Leadership in Employment for People with Intellectual Disabilities

Making progress toward real jobs for people who are likely to be excluded from genuine participation in the labor market because of intellectual disability means crossing the threshold from an approach to service that aspires to occupy people’s time in a protected, (& pleasant) setting and learning to function in a new space, where the aim is to discover & support satisfying ways for people to earn a proper wage in an ordinary job. This move calls for principled, creative leadership.

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Why work? (according to People First members)

To make money
To do or make something useful & interesting
To be part of a good company
To learn new things
To put some shape in your day
To do the same things as any other adults
To meet some people
To be more independent
To stop for a drink after work (just one)
The Myth of Ineducability
People can’t learn to be productive & successful at work

The Curse of Certainty
Professionals can reliably predict who is employable & what situations present unmanageable risk.

The Myth of Unacceptability
Employers & co-workers can’t learn to accept & support people with disabilities.
People can work at typical tasks
People can work in ordinary workplaces
People can work individually in ordinary workplaces
Co-workers & employers can help people succeed
People can work in individually meaningful jobs
People can be self-employed
Employers can customize jobs
Congregate day services are not necessary

40 Years of Accomplishment Shows That

And apparent impairments are poor predictors

People & allies
Employers & co-workers
Assistants & innovators
In 2002 the last remaining sheltered workshop in Vermont closed after 35 years of operation.

Best Practices Award—Kelley Homiller and Jodi Whalen

In 2002, the last remaining sheltered workshop in Vermont closed after 35 years of operation. Under the leadership and guidance of Kelley Homiller and Jodi Whalen, Champlain Vocational Services has taken the next step in the conversion process: the transition to community-based services. People are getting community jobs and becoming fully integrated members of their society. Kelley and Jodi have also been able to secure funding to increase job development and employment supports. They have both been active members of business groups, developing a newsletter about SE services distributed to local employers and utilizing Jodi’s marketing skills to create innovative marketing materials to promote their services in the community. They have opened new opportunities for SE as a result of these efforts.

As the doors of the sheltered workshop closed, the doors to community opened. The leadership provided by Kelley and Jodi along with their uncompromising values and determination have been a shining example of the values and philosophies held by APSE. Senator James Jeffords wrote, “As we close this chapter on work centers in Vermont, I hope that we encourage others to follow VT’s lead to a place where all of us work side by side.”
What It Takes To Make Progress

Relentless commitment to real jobs
Insane expectations of our capacity to overcome barriers & solve problems
Sustained investment over time
Personal & organizational responsibility
Deep & painful inquiry into coherence of values & action
40 Years of Accomplishment, BUT

Unemployment, underemployment rates from 55%-75% among people with disabilities, always higher among people with ID.

> 30% of adults served by DD system employed in community workplaces

Many fewer working full time, acquiring benefits, earning a living wage

Employment supports are decreasing vs increases in day programs & “community experience”

Transition rates from work preparation programs >2% per year
Some people are stuck in “work experience” that offers…

A turn at placement in a job developed (& perhaps funded) to provide many people “work experience” rather than one person a chance to discover what works for them at work

Little if any connection to the person’s job interests & no meaningful way to inform a career plan

Few hours work for a limited time, regardless of person’s desire

Little or no prospect of further employment after the work experience

Limited if any adjustments or systematic instruction customized to individual impairments (so limited access for people with severe disability

Low or even no pay on the same terms & scale as other employees (or interns)

Risk of stigma: being seen as “unable” or “inferior” because the request is for “work experience” rather than a real job
Work experience can be like a ride on a carousel: it may be enjoyable, but you have to wait in line for it, it doesn’t last too long, and you finish up where you started. This is great for an amusement but not so good as a way to get a real job that suits who you are. Sometimes what happens next is that you stand in line for another carousel ride instead of getting on with your life.
Is it because people choose not to work?

Alberto Megliori (2007)* interviewed
210 adults with ID
185 family members or caregivers
224 staff members
from 19 sheltered workshops

<table>
<thead>
<tr>
<th>Group</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>People with ID</td>
<td>86%</td>
</tr>
<tr>
<td>Family members/caregivers</td>
<td>73%</td>
</tr>
<tr>
<td>Day program staff</td>
<td>71%</td>
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Person would prefer to work in community integrated employment

Megliori (2007)
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<thead>
<tr>
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<tbody>
<tr>
<td>People with ID</td>
<td></td>
<td>54% yes</td>
</tr>
<tr>
<td>Family members/caregivers</td>
<td></td>
<td>60% yes</td>
</tr>
<tr>
<td>Day program staff</td>
<td></td>
<td>40% yes</td>
</tr>
</tbody>
</table>

Has anyone ever encouraged the person to pursue community integrated employment?
<table>
<thead>
<tr>
<th>Experience with jobs outside the workshop</th>
<th></th>
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<tbody>
<tr>
<td>More than one work experience</td>
<td>14%</td>
</tr>
<tr>
<td>One paid work experience</td>
<td>20%</td>
</tr>
<tr>
<td>No paid work experience</td>
<td>66%</td>
</tr>
<tr>
<td>Family/ caregiver concerns</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>--------</td>
</tr>
<tr>
<td>Transportation</td>
<td>69%</td>
</tr>
<tr>
<td>Safety</td>
<td>69%</td>
</tr>
<tr>
<td>Long-term placement</td>
<td>66%</td>
</tr>
<tr>
<td>Convenience of work hours</td>
<td>59%</td>
</tr>
<tr>
<td>Retention of benefits</td>
<td>57%</td>
</tr>
<tr>
<td>Work skills requirements</td>
<td>55%</td>
</tr>
<tr>
<td>Social environment</td>
<td>55%</td>
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Mindset Matters

One straightforward leadership practice is to greatly improve the chances of success by consciously adopting a growth mindset. Dweck’s research demonstrates that this apparently simple perspective shift has great leverage to improve performance.

It matters to employment for at least two reasons: 1) it encourages us to see people’s capacities as open to development with sustained effort; 2) it discourages us from framing issues we could learn to improve as completely out of our control. If we follow Professor Dweck’s advice we’ll say, “How can we deal more effectively with family concerns?” not “Families are opposed.”
Fixed Mind-set  
Intelligence is static

Growth Mind-set  
Intelligence can be developed

Challenges
- Leads to a desire to look smart and therefore a tendency to...
- Avoid challenges
- Embrace challenges

Obstacles
- Leads to a desire to learn and therefore a tendency to...
- Give up easily
- Persist in the face of setbacks

Effort
- See effort as fruitless or worse
- See effort as the path to mastery

Criticism
- Ignore useful negative feedback
- Learn from criticism

Success of Others
- Feel threatened by the success of others
- Find lessons and inspiration in the success of others

As a result, they plateau early and achieve less than their full potential.

All this confirms a deterministic view of the world.

As a result, they reach ever-higher levels of achievement.

All this gives them a greater sense of free will.

We may think of employers as unwilling to hire. This fixed mindset understanding traps us. Let’s consider…

…choosing a growth mindset & setting to work learning how we can make at least some progress, starting with how we frame the question…

…signs that some influential people are awake to the contribution people with ID can make (business people are far more influential with business people than service people can ever be)

…the possibility that we are doing things that turn employers off (e.g. selling subsidies may send a message that people are inferior workers who will bring increased government involvement in the workplace).

…what research has shown us is most effective

…the possibilities in re-arranging incentives

…the power of commitment
Michael Callahan points out that we may misguide ourselves when we think of ourselves as looking for existing jobs in which people with very substantial disabilities can compete. We have more options when we think of ourselves as negotiators of opportunities for contribution.

Of course, many people with ID who are unemployed or underemployed are capable of working “competitively” as long as they have access to reasonable adjustments and good instruction. Customized employment is for those people many now think of as “too disabled to every work”.

...starting with how we frame the question

From

“How do people with significant impairments compete for jobs?”

To

“How many ways can we negotiate a customized job by offering employers discrete contributions that relate to specific work-place needs?”
...look for & build on signs of awakening to the contribution of people with ID
PROJECT SEARCH ... Erin Riehle

“When Annie Sublett smiles— which is often—it is easy to see how much she loves her job in the dental clinic at Cincinnati Children’s Hospital Medical Center. In the past five years she has missed fewer than five days of work.” Annie, who is a valued member of the hospital team, entered her job through Project Search, an innovative supported employment program at the Cincinnati Children’s hospital. At work Annie “expertly identifies the nearly 200 shiny instruments she sterilizes and sorts daily.” (Family Circle, 9/17/02). Telling Annie’s story and that of other supported employees working throughout the hospital in Cincinnati, this article was really a tribute to Erin Riehle, whom Family Circle designated to be among their Women Who Make A Difference. In 1997, APSE recognized Cincinnati Children’s Hospital Medical Center for their support of Project Search with the National APSE Employer of the Year Award. Project Search was initiated in the mid-1990’s at Cincinnati Children’s in partnership with Great Oaks Institute of Technology and Career Development and Hamilton County MH/DD as a solution to performance problems that plagued the efficient operation of the emergency department—restocking ER supplies in a timely and dependable manner. As Director of the Emergency Department, Erin found it no problem to fill these entry-level jobs with students and other part-time workers. But their turnover was continuous, and the repetitive work of restocking ER supplies was not valued nor reliably performed. The solutions that Erin designed have grown into an impressive demonstration of how a large business can effectively use supported employment into the center of the workplace, creating new job opportunities for supported employees and workplace solutions for the company.

Her efforts were assisted by a 1995 American College of Healthcare Executives policy statement encouraging affiliates “to take the lead in their organizations and their communities in creating work environments that enhance the opportunities of persons with disabilities to gain and maintain employment.” Adopted by Cincinnati Children’s Hospital, the policy statement gave Erin the flexibility to explore new employment options. She realized that while virtually every child with a disability is a customer at Children’s at some point in their growing years, they encountered almost no role models with disabilities among the staff they saw. Putting these factors together, she recognized that the solution to her staffing problem could also help fulfill the diversity mission of her hospital in a more complete way. The idea for Project SEARCH was born—a program that strives to help people with disabilities achieve their fullest potential and improve their quality of life through meaningful employment.

Project SEARCH pioneered an innovative model of collaboration between education, employers, and rehabilitation services. Jobs are in full inclusive settings—individuals are hired by the hospital and supported with company employed disability specialists. Through Project SEARCH workers with disabilities at Cincinnati Children’s Hospital have been successfully employed in a variety of areas such as sterilization of surgical and dental tools, patient greeter, escort data entry, supply cart and cabinet stocking, grounds keeping, and lab courier services.

From an employer’s perspective, employees in the Project SEARCH program are successful for several reasons. They demonstrate improved performance in typically high-turnover, entry-level positions (such as ER stocking jobs), have lower absenteeism and have been rated highly for their work ethic, accuracy, and enthusiastic attitude. The program has helped the hospital achieve its diversity objectives and has resulted in extensive local and national acclaim for its efforts.

Project Search is expanding beyond Cincinnati Hospital, successfully replicating itself in other markets. It carries a solid message about the value of adding supported employees and the necessary support. Project SEARCH focuses on non-traditional jobs, and promotes full inclusion in the workplace for young people with intellectual disabilities by recognizing that the talents and interests of this group are varied and individual as they are among any group.”

Just as Children’s Hospital did, participating companies hire their own job placement, job coaching and follow along professionals, which enables them to function as a single conduit for the organization and delivery of SE as an integrated part of the work site. Under this approach, SS professionals are inherently familiar with the culture and workforce needs of the employer, and with on-site support, each staff member can effectively handle a larger case load with more cost efficiency.

Meet Mary Bodie

Mary Bodie, a patient escort at Cincinnati Children’s Medical Center, began her career in health care as a student in Project SEARCH five years ago. She began her job shadowing a variety of offices and as patient transporters at the hospital. She joined the patient escort team in 2001. When she received the 2003 patient escort team meritorious award, Mary stated, “I love meeting the patients and their families from all over the world. I never know what surprises are around the corner, because each day is different and I enjoy coming to work every day because it makes me feel like I am giving something back to the hospital that has given so much to me.”
What research shows is more effective, for example:

David Mank & colleagues tracked Individualized Competitive Employment for 450 people assisted by 13 agencies

Overall, more severe disability predicts that you . . .

. . . earn less

. . . have fewer interactions with non-disabled co-workers

. . . have less access to work

. . . have jobs seen as less desirable

Overall, more severe disability predicts poor quality

But

In a sub-group of agencies, people with similar, substantial needs for assistance...

...earn more
...have more interaction
...at better quality jobs
Combined practices that predict better quality for people with more severe disabilities

- More typical path to work
- More typical work conditions
- Fewer hours of staff support and more co-worker support
- Immediate informal co-worker training & available active consultation
…look at our own performance information

Which way of organizing service offer people the best opportunity to earn?

Range of Monthly Earnings

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<thead>
<tr>
<th></th>
<th>Specialized Industry</th>
<th>Group Employment</th>
<th>Individual Employment</th>
</tr>
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<tbody>
<tr>
<td>Range $</td>
<td>$0–700</td>
<td>$20-1,470</td>
<td>$160–4,380</td>
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<tr>
<td>People</td>
<td>459</td>
<td>153</td>
<td>568</td>
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King County, WA 07/02
### Distribution of Monthly Earnings

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<tr>
<th></th>
<th>Specialized Industry</th>
<th>Group Employment</th>
<th>Individual Employment</th>
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<tr>
<td>&lt;$500</td>
<td>447</td>
<td>104</td>
<td>120</td>
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<tr>
<td>$501-1,000</td>
<td>12</td>
<td>46</td>
<td>160</td>
</tr>
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<tr>
<td>$1,501-2,000</td>
<td></td>
<td></td>
<td>91</td>
</tr>
<tr>
<td>$2,001-2,500</td>
<td></td>
<td></td>
<td>33</td>
</tr>
<tr>
<td>$2,501-3,000</td>
<td></td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>&gt;3,000</td>
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</tbody>
</table>

King County WA 07/02
An Ohio pilot project paid Employment Agents on commission. In the first year:

28 people got jobs with 26 employers

People earned $3.30 for every dollar invested in the project

For every dollar paid to an Employment Agent, people earned $20.37 in wages.
Self-Determination Drives the Project

The Employment Outcome Project encourages people with disabilities and their families to take control of their employment and business opportunities. This goal goes beyond getting jobs; it creates sustained income for people with disabilities. There are two options in this project:

1. Employment Agent Commission

An Employment Agent chosen by the person with a disability helps the person find a job. The agent reviews a commission from the person based on the person's wages:
- 50% for the first year
- 40% for the second year
- 30% for the third year and 20% for each year thereafter

There are no waiting lists, evaluations, or minimum criteria. People with disabilities get jobs like everyone else, through family and friends. The difference is that agents earn commission based on their success.

2. Micro Enterprise Start-up Funds

Teams, made up of family, friends and care providers, help the person with a disability create a business based on the person's interests and talents. Most of these businesses, called Micro Enterprises, are small and use natural resources and supports in the community. The project also conducts two-day workshops to help teams get started.

Commission fees and start-up costs are limited to $5,000 per year. The County Board of MRDD in which the person receives services and the Ohio Developmental Disabilities Council provide these funds.

How do I get started?

If you received this brochure from your County Board of MRDD, they agreed to offer Employment Outcome Grants. They will help you to apply and make agreements with your Employment Agent or with your Micro Enterprise team.

If you received this brochure from some other source, call your County Board of MRDD and tell them you are interested in an Employment Outcome Grant.

Frequently asked questions...

Don't people with disabilities need special help to get and keep jobs?

Some people may need and benefit from traditional disability vocational services, but many are frustrated with delays and limited choices of providers. Vocational services often pay for assessments and initial services but do not provide for sustained support.

The Employment Outcome Project uses the same approach that non-disabled individuals use to get a job: the help and assistance of family and friends. The purpose of the project is to empower and reward those who already know and care for the person with a disability.

Who is eligible for the Employment Outcome Project?

Anyone who is at least 14 years of age and eligible for services from a County Board of Mental Retardation and Developmental Disabilities (MRDD).

Can a person receive an Employment Outcome Grant and still go to a sheltered workshop?

This is a local decision. However, to be successful there must be commitment to make Employment Outcome an alternative to traditional sheltered employment. Individuals will still have access to other non-vocational services provided by the County Board of MRDD.

Can a person receive an Employment Outcome Grant if he or she already has a job?

Yes, especially if the person is coming from a vocational service that is time limited. Students coming from school-based employment can use a grant to continue supports when school-based services end. A person with a disability may also use an Employment Outcome Grant to get a new job.

Are job coaching and transportation services available?

Whatever is needed to make the employment successful can be paid for by project funds. However, these flexible dollars need to meet all of the employment-related costs. The goal is to use resources cost effectively. For example, the grant may pay a co-worker a little extra per day to help the person instead of paying for an outside job coach.

What credentials do I need to be an Employment Agent or to help someone start a Micro Enterprise?

Most importantly, you should know and care about the person with a disability. You need to believe in the person’s potential. You must be willing to commit your time and energy without a guarantee of financial rewards. It is also helpful if you are an active member of the same community as the person with a disability.

Family and friends of people with disabilities, personal care providers, residential providers, businesses that employ eligible individuals and traditional vocational providers can all be Employment Agents. Employees of County Boards of MRDD are not eligible to be Employment Agents.

What do Employment Agents do?

They manage the relationships and critical issues on and off the job that create opportunities for employment and maintain needed supports. This is not job coaching. It is working with the employer to use and reward supports and resources that already exist.

What documentation do I need to receive the commission?

Simply turn in the pay stubs of the person with a disability to the County Board of MRDD on an agreed schedule. There are no time sheets. There is also no pay until the person with a disability is paid. The more money the person with a disability earns, the higher the commission.

What if the person loses his or her job?

Help the person find another job. When the person starts receiving a pay check, commissions start again.

What about disability benefits?

Before the person starts work, talk with someone from the County Board of MRDD or a benefits counselor. Usually, the person is better off financially with a job rather than just collecting benefits checks. Even though disability checks may be reduced or eliminated, Medicare benefits can be continued in many cases. It is especially important to have a benefits consultation if the person might be involved in a Micro Enterprise and will work 80 hours or more per month.
The power of commitment
Supports to maintain gainful employment in integrated settings in the community shall be the primary service option for working age adults.
Supports to maintain gainful employment in integrated settings in the community shall be the primary service option for working age adults.

25 years to prepare the ground

Significant tension with current reality

For a case study on the groundwork put in place before this policy was formulated, see www.communityinclusion.org/article.php?article_id=140&staff_id=2
Laying a strong foundation in debate over the meaning of values statements.
(Skeptical) parents & family members as leaders
Organize business leaders & raise the profile ("Sort Bill Gate’s mail")
Include everyone in the goal. Invest in people with substantial needs for support.
Government & unions as early adopter of naturally supported employment
Partner with schools to generate job outcomes (Goal: everyone graduates with a real job.)
Partner with more generic workforce initiatives, but don’t give up an active role & ultimate responsibility for those who do not have good outcomes
Develop new roles & new expertise to deal with arising issues (e.g. Benefits Analyst, Personal Agent)
Address family concerns forthrightly
Entrepreneurial Award—Jeffrey McNary

Jeff and sister, Sherry-Washington State

Jeffrey McNary of Seattle, WA is the sole proprietor of Doc Destruction, a document shredding business in downtown Seattle. Jeff has been in business for himself for three years. Jeff was in a sheltered workshop for thirty years in a program for people with “behavioral challenges”. For the last five years of his time in that program he sat by the front door each day with his coat under his arm waiting to leave. With the help of King County Developmental Disabilities, Jeff’s sister, Sherry McNary, convinced the workshop to provide a job coach in the community, and she procured a shredding job for Jeff at a local condominium association. Jeffrey finished what the association thought would be nine months of work in three months. Jeff and his team next negotiated with King County Developmental Disabilities to sublet an office in a building in downtown Seattle. Jeff started the business with no formal funding. Later, Jeff obtained funding from VR to purchase an industrialized shredder. Almost immediately after leaving the workshop, Jeffrey’s “behaviors” plummeted. He started making new friends. A new community formed around him in the building, with his customers, and in his office. His next goal is to pay for business expenses AND for a portion of his job coaching.

“Jeff McNary is living the values that animate APSE. The journey from the back room in an activity center to his own place of business defines the journey that the founders of supported employment visualized for the whole field.”