten long odds. Whether or not a supported employment agency chooses to collaborate with people with severe and profound disabilities to shorten those odds depends partly on its leaders' belief that they can learn to handle the challenges involved in a way that will yield meaningful results.

Following Gold (1980), we understand people with severe and profound disabilities in terms of the requirements their unique personal characteristics place on those who want to improve their life opportunities. The labels symbolize three things about a person. First, their well being depends profoundly on sustained,

intense, skillful assistance. Second, they are more different from others similarly labeled than the label suggests. This uniqueness accounts for the collection of different labels that they acquire as different specialists view them through different professional lenses. What can be described as multiple impairments occur in the lives of particular, whole and singular people who embody the limits of human variance. Third, their difference from what most people see as typical ways of relating to the world are so obvious as to obscure both their potential for individual development and the unique shape of their need for assistance. Competently assisting people with severe and profound disabilities rests on the ability to reach through apparently huge differences in appearance, movement, and communication to establish a relationship that recognizes this particular person's dignity, character, and gifts. Such relationships run against the grain of much common human service practice and can cause frustration and a desire for change, as the mother of a 17 year old woman with multiple labels (profound cognitive impairment, visual impairment, cerebral palsy, and autism) says.

> *The experience of truly loving and valuing someone that the rest of society devalues leads to a perspective that challenges the devaluing, underlying assumptions on which many service systems for people with severe cognitive impairments were built. Having service systems presume your acceptance of practices and placements (e.g. segregation, institutionalization, self-contained classrooms, and sheltered workshops) that are based on undervaluing your loved one is an extremely painful and frustrating experience. (Jordan & Dunlap, 2001, p. 287)*

The possibility of individual employment has been established

A look at the numbers provides some information on the feasibility of employment. Researchers with the broadest scope of inquiry (Wehman, Revell, & Kregel, 1997), identified about 140,000 people working with assistance from supported employment in the US in 1995, about 8,500 (about 6%) of whom were labeled severely or profoundly mentally retarded. There are three limitations of this data.

- Mental retardation is the only disability their report differentiates by assessed level of severity, so this number leaves out people with no severe cognitive disability and substantial physical disabilities, or autism, or mental illness.
- The US administrative definition of supported employment includes both individual employment, which accounted for about 77% of those reported at work, and group employment in such arrangements as enclaves and work crews, which accounted for 23% of those at work. The data reported don't tell us how many people with severe and profound mental retardation were employed as individuals and how many were part of a group placement, so the odds that a person's paycheck comes from an individual placement are probably longer than 6 in 100.
- There is no report of the total number of people with severe and profound mental retardation that agencies attempted to assist into employment, so it isn't possible to estimate a typical rate of agency failure.

The number, 8,500, suggests that a diagnosis of severe or profound mental retardation does not predict un-employability. Much smaller scale reports also support the conclusion that projects aimed at providing access and success at good quality jobs can include people with severe and profound disabilities. A successful effort to open civil service employment to 55 people with disabilities included 2 people labeled severely mentally retarded (Mank, O'Neill, & Jensen, 1999). A project focused on employment for 21 people whose physical disabilities had excluded them from available supported employment services, and consigned half of them to living in nursing homes, created ways for each of them to succeed at jobs that matched their individual interests (Inge, Strobel, Wehman, Todd, & Targett, 1999). A study of more than 450 people assisted by 13 different agencies which are exploring the use of natural supports in the workplace includes 23 people with severe or profound mental retardation at least partially supported by their co-worker in individual jobs to earn a mean wage of $286 a month over a mean employment period of almost 29 months (Mank, Cioffi, & Yovanoff, 1998). Among the 13 agencies in Mank, et al's study (1998), each of the four supported employment programs that scored highest on "typicalness", an index

of practices correlated with greater productivity and workplace inclusion, included people with substantial needs for support (Rogan, Banks, & Howard, 1999), so it seems reasonable to conclude that including people with severe and profound disabilities does not necessarily compete with other desirable practices or with serving less severely disabled people effectively. However, Rogan, et al. (1999, p. 208) report that the agency among these four with the strongest history of including people with substantial disabilities, has recently reduced its commitment to people with severe disabilities as an adaptation to outcomes required by their contract.

System policies affect possibility

This last finding introduces another important dimension of possibility. Employment may be within the reach of many people with severe and profound disabilities, but is it compatible with the goals and accountability measures of the systems that fund a supported employment agency? A survey of 30 states shows variation in the percentage of supported employment participants labeled severely mentally retarded from 0% to about 25% with 7 states counting less than 1 % of participants and 3 states counting more than 10% as severely mentally retarded (McGaughey & Mank,1999, p. 62). The higher percentages of involvement reflect system priorities on supported employment for people with severe and profound disabilities that are backed by the performance of system managers.

There is no necessary conflict between increased accountability for results (Revel, West, & Cheng, 1998) and the inclusion of people with severe and profound disabilities in supported employment. However, designing and refining accountability systems to avoid creating disincentives to serving people with substantial disabilities tests system's managers's skill and ability to detect and adjust problems in their accountability practices as they are implemented. Big changes in conditions for payment increase uncertainties for supported employment agencies and may provide a reason for them to wait and see whether the system will back its words about service to people with severe and profound disabilities.

Prudent agency leaders will assess the system that funds and regulates them to discover sources of support and administrative flexibility for their organizational learning. Learning takes time, money, and flexibility. Even when relevant procedures -such as personal profiles (Callahan, 1991)- can be imported from other innovators, it takes time and practice to become fluent in their use. Building partnerships with people with severe and profound disabilities and their allies that disclose a person's interests and skills in a way that leads to action takes time even for skilled staff. Funders impatient to run up their outcome scores regardless of the inclusion of people with severe disabilities may see little reason to invest in making room for an organization to learn to serve people who bring significant uncertainties with them.

Agencies that want to learn in collaboration with people with severe and profound disabilities have had to be as inventive about their relationship with their funders as with people with disabilities and their employers. Some have partnered with people whose parents know how to push systems. Some have found ways to cultivate relationships with system administrators and have found ways to like their interest in learning to other system priorities, such as the demonstration of individualized funding through a Medicaid HCB Waiver. Some have joined research and demonstration projects. Some have diversified their accountability and increased their resources by raising independent funding from foundations or grant funds from developmental disabilities councils. Attracting investment sufficient to allow for learning gives people in an agency the chance to exercise their advocacy skills and their entrepreneurial flair.

Emotional risks to staff can color their judgments about possibility

Though service systems have a sincere rhetorical commitment to employment for people with severe and profound disabilities, there is no effective way to enforce this commitment from above. This leaves the decision to engage in learning partnerships with people with severe and profound disabilities squarely with the supported employment agency. Staff willingness to commit to a learning process that will change their organization's culture depends partly on their prediction that their organization will be able

to handle the challenges. Uncertainties, amplified by stereotypes about people with severe and profound disabilities, can create an emotional climate that colors staff assessment of the possibility of success.

Staff sense of competence, their belief that if they don't know how to make something happen they can take responsibility for learning how, plays a major part in how they read the evidence. Low confidence in their organization's capacity to learn leads them to read long odds and a poor bet, "Only 6 in 100 supported employment participants have severe and profound mental retardation, so there is no way we should spend time trying to work with people whose disabilities are so complex." Higher confidence leads to a different reading, "Six in 100 is enough to show us that it's possible. Let's invite some people with severe and profound disabilities to help us get to work."

There is plenty to test people's confidence in their organization's ability to learn. Those who chose to accompany people with severe and profound disabilities into the world of work face emotional risks, most of which express fear of failure or fear of being exposed as incompetent These questions, produced by participants in a retreat with staff of a supported employment agency considering expanding services to include people with severe and profound disabilities, indicate some of the risks staff may anticipate.

Will I be able to communicate with the person enough to develop a relationship?

Will I be able to handle what the person needs from others to get through the day?

How will I know if the person actually wants to work or if I am just imposing on them or helping somebody else impose on them?

Will I be able to identify any capacity for work in the person?

If I can identify a capacity for work, will I be able to identify a job that the person can do for pay?

If I can identify a job, can I negotiate or provide what the person will need to be successful from the employer and

co-workers, and from my agency, and from the person's residential provider and family?

Will I be able to handle the person's and other's reactions to failure if things don't work out?

Will I be able to handle the frustration of dealing with all the barriers the person will face?

The staff who produced this list noticed on reflection that concentrating too much on these risks apart from particular real relationships would be paralyzing. They also noticed that their sense of vulnerability increased greatly when they imagined that they were solely responsible for a person finding work. It was easy to get trapped, they noticed, in a pre-judgment that people with severe and profound disabilities are, by reason of their disability, incapable of playing an active part in relationships. Even when staff felt confident that they could learn to identify doable work tasks and teach people how to complete them, they found that the label of profound disability could steal their ability to imagine a person reaching out and being with others in ways that others would find engaging.

Staff who won't take responsibility for their own pre-judgments about people with severe and profound disabilities, their own uncertainties about their prospects in the workplace, and their own need to discover new ways to work may jump to the conclusion that work is undesirable or an impossible dream. The assumption that all people with profound disabilities, family members, and co-workers mirror their unspoken concerns rationalizes avoiding the question of how an agency might learn to support some people with severe and profound disabilities and short-circuits the search for partners.

Leaders for organizational learning will find ways for their agency to give voice to fears and uncertainties and to cope with them by strengthening team relationships and partnerships, studying their environment and the field to define threats, opportunities and potentially effective strategies, maneuvering politically to build support, and developing or recruiting necessary skills. These ways of coping may themselves confront an assumption that some agencies hold but usually don't speak: that it, and its

staff, are unable to learn and innovate because they themselves feel powerlessness and victimized.

Is it relevant?

Resources for learning are scarce and the number of people with less severe disabilities who can benefit from supported employment is large. It is reasonable to consider the possibility that investment in learning how to effectively serve more people with severe and profound disabilities will lead an agency to a level of overspecialization that will not benefit all the people with disabilities that an agency wants to serve. Assessing the possibility of overspecialization requires investigating how much people with severe and profound disabilities need fundamentally different staff skills and capacities than less disabled people do as opposed to needing more imaginative, disciplined, and energetic application of the same skills needed by anyone assisted in supported employment. If people's requirements are idiosyncratic or specific to severe levels of disability, the skills staff acquire in assisting them into work will be of limited use to others.

The answer to this reasonable question remains uncertain. However, there are good reasons to think that engagement with people with severe and profound disabilities will build staff and organizational capacities that will improve the quality of service to all of the people a program serves. One experienced staff person, who also competes at a high level as a runner, draws this analogy,

> *In training, I spend some time running with extra weight on to build my strength and stamina. Learning to work with Mandy and Art and their circles has strengthened my ability to plan with people, to recruit employers and co-workers, to adapt jobs, and to deal with on-the-job problems. Of course, Mandy and Art have a lot going for them and so, in some ways they are my toughest customers but in other ways they are not."*

Mank, et al (1998) offer a perspective on the relevance of what can be learned with people with severe disabilities based on their ongoing survey of more than 450 supported employment participants with different levels of need for support. They found that,

overall, the people with more severe disabilities in their study earn less, have fewer interactions with non-disabled co-workers, and have a lower work rate and poorer work quality than less disabled people in the study do. This makes a clear case that agencies that choose to assist people with severe disabilities have more learning to do. Their other findings set the agenda for this learning. Regardless of level of disability, people with more typical conditions of employment earn more and are better integrated into their workplace than people with less typical employment conditions. Furthermore, people with severe disabilities who experience more typical employment conditions had higher levels of wages and integration than people with mild disabilities who experience less typical employment conditions. Finally, people with more severe disabilities who earned more and were better integrated worked in settings where they had fewer hours of direct and indirect support from supported employment personnel than people with similar levels of disability and more hours of staff support did.

This suggests that to serve everyone better, supported employment agencies should learn how to establish working conditions that are as typical as possible. Typical means that which commonly happens in a workplace. A practice was judged atypical to the degree that creates a different experience of the job based on disability. For example, if supervisors usually interviewed job candidates and a worker with a disability was not interviewed by a supervisor, their experience would be rated “atypical”. Four clusters of scales assessed four dimensions of a person’s work experience: the hiring process: work hours, schedule, wages and benefits; work role and responsibilities; and orientation and job training. Extra assistance in negotiating a usual work context did not reduce the rating of typicalness, so high typicalness means doing the same things and experiencing the same expectations as others on the job, with extra help as necessary. Higher levels of typicalness predicted higher wages and more workplace integration, whether the worker was more severely or more mildly disabled.

Another finding, explored more fully in Mank, Cioffi, and Yovanoff (2000), identifies an additional area for learning. More

hours of direct support predicts lower wages and lower levels of integration. However, when a person requires high levels of direct assistance, offering co-workers and supervisors in the person's immediate work area informal, small group training that conveys specific information about the person before the person starts the job greatly decreases the negative effects of direct assistance on the typicalness and the outcomes of the person's work.

Making progress on any item on this learning agenda stands to benefit all supported workers, regardless of their level of disability: make the work experience more typical, positively involve co- workers, provide direct support only when no other strategy will do, and give co-workers a chance to learn specific information about people who need direct support on the job. But maybe even more important for organizational learning than the agenda Mank, et al. suggest is the pattern of thinking reflected in their analysis.

- Ask important questions with definite answers and, when necessary, invent measures that reflect potentially important matters (like "typicalness).
- Use the tools you have (multivariate analysis) to look at the whole situation from the point
- of view of those most likely to be disadvantaged and excluded (people with severe cognitive disabilities and substantial behavioral problems) and describe how it is for them (worse results overall).
- Look closely at the group of people who signal a performance problem for things that make a difference (more typical work conditions and less direct support).
- Keep searching for ways to improve the experience of those with the worst results without compromising the assistance they need to be successful (co-worker training).
- Stay true to the principle that guided many of the founders of supported employment: those with the most need for assistance need the best opportunities for assistance.

- Instead of stating over-simple rules that might cut people off from employment, set challenges. How can we provide just as much help as people need to be successful and no more? How can we offer the help people need in ways that disrupt typical workplace patterns as little as possible? When the help a person needs does disrupt typical workplace routines and expectations, how can we help a person's co-worker's and supervisors make sense of the difference?

The improvements in thinking and creativity required to meet these challenges should be relevant to everyone a supported employment program serves.

Callahan (1991) and Inge, et al. (1999) each describe the practices they developed in two different projects designed to assist people excluded from work because of severe physical disability. Some of these practices probably have general relevanc…:

…focus on what people can do and what people are interested in doing rather than on people's deficiencies

…give people the chance to gather the people who know them and care about them and assist them to plan in a way that sets work interests in the context of their whole life

…build relationships that allow identification of skills and interests in different life contexts

…avoid stereotyped job placements by conducting a job search based on the person's interests

…build relationships with employers that demonstrate how the person can successfully contribute to the workplace

…assist the person to deal with barriers to success at work that arise from problems with community resources like transportation and lack of support from those the person lives with

…stay available to the person and the workplace as necessary through time.

Some practices, relating to assistive technology, communication difficulties, attendant care, and redesigning or carving jobs to accommodate people's enduring performance difficulties, are more specific to people with severe or profound disabilities.

Collaborating with people with severe and profound disabilities will lead involved supported employment staff to some knowledge and skills more useful to people with severe disabilities than to others. Some of this knowledge will concern the kinds of assistance specific to people's unique constellation of impairments. Some people will require alternative communication systems. Others will need specialized seating. Others will need powerful systematic instruction or personally designed behavior supports. Some of this knowledge will come from engagement with limits in people's experience and communication. Many people with severe disabilities who have been excluded from work or the expectation of work have limited ways to describe their work interests. Many people with profound cognitive disabilities have very limited if any available ways to communicate a particular sense of the future they want to work toward or the values that guide them. They bring the ethical dilemmas of substituted choice with them: if people can't clearly indicate a desire to work is it right to expect them to take a job?

Many people can benefit from employment support with much less investment than people with more substantial disabilities require. They have clear ideas of their next steps to work and plans about exactly the help they need to take those steps. Treating those people to elaborate person-centered plans or functional assessments or staff assisted job development would be wasteful and silly. Greater flexibility in personalizing support is the key to improved quality. A common agenda for better quality supported employment provides the context for all of this specialist knowledge and skill. Supported employment will work better for everyone who needs it as staff improve their repertoire of skills and connections so that they can help people find better job matches, success through more typical patterns of experience on the job, and more effective ways to arrange the support they need from family, friends, personal assistants, service providers, supervisors, and co-workers. Collaboration with people with severe and profound disabilities can contribute to the relationships, practices, and ways of thinking necessary to pursue this agenda.

Is it worth it?

Some researchers on organizational learning (Versteeg en, Scharmer, & Kaufer, 2001), clarify the relationship between shared awareness and common will in the process of significant organizational change. Many organizational change efforts fail because the people involved take the process of change too lightly by assuming that no more than a quick visioning exercise and an exhortation to "shift our paradigm" will do the trick. Change stays superficial because the thinking and deciding stay on the surface. Deeper changes have deeper roots than this. People involved in deeper changes uncover current realities and emerging possibilities together. They look for connections between what matters deeply to them personally and what faces their organization. From and after this shared search comes an organizational vision worth working for and a common will to move past current limits in order to realize it.

At least three things make it hard for supported employment agencies to do this work. It is hard work that leads to more hard work. The pace of current work absorbs almost all of people's energy and the over-commitment of service systems makes finding resources to underwrite change, much less the time to plan and reflect on change efforts, a difficult task in itself. And, uncovering the possibilities for meaningful change means taking responsibility for shifting a history of hard realities.

With a demanding change process and uncertain success on one hand and a ready supply of less challenging candidates for employment on the other, a supported employment agency will only decide to learn through partnership with people with severe and profound disabilities after thorough consideration of why employment for them is worth the effort. Here are six reasons planning retreat participants gave for their commitment to go ahead:

- Some parents of transition students with severe and profound disabilities want employment for their sons and daughters and have energy to either fight the system for denying them or to help employment happen; we should support them.
- Supported employment is about expanding opportunities; if we don't keep pushing the limits we won't be true to history.

- We already have many of the skills and contacts we need and this will stretch and strengthen us.
- People with severe disabilities have more potential than they can ever actualize by sitting at home or in a day program; they deserve the opportunity to work.
- When a person with a disability works, others see them and they see themselves in a better light; if we don't give people the option of work, they'll be stuck in the low expectations that go with their label.
- We believe in inclusion in all aspects of community life; we can't be part of leaving people with severe disabilities out of work.

The point is not to adopt another organization's list, but for each organization to do the joint thinking necessary to develop its own common will. Two illusions, one falsely positive and the other falsely negative, can bedevil deliberations on reaching for the capacities to assist people with severe and profound disabilities to work.

The notion that people with severe and profound disabilities have high quality alternatives to work makes up the falsely positive illusion. Some people with severe and profound disabilities have both a gift for social and civic life and the insanely great support necessary to fully participate in life without paid work (for an example, see Schaefer, 1998). Support of this sort demands every bit as much committed creativity as supporting a person at work, with the added challenge of filling a weekly schedule without the structure that a job provides, and it may depend even more on the presence of imaginative and personally involved assistants than holding a job does. Most community access or community experience programs and most day programs that serve people with severe and profound disabilities struggle to provide people a meaningful day without work and too often fall back into time filling rides to hang out at the mall or disconnected training activities. Those congregate programs for people who do offer people with severe and profound disabilities access to paid work struggle to provide enough work that matches a person's interests and abilities at anything approaching the wage a person

could earn with the assistance of a competent supported employment program even when that wage is disappointingly low.

In 1976, Norma Raynes summarized a year's systematic observation of life on institution wards that had passed quality assurance inspection in a paper whose title summarizes the distribution of opportunities by assessed level of disability. She called her paper, '*The less you've got' the less you get.*Unfortunately, this pattern has not passed into history. Felce, et al. (1999) studied the daily experience of people served in residential settings (56 people in 15 residences) and day services (1,370 people in 48 programs) that had passed a government quality inspection. They found that, compared to less disabled people in the same setting, the more severe a person's disability, the less the person will be engaged in constructive activity (mean = <10 minutes per hour), the more limited the person's opportunities to exercise basic choices, the less the person will be involved in everyday domestic activity (preparing food, washing clothes, cleaning, etc.), the more likely it is that the person's only social contacts will be with staff and that all activities will happen within program or residence walls, the more depersonalized the person's experience will be, and the less staff will interact with the person. Imagining what it would be like to live day after day under these conditions suggests some of what it might be like to live with a severe or profound disability in a service inspected and certified as of good quality.

Direct observation of local alternatives available to people with severe and profound disabilities will help supported employment staff avoid the illusion of positive alternatives. If positive alternatives do exist, they are worth knowing about. If they do not, then visits to nursing homes, group homes, day centers, special education classrooms and other local services will inform a realistic judgment about the need for partnership with people with severe and profound disabilities.

Just as misleading, a falsely negative illusion is harder to avoid. Unless staff have had direct experience with people with severe and profound disabilities in settings that give them a chance to see people as valued individuals, stereotypes about profound dis-

ability can overwhelm their thinking and inflate the challenge of employment to the level of impossibility. Some people with the label seem to struggle for sufficient consciousness or movement to contact and influence their environment even when they have access to competent assistive technology and good support for their health. Some people may find it impossible to reliably perform any meaningful task, even when they have access to powerful systematic instruction, good personal assistance, and creative adaptations of tasks and settings. But many people respond actively and positively to assistance and opportunity to connect, to learn, and to make things happen in their world. Engagement in positive ordinary activity changes experience and expectation for both people with severe and profound disabilities and the people around them. As one staff person said,

> *The work has been challenging, frustrating, and sometimes disappointing. But the challenges, frustrations, and disappointments feel a lot different now that I know Josh and his family than they did when I was anxious about what it would be like to try and assist a "profoundly disabled" person I didn't know. When I didn't know Josh, I figured there was nothing there for me to relate to, let alone any potential co-workers. He set me straight on that pretty quick. He can reach out to people even though he doesn't have any words. Anybody who makes room to accept him will know they are in contact with Josh. He is there with me and his co-workers; he is not just an empty space.*

The only safeguard against the falsely negative illusion of incompetence is a considered decision to seek out a few people with severe and profound disabilities and offer them a partnership through which both they and supported employment staff will learn as they work to improve the accessibility of local workplaces. This decision will feel like taking a leap into uncertainty even for people who have made reasonable provision for learning the skills, building the relationships, and gaining the knowledge necessary. People will only take that leap when they decide that the benefits of good relationships with people with severe and profound disabilities are worth it.

References

Callahan, M. (1991). *Final Report: United Cerebral Palsy Associations three year demonstration project on supported employment.* Washington, DC: UCPA.

Felce, D., Lowe, K., Perry, 1., Jones, E., Baxter, H. & Bowley, C. (1999). The quality of residential and day services for adults with learning disabilities in 8 local authorities inEngland: objective data gained in support of a Social Services Inspectorate inspection. *Journal of Applied Research in Intellectual Disability,* 12,273-293.

Gold, M. (1980). *Did I say that? Articles and commentary on the Try Another Way system.*Champaign, IL: Research Press.

Inge, K., Strobel, W., Wehman, P., Todd, 1., and Targett, P. (1999). Vocational outcomes for individuals with significant physical disabilities: Design and implementation of workplace supports. In G. Revell, K. Inge, D. Mank, & P. Wehman (Eds.) *The impact of supported employment for people with significant disabilities: Preliminary findings from The National Supported Employment Consortium* (p. 135-150). Richmond, VA: Virginia Commonwealth University.

Jordan, B. & Dunlap, G. (2001) Construction of adulthood and disability. *Mental Retardation, 39,* 4, 286-296.

McGaughey. M. & Mank, D. (1999). Empirical evidence of systems change in supported employment. In G. Revell, K. Inge, D. Mank, & P. Wehman (Eds.) *The impact of supported employment for people with significant disabilities: Preliminary findings fromThe National Supported Employment Consortium* (p. 60-64). Richmond, VA: Virginia Commonwealth University.

Mank, D, Cioffi, A., and Yovanoff, P. (1998). Employment outcomes for people with severe disabilities: Opportunities for improvement. *Mental Retardation,* 36, 3,205-216.

Mank, D, Cioffi, A., and Yovanoff, P. (2000). Direct support in supported employment and its relation to job typicalness, co-worker involvement, and employment outcomes. *Mental Retardation,* 38, 6,506-516.

Mank, D., O'Neill, C., & Jensen, R. (1999). Quality in supported employment: A new demonstration of the capabilities of people with severe disabilities. *Journal of the Association for Persons with Severe Handicaps,*

Normann, R. (2001). *Reframing business: When the map changes the landscape.* Chichester, UK: John Wiley & Sons.

O'Brien, J. (2001). *Another look at informed choice: Lessons for a changing workforce from the RSA Choice Demonstration Projects.* Washington, DC: The Presidential Task Force on Employment of Adults with Disabilities.

Revell, G., West, M. & Cheng, Y. (199). Funding supported employment: Are there better ways? *Journal of Disability Policy Studies* 9, 1,60-79.

Rogan, P., Banks, B., & Howard, M. (1999). Workplace supports in practice. In G. Revell, K. Inge, D. Mank, & P. Wehman (Eds.) *The impact of supported employment for people with significant disabilities: Preliminary findings from The National Supported Employment Consortium* (pp. 197-213). Richmond, VA: Virginia Commonwealth University.

Schaefer, N. (1998). *Yes! She knows she's there.* Toronto: Inclusion Press.

Versteegen, U., Scharmer, C.O., and Kaufer, K. (2001). Praxis of organizational learning. *Reflections: The Society for Organizational Learning Journal, 2*, 3, 36-45.

Wehman, P. , Revell, G., & Kregel, 1. (1997). Supported employment: A decade of rapid growth and impact. In P. Wehman, J. Kregel, & M. West (Eds.) Supported employment research:Expanding competitive employment opportunities for persons with significaBodynt disabilities (pp. 1-18). Richmond, VA: Virginia Commonwealth University Rehabilitation Research & Training Center on Supported Employment.