
Another Look at Informed Choice

**Lessons for a
Changing Workforce from the
RSA Choice Demonstration Projects**

Prepared for

**The Presidential Task Force on
Employment of Adults with Disabilities**

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Thanks

I am grateful to the people with disabilities, family members, counselors, service providers and Choice Demonstration Project Coordinators who shared their experience of the changes they created through these four projects. They were hospitable, candid, and thoughtful.

I am particularly indebted to the people who arranged my visits, all of whom have moved on to other demanding responsibilities since the close of the demonstration projects. At short notice, they identified people with important experiences to share, arranged my schedule, and assured that the people I met had what they needed to be comfortable in communicating with me. Michael Collins in Vermont, Abby Cooper in Seattle, Susan Linders in Pittsburgh, and Nancy Sullivan in Arkansas are not just effective change agents, but also fine tour guides.

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In brief

I have a friend back home who also has cerebral palsy. She was in the same class with me all the way through school. Now she lives with her mother. She gets SSI and sometimes goes to a day program. She is my benchmark because just before I got involved with Choice I was pretty discouraged. I didn't think my schooling was ever going to help me get a job. I was one step away from moving back home to live with my mom. My life and my friend's life would have probably been pretty much the same. Not awful maybe, but not really much of a life. Not the kind of life I have now.

Instead, because Choice helped me get the confidence I needed to go through the door, I have a good job that I love. I work hard and long hours, but I get paid well and we have a lot of fun. I like the people I work with in a way that only happens when you share the same interests.

I met my husband at work. We've bought a home and we're settling down.

I guess you could tell people that Choice made a big difference to me.

- The employment and workforce development system faces a profound adaptive challenge when confronted with contributing to a significant reduction in the exclusion of 75% of working-aged people with disabilities from the laborforce.
- This challenge poses a strategic choice with high stakes. Will the system mobilize its resources and adapt to its changing environment, risking the turbulence of deep change for a chance at building a broad and stable bridge between a changing workforce and millions of unemployed adults with disabilities? Or will agencies and their employees be driven by fear into trying to resist change?
- Adaptation will require deep change in workforce systems generally, and in the rehabilitation system specifically. The discoveries made by participants in four Choice Demonstration projects sponsored by the US Rehabilitation Services

Administration offer leaders useful policy and practice options for shaping a culture that meets the demands of change.

- These options, which proved effective for the small group of people interviewed in this study, included “fast-track” eligibility and planning, individual budgets with the option of giving the participant cash to pay directly for needed services, and planning processes that brought together people who know and care about the person to explore the move into the workforce in terms of the person’s whole life. They also included strategies for developing new service providers based on the participant’s need and network of relationships, and ways of finding the flexibility to modify or disregard practices that don’t fit individual circumstances.
- While enlisting market forces by enabling participants to negotiate directly for necessary services and authorize or make payments directly does increase most people’s reported sense of personal responsibility, this form of market incentive did not generally stimulate change in established service provider agencies. The fact that the projects accounted for only a small fraction of provider market share probably accounts for much of this disappointing result.
- Policy makers need to think carefully about the limits of market mechanisms in the rehabilitation system. Some market imperfections can be addressed by investment in brokerage and training. Others appear more difficult to address.
- Public policies should be assessed and re-designed to maximize positive effects on a participant’s ability to build a network of relationships and resources sufficient to co-produce a successful move into the laborforce. Building such a network allows people with disabilities to deal with the effect of work on their family life, and on the personal assistance they require.
- One of the most important resources for those who want a far more effective system of workforce inclusion is the imagination and emotional maturity of its workers.

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A localized response to a vital national question

*“Prejudicial treatment, individual and societal avoidance, segregation, isolation, poverty. Relationships built on obligation and pity. How do we change this history of treatment of people with disabilities? How do we create a different future?”**

My report takes another look at the lessons learned by people involved in four of seven choice demonstration projects funded by the Rehabilitation Services Administration to operate between 1993 and 1999. It reflects on the projects from the point of view of a small number of participants, selected by project coordinators as *people who taught me important lessons about the meaning of choice in employment*. Based on interviews with these teachers about choice and key people involved with them in the choice demonstration projects, this report responds to the question above, the question that impels the work of the Presidential Task Force on Employment of Adults with Disabilities. Given the pervasiveness of poverty, prejudice, and paternalism in the lives of people with disabilities, how do we create a different future?

Briefly, the answer offered here is this. For many people with severe disabilities, a better future begins with a different kind of relationship to the people and agencies designated to assist them into the workforce. To be effective, those who offer services must work in a context of policy and organizational culture that respects people with disabilities as the rightful owners of the process of moving into the workforce. The task of service workers is to take direction from people with disabilities. Some people have difficulty providing direction, so their task includes respectfully assisting those who are uncertain or unskilled to accept personal responsibility for learning how to own and direct their journey to work.

The Task Force recognizes that the changes necessary to reverse the social patterns that exclude 75% of working-aged people from the workforce must be deep, substantial, and long-term. Investments in demonstrating practice that better reflects progressive policies, pay dividends in practical innovations and in deeper understanding of required changes. However, these investments do not yield easy answers.

*“The structures and practices of our public systems have taken decades to evolve, have become cemented in their way of doing business, and have become very familiar and comfortable to many people... Altering these structures in a deep, substantive way will be difficult and long term success will require a continuing mandate for change in order to prevent the patterns and practices of the past from persisting.”**

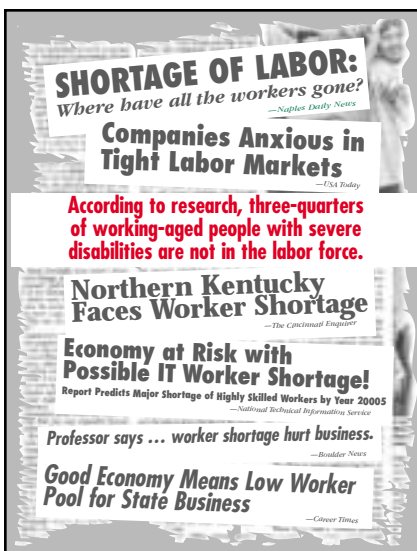
*Presidential Task Force on Employment of Adults with Disabilities (November, 1999). *Re-charting the course: If not now, when? The second report of the task force*. Washington, DC: The Task Force. Cited below as *If not now, when*.

The Task Force’s work properly focuses on the federal government’s role in making and implementing policies that set national direction and a framework for state and local action. In contrast, this report comes from the most local and specific place that federal policy touches: the relationship between individual people with disabilities and new ways to increase their ownership of a process that results in their joining the workforce. My report’s small scale

and high selectivity do not justify generalizations to larger populations, but may provide insight into what it will take to translate progressive policy into local action. Policy makers and system managers need to invest thoughtfully in creating both a deeper understanding and a more flexible capacity for implementing what choice and personal responsibility mean at the local level. Building understanding and capability among people with disabilities is as important as investing in the counselors and employment support providers who assist them.

This page (v) from the Presidential Task Force's second report vividly identifies the adaptive challenge facing the system. The rehabilitation system must make profound changes in order to build a broad and secure bridge between a productive economy seeking workers and a population 75% unemployed.

The messages I heard at the local edge of the effort to establish an inclusive workforce confirm the Task Force's insight into the depth and difficulty of the change required. They also offer good reason for confidence in encouraging a variety of different, thoughtful local initiatives.



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- Without sustained effort among local people to learn and responsibly practice new ways and to develop a new culture of service, more ambitious policy goals will simply widen the gap between government rhetoric and the reality most people with disabilities face. Such a gap not only feeds cynicism and discouragement, it wastes people's lives.
- Given the space created by commitment to a shared mission, flexibility in rules and use of resources, and support to try and fail and revise and try again, people with disabilities and the people who assist them invent workable and credible solutions to the difficult problems involved in significantly changing the make-up of the workforce.
- No one who wants to change this terrible pattern of exclusion is immune from learning. Policy makers have learning to do. Professionals have learning to do. Employers have learning to do. People with disabilities have learning to do. Friends and family members have learning to do. One part of this learning involves forming a better understanding of the changing environment that contains us all and shapes our opportunities to make a positive difference.



Steven works part time as a bricklayer's assistant in his family's business.

Difficulties in job search brought Steven and his family back to the process of person-centered career planning. Hard thought and prayer made it clear that the best alternative for Steven was to work with his father. The project made it possible for the family business to replace the time of an experienced crew member who acted as Steven's job trainer, with consultation on systematic instruction to accommodate Steven's visual and cognitive impairments. Once he had learned the basics of his job, Steven sought training in operating this brick saw, which he now does independently and with great pride.

Method, definitions and limitations

I have spent thirty years delivering, designing, and studying services to people with developmental disabilities. Much of this work has been associated with The Center on Human Policy at Syracuse University, a setting that combines rigorous questioning with a commitment to strengthening our communities by reversing habits of segregation and control. This work has given me many opportunities to learn about day services and supported employment and to explore recent initiatives to re-design systems around the principles of self-determination.* However, I am a newcomer to the wider world of vocational rehabilitation and therefore welcomed the Task Force's invitation to reflect on some of the lessons from the Choice Demonstration Projects from the point of view of the local people who made the demonstrations happen.

My work has been guided by the Choice Task Force convened by Michael Callahan under the sponsorship of Presidential Task Force on Employment of Adults with Disabilities. The members of this group include people who were active in the four Choice Demonstration Projects (and who remain active in new workforce development projects) as well as representatives of the Presidential Task Force and the Rehabilitation Services Administration. They oriented me to the rapidly changing world of workforce

development and shaped the focus of my study by involving me in their "think-tanks", reviewing my approach, selecting people for me to interview, providing me with abundant reading, and arranging my visits.

What I did

To prepare this report, I visited four Choice Demonstration sites and interviewed 10 participants selected by project coordinators as "people who taught me important lessons about the meaning of Choice in employment." Interviews lasted between one and two and a half hours and happened in people's homes, at their workplaces, or in other places of their choice such as restaurants and hotel lobbies convenient to their work. I also interviewed...

- ... seven family members who were very much involved with five participant's experience of the project
- ... the people who served as coordinators for three projects and the project consultant for the Arkansas project
- ... five vocational rehabilitation counselors who served the people I interviewed and the office manager of a Vocational Rehabilitation Services Field Office involved in the Choice Demonstration project
- ... two business consultants who assisted two of the people I interviewed
- ... two people who played project specific roles with two of the people I interviewed: an "Employment Advisor" (UCP) and a

"Community Connector" (AR)

... three other people who worked as service providers for three of the people I interviewed

I also participated in two "think-tanks" involving members of the Choice Task Force, one on 9 December 1999 and one on 14-15 February 2000." I read materials and reports compiled by the projects and reviewed profiles of an additional 10 project participants prepared by project coordinators.

To write this report, I reviewed my interview notes for important themes and then studied written project materials to see how they could improve my understanding of these themes.

My focus

I did not presume to evaluate the situation of the 10 people I met. I asked them to think about their experience of finding work with the help of the Choice Demonstration project and identify what they thought other people with disabilities and their families and friends could learn from their experiences. I asked them

** Other participants included Nancy Sullivan (Arkansas Commitment to Client Choice Project); Michael Callahan, Susan Linders, and Norciva Shumpert (UCPA Choice Access Project); Michael Collins (Vermont Consumer Choice Demonstration Project); Abby Cooper and Rosemary Gallagher (Washington State Participant Empowerment Project) and Christopher Button, Joe Skiba, and Suzanne Tillman.

to describe the most important contributions the people involved with the Choice Demonstration projects made to their finding work and to offer ideas about how the project could have been more helpful.

The limits of this report

The sample of people I interviewed is small and was purposely selected by project coordinators.

Because the Presidential Task Force decided to take another look at the Choice Demonstration projects after the projects finished, the people with disabilities and family members I met were thinking back at least two years to remember their active involvement with the projects.

Three of the people I interviewed have strong memories of their involvement with the project coordinator or with another key project staff person but remember very little about the project itself. For example, one person said, "There were a couple of delays and I had to fire one job developer and find another, but it went fine. I don't really remember the details of the process very well." None of these three people had previous experience with rehabilitation services, and they were interested to think about the fact that it is not routine for people to direct the expenditure of an individual budget. "I can't imagine any other way to do it," another person said.

People whose situations occasioned notable learning for project coordinators didn't necessarily know what the

*To learn more about The Center on Human Policy, visit <http://soeweb.syr.edu/thechp>.

coordinator had learned from them. The delays that the person above remembered as small bumps on a smooth path were times that the project coordinator had to deal with major conflicts and revise important assumptions about the way the project would work. It seems good that the person was mostly insulated from what the project coordinator experienced as upheaval, but this difference highlights an important point about the report. Both the person's perspective and the project coordinator's perspective are included in what follows, and sometimes it is the project coordinator's voice that has the most to say. When I had the further benefit of other perspectives on a person's situation from family members or counselors or other assistants, there were important differences in what people remembered and what they made of their memories. I have tried to reflect these differences in the report that follows without any attempt to resolve them.

Attributions

The people I interviewed had different preferences about how they wanted to be identified when I quoted or described them in this report. Many people wanted anonymity and are identified by their role as "a participant" or "a counselor". Other people with disabilities chose to be identified by their own first name.

I have edited extended quotations for readability by connecting people's comments into unbroken narrative. The words and images that carry the thought are the person's own, and I made summaries which I checked with the person for accuracy during the interview.

Definitions

Choice Demonstration projects – means a set of four of the seven projects funded by the Rehabilitation Services Administration under the Rehabilitation Amendments of 1992 whose former project directors have formed a task force sponsored by the Presidential Task Force on Employment Adults with Disabilities.

Choice (with a capital "C") – refers to a set of system reforms advocated by members of the Choice Task Force which have the purpose of increasing the degree to which the people who use the rehabilitation process own both the process and its outcomes by structuring services to offer people with disabilities maximum responsibility and control. Appendix A summarizes my current understanding of the concept.

Counselors – those with responsibility for assisting people with disabilities to set vocational goals, make and implement plans toward those goals, identify and arrange the assistance they require, and play a part in the allocation of rehabilitation system funds and other resources. Counselors may be vocational rehabilitation counselors employed by a state's rehabilitation agency. Others may also play all or share a significant part of this role, as they did in two of the Choice Demonstration projects.

Disabled people or people with disabilities. I have used both word orders, acknowledging a continuing international debate among disability activists and scholars but favoring, as I notice the Presidential Task Force does, the "people first" usage. Usually I refer to disabled people in a context of political activism.

Rehabilitation system – includes vocational rehabilitation agencies, employment support providers, and providers of services that function in lieu of employment.

When a document is available on-line, I have included an address, current as of May 2000.

A word about comparisons

Choice and personal responsibility have become rallying points for people who want to transform the way rehabilitation and employment support services work. One step toward such transformation asserts the difference between current practice and a system based on choice and personal responsibility. Those who want to avoid the roller-coaster of major change predictably reply, "This is really no different than what we have done for years."

Experienced counselors and employment service providers may reasonably say that this report simply describes their current good practice. That may be; and, if it is so, I hope that they will find that this account does justice to that good practice in commending it to those who want to reverse the exclusion of people with disabilities from the workforce.

This small study was not designed to compare typical

rehabilitation services with choice demonstration projects. Only a few of the people with disabilities I met had any previous experience with rehabilitation services and I did not interview any clients of the typical process. My purpose is not to compare, but to reflect on what a small group of people engaged in the Choice Demonstration projects have to say about their experience.

However, the reader tempted to dismiss these experiences as nothing new may want to pause. In addition to checking for symptoms of the defensiveness with which most of us greet the suggestion that our current practice does not represent the state of the art, consider these points. My informants included not just people who were the focus of choice demonstration projects but also key people who assisted them. Among these are a number seasoned in typical rehabilitation and employment support practice. Without exception, they experienced themselves doing something new and different, something difficult exactly because the existing system does not recognize it as familiar, and something well worth the trouble it took.

Comparison aside, there is much to learn from these ten people who were among the pioneers in demonstrating what informed choice means.



Leigh Ann combines coaching people with disabilities and office support services in a micro-enterprise.

She is committed to assisting people with disabilities to make their rights real by offering coaching in the practical matters of fluency in using communication devices and moving into their own homes. She offers staff training and conference presentations and uses the internet to advise people with disabilities and projects for people with disabilities.

In addition, she uses her computer technology to provide a variety of office services for local organizations. The home page of her web site is pictured below.



The Choice Demonstration Projects

“Individuals with disabilities must be active participants in their own rehabilitation programs, including making meaningful and informed choices about the selection of their vocational goals and objectives and the vocational rehabilitation services they receive.”

–Rehabilitation Act Amendments of 1992

This policy formed the context for the projects that produced the teachers about Choice from whom I learned as I prepared this report. The project designs differed in important ways, including those summarized in the table below.

	Commitment to Client Choice Arkansas	Choice Access Project UCP	Consumer Choice Demonstration Vermont	Participant Empowerment Project Washington State
Position in VR system	Overlap system boundaries assigned VR staff plus new roles	Separate from VR linked at advisory committee level	"Living laboratory" to develop new ways to explore issues relevant to DVR redesign Experienced field staff assigned to project	Parallel project within but distinct from VR system to maximize flexibility
Focus	Defined geographic area selected for economic and service challenges Focus on people typically unserved.	People with severe disabilities involving limitations in mobility, communication, and manipulation in 3 different cities	Match typical caseloads as closely as possible	Match typical caseloads in the state's most populous, diverse, and economically powerful county
Distinctive features of project design	Required Empowerment training. Person-centered career plan facilitated by independent contractor. Choice of a Consumer Connector to assist with links to community resources Vouchers for services	"Your money" -an individual budget directed by participant. Differentiated roles: Choice Coordinator, Employment Advisor. Highly structured individual planning & job development process Extensive technical assistance and training	Review and revise policies and procedures to support choice Direct cash payments Expedited eligibility determination and "fast track" planning Counselor role shifts toward education and support	Individual budgets under person's control Rehab teams Futures plans developed in doable steps Training seminars for participants Peer support groups available

Abstracts of each project's final report can be found in Appendix B.

Because of the differences in the project's starting points, it is interesting that common themes emerged in the implementation process, including these five.*

- Implementing Choice required both personal learning and organizational adaptation. Even experienced staff committed to Choice experienced the process as a developmental challenge for them. “It wasn’t just different policies and procedures, it was a new and sometimes pretty difficult way of relating to people and to the system. It stretched me”, one counselor told me. Most of the assumptions the four project’s designers made about how the project would work had to be revised because they did not match either the employment paths adopted by project participants, or conditions in the sponsoring rehabilitation system.
- Self-employment proved more interesting to participants than anticipated. This challenged policy and common beliefs in the rehabilitation system.

Percentage of participants who made plans employed and self-employed

	AR	UCP	VT	WA
Employed	56%	61%	86%	59%
Self-employed	9%	13%	17%	10%

- Despite dire predictions by some rehabilitation system staff, participants with access to individual budgets or cash payments generally used their resources well. Difficulties in managing funds or vouchers or possible misuse of funds, when it did occur, was almost always

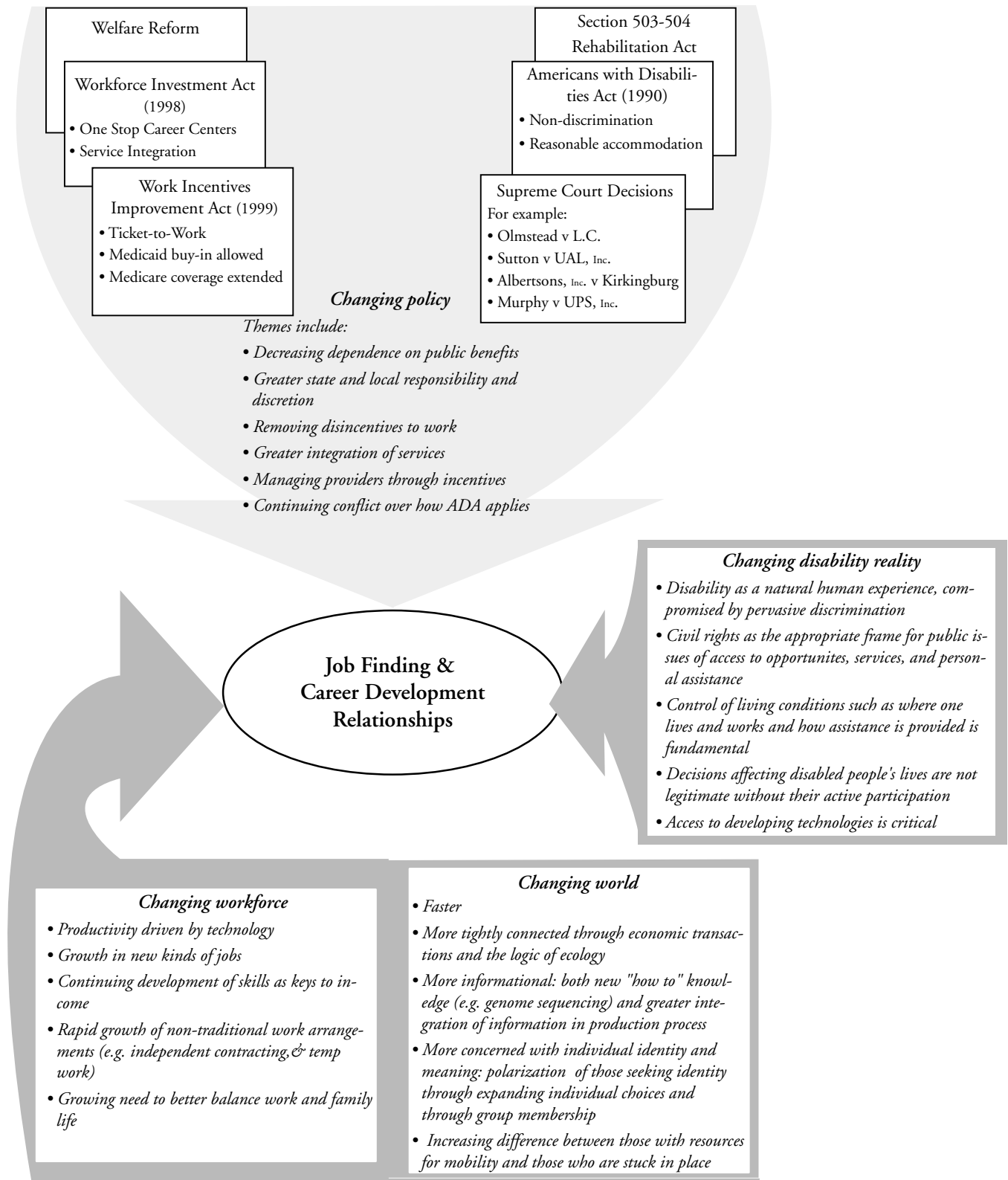
handled as a counseling issue within the program’s process.

- Some rehabilitation counselors were concerned that the Choice Demonstration projects would be an attempt to water-down professionalism or, as one person said, “My colleagues thought I was foolish to take the job as a Choice project counselor. They said I was helping the bureaucracy with a plan to replace counselors with clerks or ATM’s that people will be lining up to rob with fairy tale job goals.” In fact, the counseling function was vital for many participants, and challenging and rewarding for the counselors involved. Simply having easy access to money was not enough; many people welcomed advice and opportunities to build their skills.
- Projects experienced great difficulty helping participants locate existing employment support providers who would accept accountability to participants for agency performance or take direction from the plans that participants made with the Choice project’s support. The money available through the projects was not a powerful enough incentive to move many providers away from their familiar patterns acting as agents of the rehabilitation system, doing things to, or for, people. The Arkansas project developed 151 new vendors, including a number of new service providers. The UCP project developed 64 new providers specifically to respond to the requirements of their participants.

*For a detailed description of the projects and an account of their learning see the project final reports available at www.rcep7.org/conferences/choice. For an evaluation of all seven Choice Demonstrations Projects based on data collected through early 1998, see Susan Stoddard, Stuart Hanson, and Tanya Temkin (1999). *An evaluation of the Choice Demonstration Projects: Final Report*. Washington, DC: US Rehabilitation Services Administration. For a catalog of practices these evaluators identify as promising for replication see Susan Stoddard, Stuart Hanson, and Tanya Temkin (1999). *Promising practices in the Choice Demonstration Projects: An operations manual*. Washington, DC: US Rehabilitation Administration. Both of these documents available from www.infouse.com

The puzzle of slow change in a rapidly changing world

People with disabilities and those who assist them to move into the workforce live in world shaped and re-shaped by three kinds of changes. The diagram below suggests some relevant changes.



The listed changes each matter to the effort to build an inclusive workforce.* The news on the diagram looks good for those who promote choice and personal responsibility, but thinking about this good news in light of current reality poses a puzzle. First, notice the good news: many influences push together toward Choice. Much of our world moves rapidly toward greater emphasis on individual autonomy; “Because an authority says so” has less legitimacy in more contexts. There is a growing variety of ways that society creates and deploys the skills necessary to meet the demands of global economy, changing technology, and shifting demographics. Disabled people and their allies have transformed the very understanding of disability that once legitimized systems that decided for people while at the same time evoking many effective strategies for accommodation and assistance. Social policy reforms focus on work, increase incentives for employment, and explicitly value choice and personal responsibility.

Now consider the puzzle. The rehabilitation system continues to enjoy good support despite the enduring exclusion of 75% of adults with disabilities from the workforce and without transforming itself in response to changing disability reality. The influences arrayed in the diagram might signal profound change coming to the rehabilitation system, but if a wave of demand for workforce inclusion and a shift of power to people with disabilities is forming, it has not yet reached its crest.

I cannot solve this puzzle. It is too big for me and I am too much mixed up in it. But I can identify three themes from my interviews and discussions that each illuminate pieces of the puzzle of slow change and each inform a course of action. These three themes can be stated as questions:

- What choices face people who want to be leaders in the employment and workforce development system about deploying the power of that system?
- Why is it important to invest in organizing among people with disabilities and their allies to lengthen the reach of the disability movement?
- What implications do the emotional effects of deep and pervasive change have on the design of systems change efforts?

A strategic choice for rehabilitation system administrators

A part of the puzzle of slow change can be explained by pointing at the obvious. Big systems change slowly, especially until the resources that insulate them from the forces of change run out. In the case of the existing system of employment supports, such resources include more than political capital, the inertia of large sunk costs in existing facilities and skills, and near monopolistic control of the barriers to entry for competitors to the current

* The diagram summarizes some of the discussion from two change force think tanks and draws on four other sources: 1) *If not now, when?* 2) US Secretary of Labor (1999). *Futurework: Trends and challenges for work in the 21st century*. Washington, DC: US Department of Labor. www.dol.com. Cited below as *Futurework*. 3) Anthony Giddens (1999). *Runaway world: How globalisation is reshaping our lives*. (The 1999 Reith Lectures). London: Profile Books 4) Manuel Castells (1999). Flows, networks, and identities: A critical theory of the informational society, in Manuel Castells, et al. *Critical education in the new information age*. Lanham, MD: Rowman & Littlefield, pp. 37-64.

system. In the period of societal transition from the expectation of welfare to the expectation of work, the very marginality of people with disabilities buffers the rehabilitation system. Along with the social security determination process and the network of adult disability services, the rehabilitation system functions to manage the social boundary between those who must work and those who cannot be expected to work. In a society in a hurry to re-rig its safety nets, a system which sorts those fit for work from those unfit for work and provides a repository for those it judges incapable of employment holds a reasonably strong hand.* Those who administer the rehabilitation system face a crucial decision about how to play this hand in an increasingly complex environment.

They can play their hand in an attempt to conserve the current process, disturbing as little as possible those staff and agencies who do rehab as usual. If they choose this course, they will quibble over the definition of choice, career, and self-determination. They will claim that they have already and always fully realized those values. They will say that success simply requires more money to do more of the same. They will scrupulously ignore the dead moose in the middle of their conference table and never raise the question: “What do our ways of working have to do with the fact that three out of four disabled people of working age are excluded from the workforce.” And, if someone has the bad taste to point out the dead moose, they will quibble about the statistic before firmly fixing total blame for the problem on some other agency.

Or, with a clear eye on the vision that animates the Americans with Disabilities Act, they can play their hand to purposely conserve the values of employment and respect for the unrealized contributions of people excluded from the workforce by prejudice and underdeveloped accommodation. This path would lead them to actively champion the values that preface the 1998 Amendments to the Rehabilitation Act – informed choice, personal responsibility, and meaningful careers– as a practical frame for evaluating and re-shaping policy and practice and redirecting current expenditures rather than as a mission already accomplished. They would proudly convene “Dead Moose Dialogue Groups”, encouraging and supporting people with disabilities and their allies to join their employees in searching for actionable answers to the question, “What do **our** ways of working have to do with the fact that three out of four disabled people of working age are excluded from the workforce?” They would make space for many trials of new ways to invite historically excluded people into shaping the rehabilitation system and realizing its benefits, recognizing that race or membership in an ethnic or language minority as well as severe disability are the surest predictors of

* See Zygmunt Bauman (1998). *Work, consumerism, and the new poor*. Buckingham, UK: Open University Press and Michael Oliver and Colin Barnes (1998). *Social policy and disabled people: From exclusion to inclusion*. London: Longman.

**National Council on Disability (1999). *Lift every voice: Modernizing disability policies and programs to serve a diverse nation*. Washington, DC: The Council www.ncd.gov. A bias revealing aside: I misread and typed “serve” as “save” as I first recorded the title of this document.

exclusion.** They would realize that the most powerful role people with disabilities can play in re-designing the system is not as a member of a board, committee, commission, or task group, though such active representation is a precondition of the legitimacy of such groups' work. Choice Demonstration project participants show that people with disabilities powerfully re-design the rehabilitation system when individually supported to own the process of moving into the workforce.*

Organizing people with disabilities and their allies

Another part of the puzzle of slow change arises from changing disability reality. Many people with disabilities are untouched by the disability movement. The reasons for this are obvious but difficult to change: the consequences of disability isolates disabled people from the very connections that shape a new consciousness and enable action. As the only person I interviewed who identifies in any way with any part the disability movement,** told me,

“If you don't have a ride, you can't get to self-advocacy meetings. If you don't have a computer, you can't log on and find people and information. If you don't have a Liberator [an aptly named communication device] and feel good about using it, you can't have much of a discussion.”

* Appendix A, below, abstracts conditions for people owning their rehabilitation based on discussion with Choice Demonstration Project coordinators.

**This observation needs qualification because the small number of people I interviewed can not possibly represent the hundreds who participated in Choice Demonstration projects. For instance, I know that the UCP project was strongly influenced by parents' advocacy for better opportunities for their young adult sons and daughters, but I did not interview any of these parents. One interview with the parents of a Choice participant suggests a distinction between advocating for services for an individual family member and identifying with a movement to change society and its institutions from the standpoint of human and civil rights, but I have no way to see if that distinction holds up for any other family advocates.

Disabled activists have shaped policy and articulated a diverse, contentious and exciting disability consciousness. Nonetheless, the two people I interviewed who are most assertive of their rights, the only two people who talk about the Choice Demonstration projects in terms of their rights, purposely distance themselves from a disabled identity and the politics of disability. They choose instead to frame their rights as individual entitlements to service. As they understand their chosen spheres of work, disability is not a natural human experience or the foundation for a rights-based claim on reasonable accommodation. Rather, they see disability as a powerful hindrance to their success if it is raised to colleagues' awareness. For them, disability is a clinical condition, and none of anyone's business apart from the professionals they have chosen to treat it. For both of them, a significant appeal of the Choice project was that it allowed them to assert their right to services while remaining in substantial control of the information the system has about them.

This respect for privacy is a positive feature of Choice, and I have neither right nor reason to question these two people's chosen course of action. However, I do think about their decisions as an “unreasonable and unfair accommodations” pressed on them by the enduring social stigma attached to disability. I bring them into the discussion as a reminder that the understanding of disability newly articulated in policy is not yet widely enough shared,

even among people with disabilities. Those who best understand the Change agenda will have trouble moving it forward unless there is significant investment in organizing disabled people to understand it.

If people with disabilities have limited contact with the growing disability movement, it is even more so for rehabilitation workers. One experienced administrator told me that, though the same act funds both Independent Living Services and Vocational rehabilitation Services, the two programs typically function as if they operated in separate silos. Two rehabilitation counselors told me that, despite years of service, it was the Choice Demonstration projects that brought them for the first time into face-to-face contact with disabled activists. As one counselor said,

“I didn’t agree with a lot that [the activists] said, but the difference between the way they see things and what I look at every day at work was a small revelation to me. It’s given me a better idea about why Choice really does matter.”

*Two asides illustrate some of the values contending in the new economy. 1) Posters in Atlanta’s subway cars in May 2000 appealed for workers to staff a warehouse for an internet based grocery delivery business. They offered “friendly, responsible, service oriented people” a starting wage of \$14.00 an hour, full medical and dental benefits, the promise of stock options after one year, shuttle service to work, and a free daily meal “prepared by a trained chef.” In our labor market, personal assistance to people with disabilities typically offers minimum wage, no health insurance, no ride to work, no stock options, and no chef. Work as a job coach does not typically pay very much better. 2) Despite a critical shortage of direct care staff for people with developmental disabilities, a member of the President’s Committee on Mental Retardation told a recent conference on Disability and Poverty that welfare to work training programs in her state considered this work too poorly paid and too limited in its possibilities for advancement to make it a specific focus of their training efforts.

Designing change to acknowledge emotion

The waves of change have not yet crested, but their rise and swell powerfully affect the emotional field in which organizations and people make and play out their decisions about their part in the creation of an inclusive workforce. To think about the implications of this, allow two more statements of the obvious. First, these forces for deep change affect everyone emotionally: employers, rehabilitation counselors, union leaders, employment support providers, policy makers, people with disabilities, researchers and commentators, even advocates for Choice. No one stands apart from these forces as sovereign observers, able to act based on detached calculation. Indeed, the posture of objective rationality is itself an emotional defense; sometimes an adaptive one. These emotional effects are not just personal but also organizational: our families are affected, our workplaces are affected, our associations are affected, our political institutions are affected. Perhaps the fact that interest in ideas packaged under the label of “emotional intelligence” has extended from the best-seller lists onto the pages of the Harvard Business Review reflects a recognition that the emotional level of our organizational and societal life can only be ignored at the risk of deep confusion and inept performance. Second, though these change forces undoubtedly generate opportunities, the new economy produces not just winners, but losers too. Both people with disabilities and service workers have reason to believe that powerful interests number them among the losers.* These change forces also generate risks of

two sorts, specific risks and pervasive risks.* Specific risks take a potentially manageable form. If more manufacturing jobs go offshore, how will displaced workers make a good living? If I take a job for pay, will I lose my Medicaid? Specifying these threats defines a solvable problem, if a difficult and contentious one. We can figure out ways to support workers to re-train themselves. We can figure out ways to protect people's access to the services paid by Medicaid. Pervasive risks loom as a background sense of rising uncertainty about the practical effects of rapid changes. Does a faster, more economically interconnected world move us more quickly to poison our environment with dangerous chemicals? Will a more highly informed new economy make far more room to include and support workers with disabilities; or, will people with disabilities come to be treated as living lives of such low quality that they are better off dead? Can I, as a rehabilitation counselor, deal with the welter of escalating demands and requirements in a way that lets me stay sane and healthy and satisfied with my performance; or, must I always exist in a world where one impossible demand follows the next? These questions have deep uncertainty at their heart. What we decide to do individually and collectively makes a big difference to how these threats play out in our world, but, by their nature, they are beyond the reach of our ability to predict and control them.

Acknowledging the real world consequences of these threats and their interactions sets a limit on responses based purely on economics and individual psychology. To deal with specific risk it makes good sense to implement practical forms of prevention and insurance. To live with the reality of pervasive risk, it makes sense to encourage individuals to change in any of the following ways: develop the habits of an effective person, cultivate an empowered attitude of embracing change, become a life-long learner, focus faster on opportunities while letting go of what is beyond our control, and balance the demands of work and family.** But there is more to it. The challenges of change invite us to become more reflective and purposeful in making room for inter-connectedness and learning to intentionally build the kinds of relationships that give us the best chance of resiliency in the face of rising risk and uncertainty.

New mandates, different contract language, better information, and good technical assistance will help shape an employment and workforce development system better able to adapt to the demand to bring the proportion of adults with disabilities in the workforce in line with the proportion of non-disabled adults at work. But these necessary steps will not be sufficient. The Choice Demonstration projects show that change at the necessary depth requires a thoughtful design for shifting power that engages system staff and people with disabilities in new kinds of relationships. Such power shifting

*See Ulrich Beck (1992). *Risk society: Towards a new modernity*. Thousand Oaks, CA: Sage Publications.

**This inventory results from browsing a recent edition of a periodical called *Fast Company*. The cover page proclaims, "speed wins". www.fastcompany.com

system designs generate a greater variety of paths into the workforce by increasing the control people with disabilities exercise over discovering their goals and mobilizing resources.

Shifting power in these ways demands a higher level of personal responsibility and investment from people with disabilities, which brings people with disabilities sooner into facing the forces of change in the economy and social policy. Finding the balance of opportunity and risk generates uncertainty and concern that moving toward work means losing a social status which offers a buffer against the forces for change, even though this protected status is marginal to the world of work and associated with poverty or control by paternalistic others. Finding ways to negotiate this trade-off between opportunity and the demands of higher expectations shapes the relationship between people with disabilities and their counselors and advisors.

Shifting power also exposes counselors and employment support providers to the forces of the new economy and the new policy themes. Along with people with disabilities, they feel the press of new forces and the personal and organizational emotions their uncertainty stirs. This sets up two possibilities for resolution. Professionals and people with disabilities can escape the demands of new responsibilities by colluding to reinforce the belief that

“The traditional rehabilitation system values a linear approach... Implementing informed choice is complex and non-linear.”

– Washington State Project Final Report

people with disabilities couldn't possibly succeed and must stay outside the workforce for their own good. Or, professionals can help people with disabilities figure out what the changing work world could offer them and find practical ways to balance the real risks that moving into work poses for them. This is the harder path and the path with the greatest potential rewards.

The whole employment and workforce development system will have to undergo a deliberate cultural change if it expects counselors and employment support providers to take the harder path as a matter of course.* This process of change will purposely question and experimentally modify policies, structures, procedures, and practices to improve their contribution to the mission of greatly expanding access to the workforce for people with disabilities in ways that leave them with skills useful for navigating the future demands of a changing workplace. The success of the process will rise or fall depending on the system's capacity to surface, learn from, and design ways to deal with dilemmas like the one described in the following section.

*For a brief and serious overview of what this level of culture change means, see Edgar Schein (1999). *The corporate culture survival guide: Sense and nonsense about culture change*. San Francisco: Jossey Bass.

A counselor's dilemma

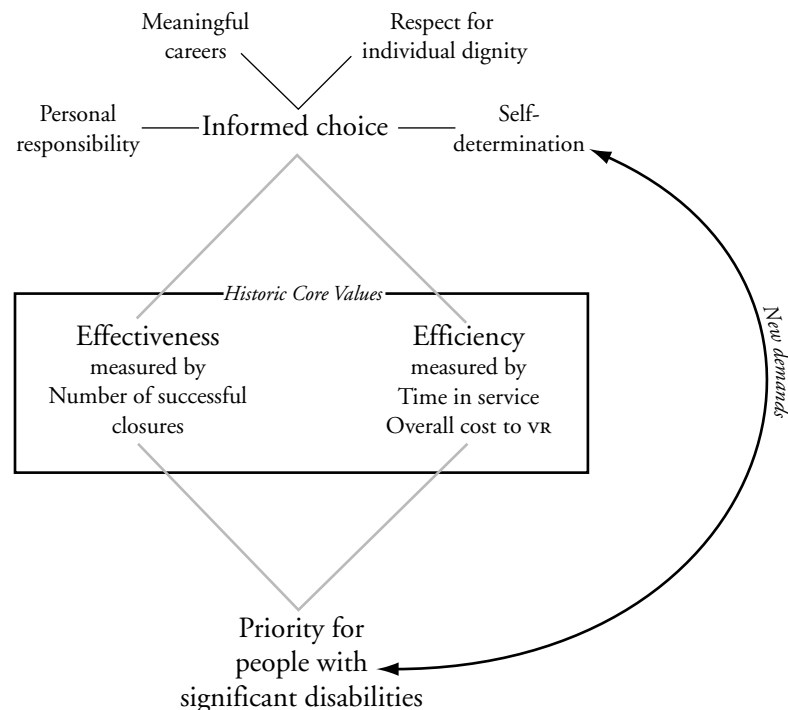
For example, consider the changing work world of the rehabilitation counselor. Three of the counselors I interviewed discussed their perspective on the dilemmas created by introducing new values into a system with a well established measure of performance. The diagram sketches the dilemma. The rehabilitation system has built its credibility on its rate of successful rehabilitations (denominated "26's"). Having a clear measure of effectiveness allows the computation of efficiency measures: how long it takes and how much it costs to achieve successful closures. As another experienced rehabilitation administrator explained to me,

"People inside the system see this measurement system as almost sacred. The system's political survival is staked on it. It is at the core of the rehab organization's culture."

New values create conflict

It is the policy of the United States that all programs, projects, and activities receiving assistance under this Act shall be carried out in a manner consistent with the principles of respect for individual dignity, personal responsibility, self-determination, and pursuit of meaningful careers, based on informed choice, of individuals with disabilities.

– Rehabilitation Act Amendments 1998, Section 2(c)(1)



...individuals with the most significant disabilities are generally presumed to be capable of engaging in gainful employment and the provision of individualized vocational rehabilitation services can improve their ability to become gainfully employed.

– Rehabilitation Act Amendments 1998, Section 100 a (3)(A)

As the diagram above suggests, policy enforces new values in the rehabilitation system. If there is a scarcity of service, priority goes to people with the most severe disabilities. Services are to be delivered in ways consistent with the principles of personal responsibility, pursuit of meaningful careers, respect for individual dignity, and self-determination. These principles are based on the informed choice of people with disabilities. Consistent with the policy theme of devolution, the states are left to operationally define both “severe disability” and “informed choice”.

One question posed by these policy statements concerns how these additional values should be read. One reading, preferred by Choice advocates, promotes access for people with severe disabilities and informed choice as values in their own right, to hold equal weight with the rate and efficiency of closures in judging the rehabilitation system’s performance. In terms of the diagram, this would create four equal corners specifying the system’s performance. This reading introduces two significant constraints on the rehabilitation system’s work. It generates the requirement for learning how to redirect the system’s policies and practices toward including more people whose rehabilitation might require greater resources and resourcefulness, and doing so in a way that offers them, and everyone else the system serves, informed choice. This significantly increases uncertainty: does a commitment to the values of greater inclusion and informed choice mean sacrificing successful closures or significantly increasing costs? And, if it does, how should the rehabilitation system’s sponsors look at increasing costs or declining performance. This reading cuts across the grain of the rehabilitation system’s culture, disrupting a successful performance system for an uncertain result.

Another reading is available. Both the Congress and the Secretary of Education are minded to leave the states to define the terms, a sensible strategy if you believe, as I do, that the kind of learning necessary to realize these values is hard to command from above. However, this latitude opens two escape hatches. 1) Those responsible for implementation can read the two new values as subordinate to the values of maximizing closure and minimizing costs. This leaves the burden on those who advocate for changes in policy, structure, and practice to prove (usually in advance) that increasing the rehabilitation systems inclusiveness or level of informed choice will result in a better rate of closures or a lower cost of closures. 2) Those responsible for implementation can operationally define the terms so that they reflect about what the system is already doing and take the position that though marginal improvements are possible, they would require substantial new funds.

One counselor who returned to the regular program after involvement in a Choice Demonstration project that operated parallel to that system summarized the personal side of this dilemma.

“The [Choice Demonstration] project gave me a chance to really act on the beliefs that brought me into the field. I had time to get to know people and figure out what would work for them and I had time to do the work it took to get the system to let up a little bit and interpret its rules a little more flexibly. There is still talk about informed choice. No one would dare say we act otherwise. But I know that the quality of the information and the range of the choices I can bring to my current caseload isn’t near what I did with the project caseload. In the project we argued about things with each other and we could bring issues to the higher-ups. We don’t have the same chance to do that now. I have a bigger caseload because of staff cuts and I’m expected to move them to closure as fast as possible. The system has a bottom line: ‘26’s’. The system is crazy for ‘26’s’. So in a way, I’m doing a better job now by moving people faster into any available job than I was when I was taking only a little bit longer helping people find a job that fit them better as an individual. It frustrates me when I think about it, so I try not to think about it that often.”

As I think about what this counselor told me, I wonder about the effects of this dilemma on the whole system’s performance. What seems to me most likely to sap energy from staff is the lack of opportunity to take hold of the dilemma, argue about what it means in the context of specific situations, and work for changes when they seem necessary. I have no information about this system’s management, but I believe that they could honestly say that they value informed choice and employee initiative. But these managers may be starved of feedback because, outside the now finished project, the counselor I listened to reads the informal rules as making his concerns undiscussible. This was the response the counselor would expect if he raised the dilemma with system administrators.

“If I brought it up, I’d probably get a sympathetic comment about how stretched the system is and how hard we are all working. I’d probably get told that I do a good job with what I have and that I shouldn’t expect to provide Cadillac services to everyone who comes through the door. And I might get some encouragement to take a course on time management so I can do a better job of managing priorities.”

This assumption may or may not be valid, but without a well designed shift in power and responsibility toward counselors, neither the person nor the system will get a chance to test it.

The counselor quoted above may have made a reasonable diagnostic comment on the organizational emotion stirred by threat of incorporating new standards for performance by observing, “The system is crazy for ‘26’s”.

As I wonder about what sort of craziness this might be, I think about the normal madness of taking refuge in denial that the system's relevant worlds are shifting in ways that will, sooner or later, shake it to the core. I think about clinging to the ritual of obsessively watching one set of internally derived numbers as if looking at a self-defined bottom line could assure legitimacy despite changing demands. I think about indulging the fantasy that more of the same could be enough to respond to the demands already finding expression. I think about an analogy to the way the world of American car makers was in the late 1960's when its executives could confidently make fun of "those little motorized roller skates" from Japan. I think that Charles Hampden-Turner well describes the situation I have been learning about:

"The most stubborn habits which resist change with the greatest tenacity are those which worked well for a space of time and led to the practitioner being rewarded for those behaviors. If you tell such persons that their recipe for success is no longer viable, their personal experience belies your diagnosis. The road to convincing them is hard. It is the stuff of classic tragedy."

The kind of change that the Presidential Task Force on Employment of Adults with Disabilities demands can only be delivered by organizations whose leaders will learn from the counselor's dilemma. The current measurement system, like every other aspect of the system, must be open to question and redesign in light of the enduring exclusion of three out of four adults with disabilities from the workforce. Such questioning calls for leaders able to engage diverse interest groups in disciplined dialogue with the facts of our changing worlds.

"People around here like to say, 'If it ain't broke, don't fix it.' But some things have been broke so bad for so long that we've stopped noticing they are broken and decided that's just how the world is. If we don't want to waste the dreams of people with disabilities we all have to have the guts to open our eyes to what can be and what should be."

—Community Connector

* Quoted in Jamshid Ghara-jedaghi (1999). *Systems thinking: A platform for designing business architecture*. Boston: Butterworth-Heinemann, p. 3.



Steve works in recycling at Seattle Community College

His collection route takes him all over the campus and gives him a chance to see people and find out what is going on. He separates and processes recyclable materials. His job gives him the chance to “help the world stay green”. He wanted a picture with his supervisor to appear here because, “We’re on the same team. He is a good leader. He knows that people have to care about each other to do a real good job”

Choice in a static system

People within the rehabilitation system might argue that their system works well now and would work even better if it simply had more money to relieve overcrowded case loads and pay better rates for services. While there is always room for improvement, the system's pattern is sound and big shifts would be both risky and unnecessary. To fend off change, defenders could quote the VR Longitudinal Study:^{*} three out of four consumers surveyed have severe disabilities, believed they had enough choice in selecting their vocational goal, and rate the services they received from the rehabilitation system as excellent or good.

Quoting the Executive Summary:

- *At minimum, 75% of all VR consumers have disabilities classified as severe, including 26% who have most severe disabilities....*
- *A substantial majority of consumers reported either that they themselves selected their goal (31%) or that they and their counselor jointly selected a goal (42%).*
- *Three-fourths of consumers believed they had enough choice in the selection of their vocational goal and 76% were satisfied with their vocational goal.*
- *Of those consumers whose service providers had been selected at the time of our interview, 46% reported that they and their counselors jointly selected service providers, 23% selected their providers by themselves, and 17% reported that their counselor was the primary decision maker in the selection of providers; overall, 81% of consumers were satisfied with their choice of providers.*
- *Overall, 46% of consumers reported having taken charge of decision making during their VR experience to a great extent, 41% to some extent, and 10% not at all.*
- *Approximately 60% of consumers believed that their services had met all or most of their needs; 12% reported that the services did not meet any of their needs....*
- *42% of consumers thought their services were excellent, and another 33% rated their services as good.*

*“Each year about 40,000 eighteen year olds are subject to an eligibility review for SSI benefits, but only 25,00 are determined eligible for such assistance. On average, young adults determined eligible will remain on SSI for 27 years, while those not determined eligible will live in poverty.”^{**}*

^{*}*If not now, when?*

^{**} Becky Hayward and Michael Tashjian (1996). *A longitudinal study of the vocational rehabilitation service program. Second interim report: Characteristics and perspectives of VR consumers.* Research Triangle Institute (www.rti.org)

When an agency whose managers and workers have reason to understand “business as usual” as a highly desirable state encounters a new requirement, the agency will make sense of that requirement in a way that reinforces the its stability. Given the requirement to assure informed choice and the further requirement to define it operationally, it is reasonable for that agency to reach for a definition like this one.

*Informed choice results from a rational and systematic decision making process that occurs in a context that is free from duress and coercion and that is characterized by: 1) identification of available alternatives or options; 2) identification of the consequences (both favorable and unfavorable) of pursuing each alternative or option; 3) selecting an alternative option after weighing and deliberating each one and its consequences in terms of a personal scale of values; and 4) commitment and action to pursue the selected alternative or option.**

This thoughtful definition establishes informed choice as a set of criteria for the counseling process by delineating a rational problem solving process. The agency satisfies the requirement for informed choice if its counselors guide their clients to commit to an available alternative after identifying available options, enumerating their consequences, and weighing them in terms of personal values. This sort of definition minimizes disruption in at least four ways.

- Informed choice is a matter of making the best of the available menu. The definition excludes responsibility for generating new alternatives or creating new options.
- Informed choice is a quality of the counseling process, not of the rehabilitation system as a whole. The agency avoids putting itself on the hook for expanding the menu of options.
- The contextual requirements for informed choice are satisfied negatively by avoiding “duress and coercion”. To test the stringency of this impressively legalistic criterion, imagine what a counselor would have to do in order to impose conditions of duress and coercion.
- Informed choice is a matter of logically exercising verbal intelligence. It is linear, rational, and best exercised in a mood of detachment. Excitement threatens this process, as does anger. Cognitive impairment and language impairment could be acceptable reasons to excuse a client from the rigors of informed choice.

Choice in a static system is choice inside current rules and habits. It is a way to keep the rehabilitation system doing what the system has been doing so the system will keep producing what the system has been producing. Those who believe that the system in its current form is making its highest contribution to the goal of significantly reducing the proportion of unemployed adults with disabilities will define informed choice in ways that call for small changes within the current rules. Those who see far more potential in the rehabilitation system will use informed choice as a way toward deep change.

*A 1995 state VR plan quoted in Michael Collins (1999). *The implementation of informed choice in vocational rehabilitation: A functional definition and self-assessment process*. Vermont DVR. A thoughtful reviewer points out that this definition was generated soon after Congress endorsed informed choice, with limited guidance from the Rehabilitation Services Administration and that this agency may have revised its definition by now. These points provide an important context for my comments. However, I think that the definition clearly articulates a well reasoned understanding of informed choice and I am grateful to its authors for the opportunity to disagree with them. For a current working definition of choice within the rehabilitation system, see www.rcep7.org

Choice as a way to system change

The Choice Demonstration projects indicate how following Choice could be a way to deep change in the employment and workforce development system. Such change requires more than imitating promising practices, it requires joining a community of practice whose members find excitement in discovering ways that significantly more people with disabilities can own their own move into the workforce. Those who designed and carried out these projects did so from a conviction that the rehabilitation system needs to change in significant ways at every level if it is to include far more people with disabilities in the workforce. They worked from a commitment to expand the menu of available alternatives by shifting responsibility and control to people with disabilities. They understood Choice as something worth inventing the capacity to achieve, not as an already established feature of the system. Their experience confirms the practical usefulness of their understanding, their commitment, and their conviction. It seems unlikely that others will be able to make full use of the many promising practices they developed unless they come to share this understanding, this commitment, and this conviction.

Reflecting on what I learned in my interviews and discussions, I can identify two kinds of systems changes, each deriving from a different image of the logic of rehabilitation process. I will borrow metaphors from the field of business strategy and call one image and logic a value chain and the other image and logic a value constellation.* Looking at the rehabilitation process as a value chain reveals a linear set of steps where each step can be assessed for the value it adds to the process and revised or even deleted to improve its contribution to the desired results. Looking at the rehabilitation as a value constellation highlights the formation of relationships through which participants co-produce mutually valuable results.**

*Richard Normann and Rafael Ramirez (1994). *From value chain to value constellation*. New York: John Wiley & Sons. The logic of the value chain is the more common of the two images and underlies such approaches to organizational change as process re-engineering.

**Please note that I am using these images to organize what I heard about changes made through the Choice Demonstration projects. Those who informed me did not use these images. The projects created the changes, I am the one explaining them in terms of value chains and value stars.

Choice helped us open our eyes and look at our own workplace from the customer's point of view. I used to sit behind a wall and people would come to a little window and ask permission to come in. Now people come in to an open area. There is lots of information around and easy access to the computers and fax machine. The whole office is a more welcoming and friendly place for people to come.

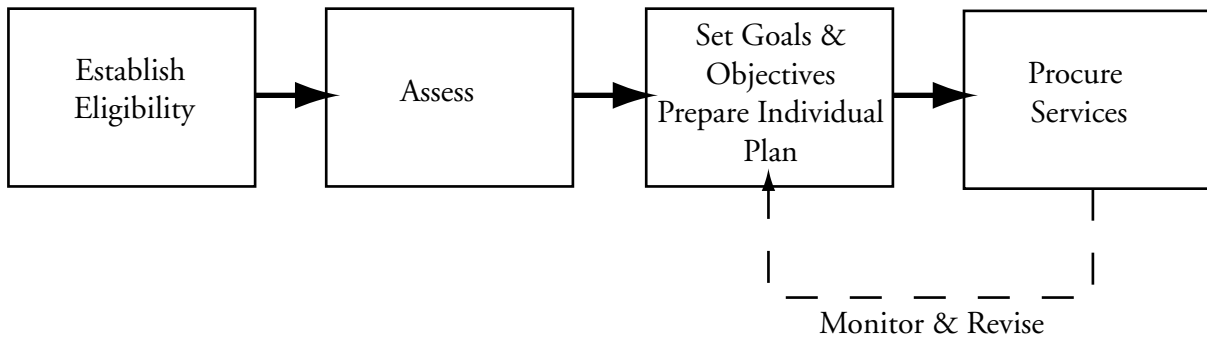
We extend respect to people by writing them a check that they can deposit in their account. So the community college gets a check for their tuition with their name on it, not a check with our name on it. If people want to keep their connection with us private, it's their business.

We work more as a team. I'm not a counselor, but I get to know a lot of the people who use our services. There are some things I can do for them, and I can always ask them how things are going and offer some encouragement. Things are less rigid. The rule around here is, "If you know how and have time, do it."

—Office manager

The value chain and the fast track*

This diagram describes part of the vocational rehabilitation process as a value chain.



Examining this short chain against criteria of value such as these suggests a number of ways to improve the value each step adds.

- Does each of the activities in this step communicate respect to participants?
- Do any of the activities in this step hinder the speed of participants' movement to define and pursue their vocational goals or otherwise make it more inconvenient to the participant?
- Do any of the activities in this step take away responsibilities that at least some participants could assume?
- If an activity communicates disrespect, hinders the speed with which participants can move, or usurps participant responsibility, is the activity simply done for the convenience of the system and its employees?

Any activity that fails the tests of respect, facilitating rapid movement, promoting personal responsibility and putting the participant before the convenience of the system becomes a candidate for re-design.

Pursuing such a re-design yields insight into the system. Applicants to VR can be usefully differentiated along three nested dimensions.

Clear eligibility. A number of applicants can easily demonstrate that they have a disability and that a VR service could help them into the workforce. Given the requirement of “clear and convincing evidence” to rule an applicant who could benefit from services ineligible, it makes sense to presume eligibility for many if not most applicants.

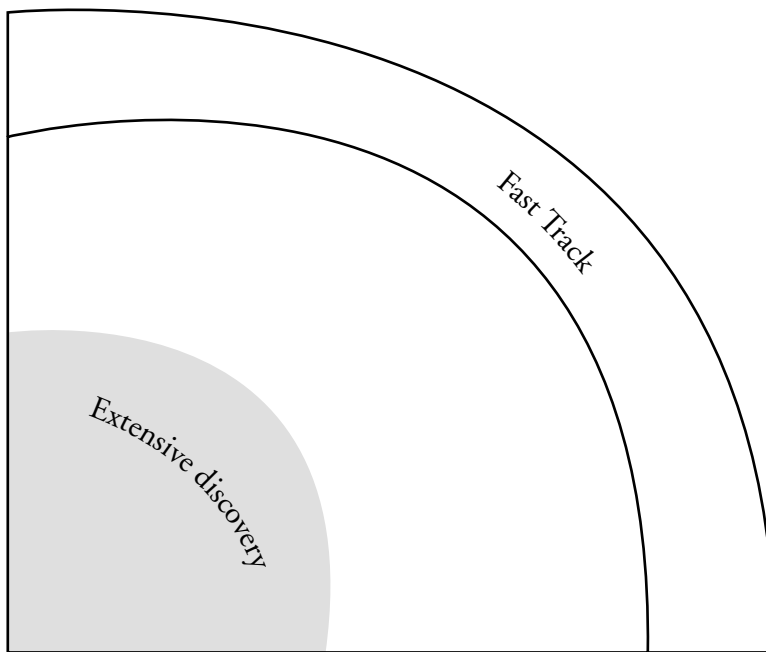
Clear plans. Some people with disabilities have a plan in mind when they apply to VR. They have a clear vocational goal and a definite idea of what VR can do to help them move toward it. In many, if not most situations it makes sense to write these people's Individual Plans for Employment from the ideas they have in mind, leaving necessary revisions to be made in light of experience.

*The fast track example is drawn from Vermont's Consumer Choice Demonstration project. The diagrams and the way the criteria are stated are my interpretations.

Reasonable expenditures. Some people who have a plan in mind can identify a step toward its implementation that depends on a reasonably small expenditure of cash. If this expenditure seems reasonable, the most respectful way to encourage personal responsibility is to write a check to the person for cash and set a time to follow-up on the results of the expenditure.

*There is no
reason to question
my eligibility*

I have a clear
employment
goal in mind



I want to work & VR can help,
but I need help identifying
what jobs would suit me &
figuring out how I could be
successful

I know what
I need from
VR to move
toward my goal

*The expenditure is
reasonable*

* The fast-track is not for everyone. Those in the lower left quadrant of the diagram need an equally well developed opportunity to move more slowly. The over-arching value is to assist each individual to move at their own pace.

Those people who appear eligible on application, who have a plan, and who can define a reasonable first step constitute a “fast track”. For them, the standard of system performance is that applicants walk out of their first meeting with a plan and a check, on the way to make the first purchase that will move them into the workforce.*

Re-designing the value chain to establish a fast track raises many practical questions and stirs all of the emotions that any shift in power and responsibility does. If people on the fast track are to carry a check away from their first appointment, counselors need checkbooks. As well, counselors need to be given and accept greater discretion and responsibility around determining eligibility, authorizing plans, and committing funds. Some counselors respond gladly, others anxiously. For some, anxiety takes the form of negative attributions about clients' credibility and personal responsibility ("They will misuse our money." "They will rob us blind."); others will make negative attributions to blame system managers ("They want to downgrade us to just giving money away to whoever comes through the door.").

Working through the practicalities and the emotions of change not only increases the system's capacity to increase people's ownership of their rehabilitation, it also contributes to the system's efficiency. Counselor time saved with people on the fast track is potentially available to assist people who will require an extensive process of discovery in order to define their goals.

The rehabilitation process as creating a value constellation

The logic of the value constellation complements the logic of the value chain, it does not replace it. While the image of the value chain helps re-design policies and procedures, the image of the value constellation seems to me to capture some critical aspects of the day-to-day work of facilitating Choice. Instead of highlighting activities, like completing an individual employment plan or securing a provider agreement, the value constellation highlights relationships that cross boundaries to co-produce valuable results.

Looking at Choice in terms of co-productive relationships helps me understand a key theme in my interviews: people have more power and a greater range of options when they have people they can count on. The people I interviewed do not tell stories of choice and personal responsibility as doing things alone or issuing commands.* Reviewing what mattered to them about the Choice Demonstration project, participants talk about the importance of people taking an interest in their future, listening to them, encouraging them, believing in them, collaborating with them to figure out what to do when they hit problems and disappointments. One person put it this way,

"I got a list of providers from [the project coordinator], and I made the phone calls and arranged the appointments for myself. I did it, but I didn't do it all by myself. [The project coordinator] was right there with me every step of the way. She called several times to see how it was going, but it didn't feel like she was policing me. It felt like she

*I did not interview any of the fast-track people mentioned above, so I have no way to know how this theme of interdependence might come up for them.

was concerned for me, because she knew how hard it was for me to get up the courage to make those calls. But she wasn't going to make them for me; they were my responsibility. And when I made them she celebrated with me."

Even the two people who maintained the firmest boundaries between themselves and the rehabilitation system spoke at length about the quality of their relationship with a Choice staff person. They highly valued the features of Choice that put them in charge of purchasing exactly what they needed from the source they selected, but they see these purchases and their effects in the context of their relationship with Choice staff.

These two summaries of points made by the counselors and service providers I interviewed illuminate some of the relationship dimensions of Choice.

Questions I'm asking a lot more often

- *"What works best for you when you want to get new information... to learn new skills? Listening... reading... talking to somebody whose already done what you want to do..."*
- *"Have you thought about...?"*
- *"What would your best possible job be like...?"*
- *"What do you think it would take to...?"*
- *"Who do you know that could help you out with ...?"*
- *"What have you figured out so far...?"*
- *"What will your market be...?"*
- *"How have you thought about finding out...?"*
- *"What are the pro's and con's of...?"*
- *"What other options are there to...?"*
- *"Exactly what do you need to take the next step?"*

Things I want the people I assist to say about me

- *"You really listened to me."*
- *"You believed in me."*
- *"You invested in me."*
- *"You stood with me when I had troubles."*
- *"You didn't do anything for me that I could do for myself."*
- *"You helped me discover new possibilities and new ways to do things."*
- *"You helped me figure out what's really important to me."*

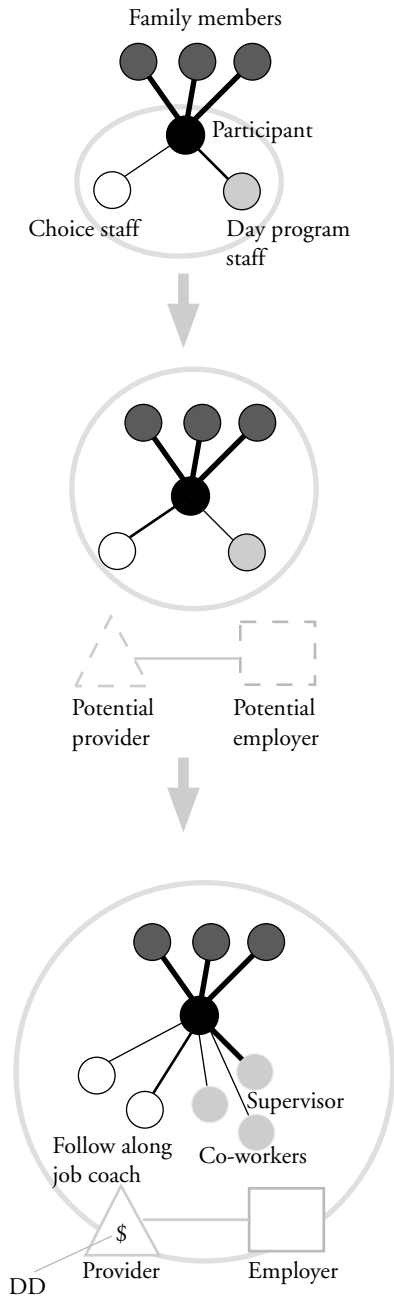
The importance of relationships also shows when counselors and service providers describe the support that they need to sustain them in their work.

What supports me as I do the work?

- *The work fits my style. I don't like to feel like my worklife has to be run according to a manual. I like the responsibility of getting closely involved with people, making decisions, and working through the consequences with them.*
- *Being part of a team that has the strength to demand honesty and accountability for each other.*
- *Having access to lots of information. Not just from reading or going to training but also from conversations with people who are doing similar things. Being able to phone or e-mail really helps.*
- *Supervision from someone who will listen carefully, honor the complexity of what I am doing by resisting the temptation to jump in with easy solutions, stimulate my creativity, and push me to bring what we talk about back to my work with people.*
- *Flexibility from the organization that employs me.*
- *Competence and timeliness from the people who do bookkeeping, bill paying, and reporting. If they aren't on board, it can really gum things up.*
- *Taking a step back every once in a while and thinking about how my work is going and what I'm learning overall.*
- *Remembering (being reminded) that this is about inventing new approaches. It's ok if I don't know how to do everything the first time. In lots of situations there are principles to honor but there is no pre-existing script. We have to make it up.*
- *Sometimes it can be just essential to a person's being that they try something. When I can help someone honor that essential thing and make it a little easier for them to give it a try, I feel a great satisfaction.*
- *Knowing that I am part of an important social change.*

Value constellations form around the purpose of creating a way into the workforce that the participant owns. They grow and change as more people join in, each bringing an important resource. Here is an example to illustrate how value constellations develop, constructed in simplified form from interviews with four of the people involved in one participant's success at work.

The growth of a value constellation



The participant came to the project with the encouragement of a staff person from the day program he attended. He lived in his own apartment, with assistance from a residential service agency and highly values the support he gets from his family, including his father and his brother, who is his legal guardian.

He attended some project related training, gathered a small group of people to support him, and began the process of making a plan. In the process he developed what he describes as a real good relationship with project staff. He was increasingly interested in a job, but his family was unsure of his ability to succeed in open employment. The counselor was able to negotiate family support for the next steps in the plan with the understanding that, as members of the person's team, their concerns could be heard and they could help define and implement the next steps.

The counselor identified a potential job, the participant and the team agreed that it fit the person's requirements, and then the counselor and the participant settled on an employment support provider, an agency with a strong track record with the employer.

One of the positives in the job was the strong potential for supervisor and co-worker investment in the person's success at work.

Looked at from this angle, the counselor's task is to build relationships that align people's and organization's resources to move the person into the workforce. Sometimes this involves assisting people to add people to their lives. Sometimes it is a matter of acknowledging the importance of the relationships the participant brings into the rehabilitation process. Sometimes the task is to help important people make the decision to invest in the person's job success. The diagrams to the left show this as an increasing number of people moving inside the boundary of the circle of those enrolled in the person's job success.

It is not the counselor's sole responsibility to build this constellation. This participant's supervisor encouraged his co-workers to build a positive relationship with him. But it is up to the counselor to assure that enough people and organizations join the value constellation to create a good opportunity for success.

Each person in the value constellation joins as a source of help and support. People can remain a support even after the participant moves on from regular contact with them. In the example above, the participant identified the Choice counselor as an important part of his continuing job success. “I don’t see her very often at all, but she is right here in my memory.”

People who are part of the value constellation don’t necessarily attend meetings with or about the person, or even know one another, though some of the people I met have found it helpful to bring together a circle of support or a rehab team. The participant’s co-workers have never to my knowledge met the family members, though both sets of people have been important to his success.

The value constellation functions as a network for discovering and making sense of information.

“I was really worried about my Medicaid and so was my brother. But then I went to a seminar and they explained it all to me. And they got a bunch of papers for my brother to study and that took care of his questions. Between the two of us and [the counselor] we figured it out.”

Roles and linear sequences matter less than relationships that facilitate action. In this example, the counselor began job development with the participant’s consent because, as she put it, “I thought of a job that just seemed like it fit him.” Then, when the job was identified, the counselor assisted the person to hire a provider to assist in the participant’s transition into the job and to provide follow-along through their contract with the developmental disabilities system. Boundaries and responsibilities take shape as action matches the participant’s changing capacities and preferences.

Each value constellation takes its shape from the task of assisting this particular person to move into the workforce in a way that makes sense to him or her. This means that counselors must hold structures loosely. For example, the participant whose path to work is sketched here found it helpful to gather a team around him to plan.

I believe in the teams. It’s silly for you to try to do it all for yourself alone. The way it works is, as long as I do my part, I don’t have to worry.

But another participant in the same project reacted very differently to the idea of having a team.

I did not see the point of having a team. It seemed like something that would be done to children. It seemed contradictory to me that a project

that said it was about individual choice would require such a thing if a person didn't want it. If the project had insisted, I don't think I would have continued as a participant.

“The failure, absolute or relative, of most programs in human service (and the resulting cynicism about mounting any successful program) is in large measure due to unexamined, oversimple, and invalid conceptions of the nature, extent, and bases of human relationships.”

—Seymour Sarason

Policy makers need to think about the variety of different value constellations that will need to be assembled to assist people who don't presently entertain the idea of working to join the workforce. Policies don't produce value constellations, people do. But policies and structures based on knowledge about necessary relationships can contribute to staff developing relevant skills and organizations developing relevant supports for their work.

A rehabilitation process and a job that people can take pride in owning is usually a co-production. It depends on people orchestrating one another's contributions to build on strengths and compensate for or accommodate weaknesses.

“I know how to work, but I don't know about how to find a job and I wanted to stay at the workshop until I had a job to go to. So I didn't hunt for a job, they got paid to hunt up a job for me. I don't really know all they did. I guess they wrote letters and made calls all over. Anyway, they found this job and I'm glad they did.

Then it was up to me to get it. It was up to me to show [my supervisor] that I could do the job right and learn the parts I didn't know.

Now, my job is to work. I show up on time. I am a good team member. I do my job and, when they need me to, I learn new things. [My supervisor's] part is to make sure I have what I need to do the job. My brother's job is to look out for the money and do my taxes. [My job coach's] job is to check and make sure things are going ok.

What I learned is, I don't have to worry about every little bit of it. If I do my part and the others do their part, there might be problems once in a while but it all comes out right.”

*Seymour Sarason (1977). *Human services and resource networks*. San Francisco: Jossey Bass, p 14.

What sort of consumer, what kind of market?

The move to re-invent government encourages those who offer public services to think of those who use their services as customers. This idea has its limits because many public services lack competitors –I can't decide to get my drivers license from a competing licensing agency if the length of the line wears on my patience any more than I can access VR funds without a plan approved by a designated agency. However, standing in the familiar shoes of the customer and looking at public services has led to many innovations –now there is less chance of being caught in a line because the license inspectors have dispersed into kiosks in a neighborhood supermarkets and in some places there is a fast track to an authorized Individual Employment Plan.

The Choice Demonstration projects intended to go further than this and generate and then tap the power of informed consumerism to accomplish two ends. First, the projects wanted to increase personal responsibility and the ownership participants would experience from the process. Second, they wanted to shape the way service providers did their work by exposing them to the pressure of consumers who could negotiate for exactly the assistance they wanted to pay for and “vote with their feet” if services were unsatisfactory. With varying amounts of bureaucratic difficulty, three of the four projects established ways that people could either get cash payments for some services or control the disbursement of funds to service providers. The fourth project couldn't unsnarl state government strings on disbursements sufficiently to offer people direct control of funds, but state agency representatives acted at people's direction and worked hard and generally successfully to justify expenditures that seemed unusual to their system.

Many proposals for increasing the rate at which people move into the workforce call for making a market in services, or at least making a sort-of-market in which consumers use system approved amounts of money to purchase services specified by system approved plans from a network of system approved providers through system operated payment mechanisms. Based on what worked and didn't work for them, the project participants who were my teachers about Choice have important things to say about this policy direction.

For eight of ten of the people I interviewed, control of expenditures was a very important feature of Choice. They would strongly agree that it is a good idea for people to be in charge of purchasing what they need to pursue their move into the workforce. Indeed, this seems self-evident to two people whose only contact with the rehabilitation system was through participation in the Choice Demonstration project. They had difficulty imagining a system

in which people did not have control of expenditures. Thus, the Choice Demonstration projects satisfied their first objective: those I listened to felt and acted responsible for their purchases. The second objective, shaping service provider behavior, proved elusive for reasons that I think are instructive for employment service reformers.

Market functions

Control of funds worked well when the person with a disability could purchase what they required on the open market. In general, people comparison shopped and often negotiated for better prices or better conditions, though some people needed education in why and how to do so. People who wanted to purchase training or the tools necessary to do their work or tires to make their vehicle safe for travel to school or work were satisfied to do so. Participants in two of the projects significantly increased the number of vendors used by VR through their purchases. People did not make outlandishly expensive requests, no one asked to take a course offered in conjunction with a Caribbean cruise or felt that they would have more energy for work if they had caviar for breakfast each morning.* Once people understood that purchases had to be related to a vocational goal, most did not make improper requests, though some requests appropriately stretched the system's boundaries and a few exceeded them. The projects report few instances of misuse of funds, most of which were adequately handled through the counseling process.

Improper requests or misuse of funds were not concerns for anyone I interviewed. On the contrary, counselor perception was that people had selected what they wanted to purchase thoughtfully and shopped carefully and well. Six of the ten people counted heavily on family members for help in understanding and managing their expenditures, as they count on them for most matters of personal finance, but this only seemed to increase the acuity with which they shopped for things. For example, one family did extensive research to select the exact software and hardware adaptations necessary and, through their personal network, found a local person well qualified to provide the set up, training, and technical assistance the whole family needed in order to assist their daughter to use the computer in her micro-business.

*Cruises and caviar are hypothetical examples used in a recent conference presentation by a critic of individualized funding to invoke the anarchy unleashed if people with disabilities gain control of expenditures.

Market flaws

Lack of information flaws a market. Information flaws were mostly overcome as staff, and sometimes participants, located a necessary service that was obscure to participants and took on the role of broker and even salesperson. The leading example of discovery and brokerage I encountered involved small business consultants. All of the four people affected would agree with one who said,

“I knew what business I wanted to be in. And I know how to [do the work]. But I didn’t know how little I knew about the business end of running a business. In fact, I knew so little that it wouldn’t even have occurred to me to look in the yellow pages for a small business consultant or to go to the technical school to look for a course. I never even heard of a micro-enterprise until I found out that is what I am.”

Brokerage overcomes this sort of market flaw, as long as there are suppliers of what’s needed ready to do business with people with disabilities at a price they can afford. Project staff made efforts not just to locate business consultants and business training opportunities but to engage them in ways that would improve their competency and interest in dealing with people with disabilities.

Markets can not deliver what is technically impossible (though there is an impressive trade in snake-oil which, fortunately, did not profit at the expense of any of my informants). In only one instance was someone looking to purchase a service that was unavailable because of limits in technology. Despite an extensive search, one participant was unable to find anyone offering the sort of cognitive coaching that would assist in meeting a requirement for professional advancement. Many of the professionals she contacted agreed that the service she described would be highly desirable, but no one knew who could provide it.

The market flaws that most commonly frustrated and delayed Choice Demonstration project participants are surprising, since they involve services offered by employment support providers. Many of these employment support providers might even have certificates of accreditation testifying to their commitment and competency in delivering individualized services that promote choice. But often, being a customer with money to spend turned into a source of frustration as providers refused to negotiate with participants, refused to modify their offerings to respond to the specifications of participant’s individual plans, missed agreed deadline, and even refused to recognize participant’s authority to approve payments. This non-responsiveness was not confined to established agencies, it even affected individual contractors who attended training in order to qualify to work with participants.

It is an irony worth exploring that many participants in the Choice Demonstration projects had more difficulty exercising the power of informed consumerism the closer they got to the services that exist specifically to serve them, services that commonly label them as “consumers.”

Consumer vulnerability

One participant’s experience demonstrates the bizarre lengths to which provider deafness to people with disabilities can go.

“I graduated with good grades from a well respected school in my chosen field. The placement process, which is one of the reasons I chose the school, just fell apart for me. Basically, they told me that they couldn’t place me because of my disability. That made me discouraged and I dropped the idea of working in my field for a year or so. I was a live-in personal assistant for another person with a disability. When that situation came to a close, I had a big choice to make.

A friend told me about the project and I decided I’d make the move to work in my field. I wanted to hire a job developer to help me over the hurdles of making contacts and figuring out any accommodations I might need. Maybe I should have been able to do that myself, but I just didn’t have the confidence to do it by myself. But [the project coordinator] encouraged me and said it would be a good investment, sort of like hiring an agent.

I made an agreement with an individual provider off the project’s list and told the provider how important it was to me to get to work as fast as possible. I told the provider where I wanted to work. The provider acted enthusiastic, but then time kept going by and nothing happened. Then she told me that she had decided that she would develop a job for me in a restaurant or a store so that I could make the transition into employment. I can’t imagine where she got that idea, but for a little while I almost agreed. I thought maybe the provider did know best and that I would be biting off too much by trying to work in my field.

[The project coordinator] helped me get straight: that kind of job wasn’t in my plan and I needed to find another provider who would listen. I had classmates who work around here, so I told the second provider exactly where the vacancies I was interested in were. That provider had it pretty easy because it was just a matter of making some visits to pave the way for me. The second time around, I was at work in no time.”

This brief example holds many lessons about the workings of the market in services. I offer four readings of the example. Two concern the vulnerability that people with disabilities can experience as consumers. Two concern the cluelessness of even able employment service providers. I argue that without mindfulness of these sources of market imperfection, it will be hard to design bridges to work that are wide enough and strong enough for everyone to roll or walk over.

Some people might read this example as a process of developing better consumer skills. The participant lacks and then gains the assertiveness and the ability to give clear directions and then follow-up on them. She learns to check-up on progress and not to accept poor performance. A competent consumer will check the delivery against the order and refuse to pay for shoddy merchandise. No thoughtful consumer will be surprised by slipping deadlines, unanticipated cost rises, or even poor workmanship.

Another reading can sit beside this one. This person is vulnerable not only because of a lack of skill, but because of the erosive effects of internalized prejudice. She is almost ready to decide that the service provider knows her better than she knows herself. She has more to overcome than just a lack of skill or shyness, as she says,

“Until I got to work, where people know me for what I like to do, it got to where I would walk into a room and feel people looking at me and only seeing my disability. The way I saw people looking at me just shrunk my soul.

Not everybody was that way. My friends with disabilities were not that way, but they weren't much interested in the field I wanted to work in. The more I stayed just with them, the farther I got from the career I wanted. My friends from school were not that way, but they were really busy with their careers and I lost touch. [The project coordinator] was the first person I met who didn't look at me that way and who could help me plan a way to work.”

I think it would be disrespectfully superficial to dismiss this person's experience of a soul-shrinking gaze experience as a symptom of psychopathology, a manifestation of “ideas of reference” or “low self-esteem”. I prefer to understand her report as she does, as a heightened and disturbing social sensitivity. She can decode an image that expresses what many people with disabilities feel but do not find words for until they meet others with a common understanding of the reality of discrimination and the ways that discrimination can invade and undermine identity. This understanding discloses the importance of someone like the project coordinator. Someone gifted in seeing and reflecting more than incapacity; someone who notices

and celebrates disability as a natural human experience. Someone who can be a bridge between the person's current world and the world of work by acting as a sort of underwriter of the person's claim, as a disabled person, on full citizenship.

Another person I interviewed had a more internally focused experience of discrimination.

"I got to where I just didn't think I could do a single thing, like I had no marketable skills and no way of getting any. I got pretty down on myself and it showed up in lots of ways. Like I would get my epilepsy medication all messed up and then get angry and suspicious and not tell the whole story to people who could help me. My health got pretty bad.

I didn't really think the project could do anything for me. I was really isolated—I still keep pretty much to myself, but then I was really cut-off from other people. I went to one of the project seminars; the counselor said it would be ok to just listen in, that I didn't have to participate if I didn't want to. I started hearing from other participants. What they were experiencing, and what was working for them and what they were going through. I went to more and more seminars, and I kept picking up useful things. I started going to the project office and using the computer. I used a typing program and showed myself I could learn something. After a while, I used their printer and their fax machine to send my resume everywhere."

This participant makes the bridge between a much more private disability world and the world of work in a different way. He forms an important part of his bridge from attending project seminars and spending time in the project office using the machines. The job he found through the project involves doing individual office work and gives him the opportunity to belong to his workplace and be mostly in control of how much he joins in the social life of the office.

Provider cluelessness

Why would a provider who had made a carefully negotiated agreement to deliver services according to an individual plan ignore deadlines and unilaterally reverse that plan when payment is contingent on timely and accurate performance? Why do this after participating in training in individualized job development and choosing to join the Choice Demonstration project's vendor list? Why do this even when the person with a disability provides information that would make the provider's job easier? I did not interview the provider involved, so I can only use the example as a platform for speculation.

One way of understanding provider cluelessness is economic. On this view, the market in services is flawed by the power of a few block purchasers, whose contracts amount to all but the tiniest proportion of provider income. This structure clearly differentiates consumers – who are expected to beneficially consume what the system buys for them– from customers, the agents who purchase on behalf of VR or another large human service program. The answer is to greatly increase the amount of money flowing through individual budgets and, taking account of the possibilities of consumer vulnerability, to empower individual consumers and encourage consumerism.

This argument has merit but needs a complementary understanding. A glib understanding of competition may lead those policy makers who want to make a market by individualizing payments to flaw it by design. More people selling services that are all generated by the same paternalistic mindset that currently colludes to exclude 75% of working-aged adults with disabilities from the workforce will leave choices that are only different in non-essential details amplified by the marketing efforts stimulated by the entry of more players. Unless policy makers complement what would be a very welcome increase in individual purchasing power with efforts to create services based on a fundamentally different mental model, I think that the effort will be hollow, especially for the people most likely to be marginalized by the current system.

What could it mean to generate services from a different mental model? A number of the participants in the Choice Demonstration projects point the way. With skilled and committed facilitation, some of them have collaborated in the creation of services that do respond to their individual circumstances and talents. Partnership in the design of services between people currently excluded by the system and skilled people within the current system is the necessary first step. Without such direct partnership, efforts to re-design will go wrong because they started out wrong.

It is important to acknowledge that not every employment provider is clueless.* Two of the ten people I met have had a smooth and satisfactory relationship with their employment support provider. Five people experienced a combination of long delays in delivering products within the providers' control (for example, a copy of their plan or a completed profile), or defaults, or unilateral unwillingness to pursue agreed objectives, or unwillingness to take account of revisions to a plan from one or more employment support providers before finding a provider that met their requirements. Three people's plans required no assistance from an employment support provider. Given the way my study was constructed, there is no way to know how representative these experiences are.

*The importance on this issue was impressed on me in discussions with the Choice Task Force, most of whose members have thought and written about it at length under the heading of “provider reluctance,” a more neutral label that does not carry the causal attribution that “cluelessness” does. See especially the UCP Choice Access Final Report and Michael Callahan and Abby Cooper, *Provider issues relating to consumer choice*. Available at www.rcep7.org.

My main point is that what I have labeled cluelessness is far more a sign of differing mindsets about the relationship between providers and people with disabilities than it is of incompetence or bad will on either side. I hope that the label, which I have borrowed from one of the participants I interviewed who is a regular *Dilbert* reader, does not distract from the point.

Clearly, the process of increasing people's ownership of their move into the workforce involves more than simply handing over the vouchers.

Do people with disabilities slow the move into the workforce?

Puzzlingly, given their decision to be part of the choice project and the opportunity to exercise control over their way into the workforce, some people with disabilities moved much more tentatively and slowly toward work than advocates for Choice predicted they would. As the Final Report from the UCP Choice Access Project puts it,

One of our fundamental assumptions... was that offering participants control of resources would speed up the attainment of desired employment outcomes... However, it didn't happen in that manner. Instead of speeding up the process, control of resources by participants seemed to have a complacency effect on many participants. Once they knew the money could not be touched, except through the delivery of outcomes that they approved, many participants seemed to relax their advocacy efforts and accept a lack of movement by providers. (P. 32)

Some participants may indeed be complacent. However, I think it is worth looking at participant related sources of delay in more detail.

Some delay probably arises from causes discussed above: some from participant uncertainty about the reasonableness of their expectations of providers, some from a lack of assertiveness due to lack of skill or confidence, and some from a calculation that the costs and inconvenience of changing providers outweigh the possible benefits of working with a new provider.

"The first provider was nice to me and agreed to do what was in my plan. She brought up how long it was taking. She said she had gotten really busy with other stuff and that it was a lot harder to locate a job for me than she had thought it was going to be. I thought about switching, but how was I supposed to know if another provider would be any better than the one I had? That kept me from deciding for quite a while."

Two other sources of delay deserve consideration. It takes many people time to work out a new balance between their work and their family life, and problems with personal assistance often exert considerable drag on people's success at work.

The consumer metaphor helps orient efforts to recognize disabled people's self-determination by focusing attention on people's ownership of the rehabilitation process and by insistently raising the difficult question, "Whose money is it?" But, like any appealing metaphor in a complex human situation, it needs looking behind. Recognizing the flaws in the current market for services will help advocates and policy makers form more comprehensive strategies than simply issuing vouchers. Realizing that, for many people with significant disabilities, the decision to move into the workforce is not like a decision to purchase a haircut, a holiday or a car. It is a decision to make a big change in the way life goes for oneself and for important others. It is a decision that touches virtually every detail of life. No wonder it takes time for people to weigh its uncertainties.

"Too often, people tend to settle for any old job they get placed in. I don't believe that's really responsible. There is a job out there that fits you, that gives you your best chance to grow and be really productive. There is no sense doing somebody else's job when by looking a little harder you can find your own.

Settling for any old job didn't work for Mike. He was miserable. He made the people he worked with miserable. He didn't last. Service providers decided he didn't really want to work and left him alone for a long time. The best thing about [Choice] is that a team of people who really know Mike and care about him got together to figure out the sign's of a job that would truly fit Mike. And, then [Mike's counselor] found the just right job for him.

—Mike's sister

Lezlie's microbusiness creates inspirational art.

The person-centered vocational planning process supported Lezlie and her parents to discern a way that she could serve her life's mission of Christian witness by partnering with her mother to produce artistic renderings of her favorite scripture verses and devotional readings. Lezlie selects and types the content of each piece and selects paper and clip art to complement the verse she has chosen.

Lezlie has extremely limited movement, and controlled movement is extremely tiring for her. Her mother assists her in using the computer and printer, and she hand colors and frames each piece. Lezlie's mother and father also deal with the physical process of marketing and order fulfillment.



Finding the balance between work and family

Working families will continue to pursue stability in the midst of dynamic changes in the economy and population. Three major challenges for the twenty-first century workplace and workforce will result:

- *The challenge of being skilled, not stuck in the new economy...*
- *The challenge of flexibility and family—as employers seek more flexibility to compete in the global marketplace and workers pursue more opportunities to spend time with their loved ones.*
- *The challenge of destiny and diversity...**

In common with the rest of the workforce, the people I interviewed thoughtfully seek a reasonable balance between making a living and dealing with the responsibilities of family life. For eight of the ten people I met, decisions about work are decisions about family life. Work and family life intertwine tightly for one or more reasons.

Family members partner in work. Two people count on their spouses and one person counts on her children and grandchildren for material help in making their living. One person works alongside his father in the family business and one self-employed person counts on her mother for assistance with all but one of the steps in producing and marketing her product.

Family members provide personal assistance and a place to live. Two people live with their parents and one lives with his sister. All three rely on family members to provide a significant amount of personal assistance. Each of these living arrangements reflect a mix of personal preference and the inability of the human service system to offer a viable alternative. Two other people live in their own apartments, but still count on family members for a good deal of day-to-day help to supplement the assistance they get from the human service system.

Family members make important decisions for five people for whom parents or siblings hold legal guardianship.

People with disabilities play important roles in their families and in their communities. Most people are not just sitting around passively; they have given their days structure and meaning outside the workforce. For many people with disabilities, the pattern of daily life, built around their exclusion from the workforce, defines an identity and opportunities to contribute to others that they and those who love them value.** Plans around work have to take careful account of these obligations.

**Futurework*, p. 3.

**To take a deeper look at this key factor in creating a more inclusive workforce from the perspective of a family all of whose members have disabilities, see Steven Taylor (2000). "You're not a retard, you're just wise" Disability, social identity, and family networks. *Journal of Contemporary Ethnography*, 29, 1:58-92.

Mike loves his job at Tube Art, a firm that makes back-lit signs and neon signs. He sands letters for the signs, but says most of his job is to “sweep, sweep, sweep”. The 49 men who are his co-workers “really make a big mess making signs.” Mike has worked three days a week for the past three years. His co-workers enjoy his company at work and at after work gatherings and parties. He says, “I like the work, I really like the guys, and I love getting paid!” He could work more, but he and his sister decided during the planning process that three days suits Mike best for two reasons: 1) it gives him time to do the housekeeping that his sister and her children rely on him for; and 2) it allows him to continue to participate on weekdays in a program operated by the Parks and Recreation Department for people with disabilities. He has attended for many years both as a participant and as a volunteer helper for several people with physical disabilities. This program is a major part of Mike’s Saturday’s and his summer vacations. They have reviewed this decision regularly and continue to think it represents the best balance for the whole household.

Dave is a caregiver for his grandmother, who needs personal assistance, in the morning and at bedtime. He also helps to look after his niece and nephew, making sure they get safely to and from school in their sometimes dangerous neighborhood. Because Dave could not decide what work hours would allow him to fulfill his responsibilities, he and his planning team identified what was important in a job for him and decided to locate two jobs, one during the day and one with evening hours. With support from his extended family to shift the times he was needed at home and think about his decision, Dave decided to take both part-time jobs, arranging his day and evening hours so he is home at times critical to the family. Dave has been successful at both jobs.*

Personal assistance paid for by Medicaid makes an important difference to people and their families. People have to take careful account of the impact work will have not just on their income from SSI or SSDI or their health care, but on the in-home assistance or residential program that makes their life manageable. For those people who live at home, decisions about income are in an important sense family decisions. The four people I talked to who know about the recent increase in the Substantial Gainful Activity (SGA) amount allowed by the Social Security Administration have adopted a cautious, wait and see attitude toward it because they do not completely trust a social security system with a history, as they see it, of reducing the number of disabled beneficiaries for political reasons.

*From a profile prepared by the project that assisted Dave.

Lezlie's parents provide most of her personal assistance and manage most of her personal and business affairs. Her father has retired and operates a successful consulting business that allows him plenty of time off for travel. She enjoys traveling with her parents and they very much enjoy having her along with them. This means that her business now gets somewhat less attention than it did in its first year of operation before her father's retirement. Her parents are also concerned to keep her income below the level that could threaten her eligibility for Medicaid. Her father says, "I advocated my heart out and we waited five years for her to get an HCB waiver slot that pays for some hours of in-home care. I don't want to do anything to jeopardize that. I know that the amount she can earn has gone up, but it remains to be seen how that will be interpreted in practice. I know too many horror stories about eligibility denials to take a risk."

Steve also limits his earnings. He says, "I have to keep in Medicaid or else my brother would have to pay for the people that help me out at my apartment. You can't let your money get too big or they'll snatch it away."

Sometimes rehabilitation system staff bundle all of these elements of balancing work and family life under the single heading of "family resistance." Sometimes staff un-helpfully construe the bundle they have made as over-protectiveness or greed for the person's SSI check.

People's incomes from SSI or SSDI often do make a difference to household budgets. People's family members often do have a heightened awareness of the person's vulnerability, especially when they begin to imagine the person moving from a familiar routine into a new world of work. People's family members do have their own ideas and priorities about what would be of greatest long term help. It is easy and dangerous for staff people to roll their eyes at what they label as family stubbornness or naivete or unwillingness

Family Concerns Confronted in the Choice Planning Process

- The person won't be safe at work or on the way to and from work.
- What will the person do when he or she is not working? Will the family have to fill in?
- What will the person do during the time it takes to develop a job? Will the family have to fill in?
- What will happen if the person gets laid off or fired? Will the family have to fill in?
- What effect will this have on the person's benefits? If we have been waiting for a Medicaid HCB Waiver funded residential service, will the person's working jeopardize their Medicaid eligibility? If the job has benefits, will the employer's insurer treat disability related medical needs as a pre-existing condition?
- You say that education and technology should be specific to a particular job. Doesn't that limit the person's skills and chain them to one specific job? Will there be money to invest in different skills if the job disappears or the person wants to move into a different line of work?

to do their part. Anyone who remembers the effects of having their own family's childcare or eldercare routine disrupted by the loss of a satisfactory arrangement can identify with these family concerns from a more productive angle.

Families differ in their boundaries. Sometimes a family's boundaries look too tight for the comfort of rehabilitation system staff. Sometimes a family's values don't seem to rehabilitation system staff to offer adequate support for individual freedom. One father I talked with wondered why some of the same people who were on a system mission to be culturally responsive to his family's race seemed to have trouble valuing his family's strong Christian commitment to a way of everyday life that keeps his family determinedly separate from the temptations of sex and drugs.

All of these complex issues form a part of the work of assembling a value constellation strong enough to support the work of moving real people with real families into the workforce. The art of supporting families, and individuals with disabilities as family members, to discover practical ways to think about and act on their concerns is fundamental to significantly increasing the proportion of severely disabled adults in the work force.

“To make real change in the world today, you have to start with the young child. If we want schools where kids really learn, schools that aren’t violent, schools that aren’t wrecked with drugs, then we all have a responsibility to make sure that no child falls through the cracks.

Day care has to become more and more important in the next five years. If we want to deal with illiteracy and school failure, day care can’t just be a holding tank. If single moms are going to be successful on their journey from welfare to work, they have to have affordable child care that they can really trust.”



Carol operates Hidden Rainbow Daycare.

After recovering from a car accident that left her near death, Carol decided that what mattered most was making a positive contribution to her community. With the support of her son, who “keeps remodeling and building new things for the kids” and her daughter “who takes care of all the book work” and her grandchildren, she provides affordable, inclusive child care. Her focus is on the single mothers in her community who are moving from welfare to work, and she sees her work as a support to whole families. “To help kids grow you have to build on their strengths. It’s the same with adults. Her concern to include children with severe disabilities and to better understand the school experience of all the children she looks after led her to a second job as a classroom aid in a nearby elementary school.

Difficulties with personal assistance

“ People with disabilities... often call for, but seldom receive, consumer driven personal assistance –that is the ability to manage, direct, and, in many cases, hire their own personal assistants...”

The five people who rely on the human services system for personal assistance are not among those who receive adequate, consumer driven personal assistance. Three people live with their families, one with a few daily hours of personal assistance. Two people live in their own apartments, one with twice daily come-in assistance and the other with come-in assistance three times a week and on call.

Available personal assistance alternatives do not offer the people who live with their families a reasonable alternative. “If not here, our family nightmare: a nursing home,” as one mother summarized her family’s situation. Even though the people who now live with their families would have good reason for doing so even if a viable alternative were available (and it is not), the question of who will be there to look out for the person when the family members who currently provide a home and most if not all personal assistance no longer can is a source of deep anxiety. This is so even when a plan is in place for the person to move in with another family member. As these people and their families look down, they do not see a welcoming safety net. They see a very long waiting list or the nightmare of institutionalization in a nursing home.

Many project participants who use some form of in-home or residential services find themselves in what one project coordinator described as “the 50-50 choice bind, which means that in one part of your life you are expected to exercise adult personal responsibility and be in control while in the rest of your life service providers expect you to act like a compliant and grateful child.”

Even when a person can establish their own home and exercise some control over hiring assistants, limitations in ways personal assistance is available to them can drag on their success at work.

Leigh achieved a big part of her dream when she moved into her own apartment. Arranging for sufficient personal assistance to assist her with the many daily tasks ruled out by her impaired movement, and satisfying her mother that she had the right schedule to keep her safe and well fed, took a lot of determined self-advocacy.

* *If not now, when*, p. 31.

The help she gets is funded in a way that ties her personal assistants to a round of prior approved routine tasks in her home. This does keep her safe and well fed, but it takes a lot of time and energy to hire and train new personal assistants as more experienced assistants move on, often to better paying jobs outside direct human services.

What her current personal assistance arrangements do not support, however, is another vital part of her dream. Leigh is an accomplished user of augmentive communication as well as an experienced and successful creator of her own household. Her business plan calls for her to provide services as a coach, consultant, trainer, and speaker on topics related to disability rights, moving into your own home, and skillfully using augmentive communication devices. She has been able to provide some of these services via e-mail through her paid participation in two projects experimenting with on-line support for people with disabilities and to coach another Choice project participant in increasing his fluency with his communication device. This small coaching contract stopped because his arrangements for transportation to Leigh's apartment fell apart. She has had an offer to provide paid training to the special education staff in a place nearby, but across the county line that defines the reach of the transit system she uses, "So it might as well be on the moon."

Leigh markets her services and sharpens her own skills by attending conferences, especially conferences with strong participation by self-advocates, and sometimes these conferences offer the chance of income.

Leigh's paid personal assistance system does not support her moving outside the house. "So lots of time getting to go someplace important means dialing 'm'-o-'m'."

Until there are profound changes in the way personal assistance is designed, funded, and delivered, * much of the time and imagination of the people who make up the value constellations assembled around people with significant disabilities will be spent working around the difficulties of another system dominated by low expectations and paternalistic attitudes.

*For resources on consumer-driven personal assistance, see the World Institute on Disabilities web site at www.wid.org

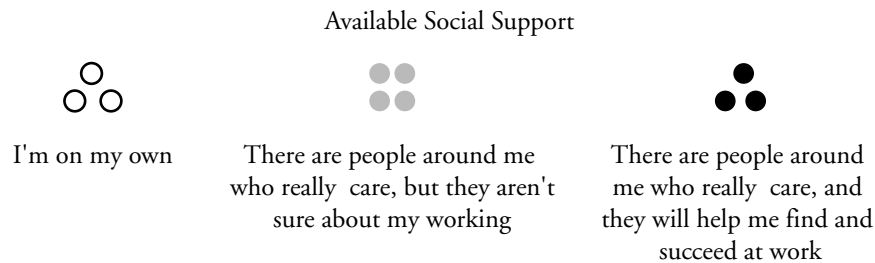
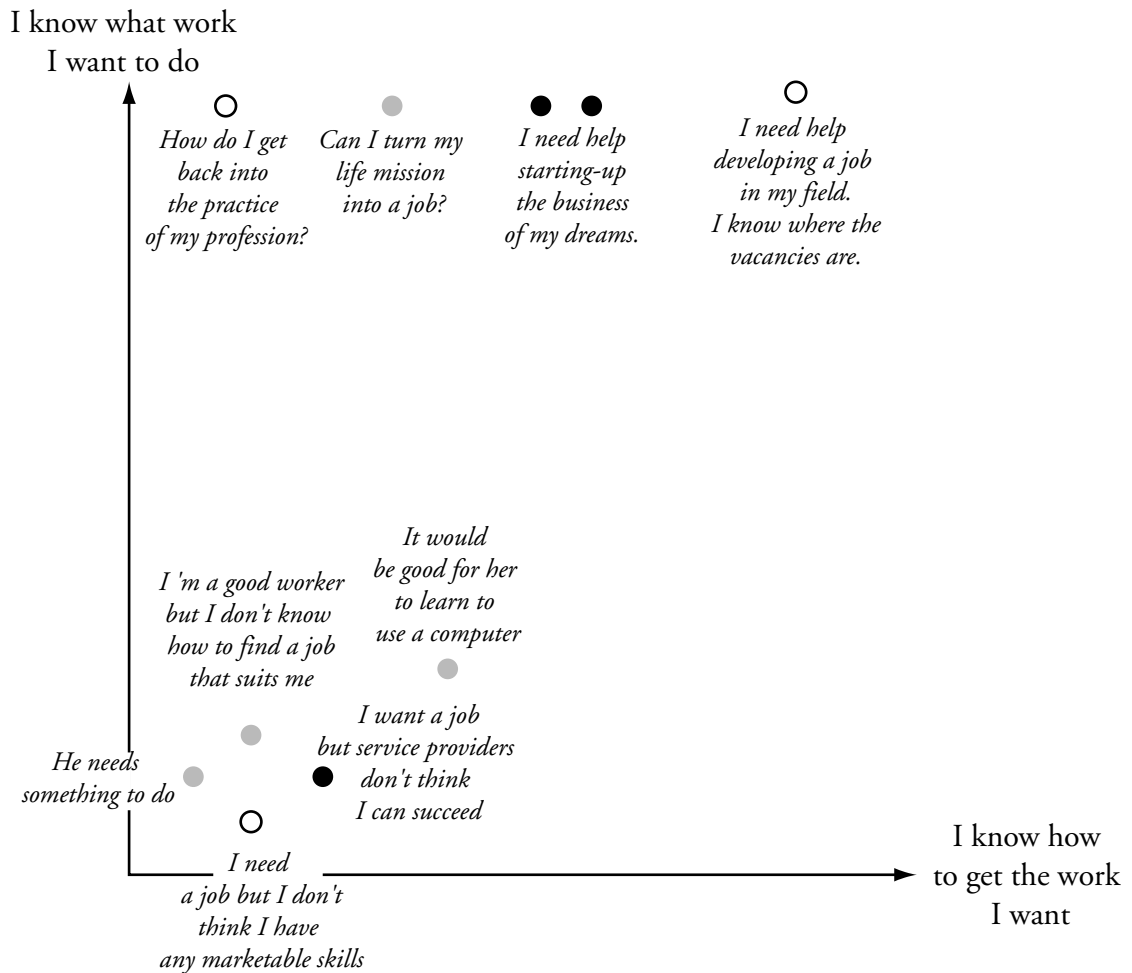
Many origins, many paths

To adapt to the demand to significantly reduce the proportion of working-aged adults with disabilities excluded from the workforce, the rehabilitation system needs to purposely discover a wider variety of ways to engage and support people.

These necessary system capacities are of three kinds. Some system capacities can be represented procedurally in such things as the policy for generating checks made out to a program participants. Some system capacities inhere in a growing network of relationships. As counselors help growing numbers of people with disabilities assemble the value constellations necessary to their move into the workforce, they can make more connections available in a first hand or second hand way. In this way a participant with a talent for building computer data bases turns up as a coach in another participant's value star. A guardian with experience of the journey to work can advise another parent with the questions and concerns that come at the beginning of the journey. Some system capacities are carried in the self-management repertoires of staff whose experience teaches them greater confidence and more effective ways to deal with their own fears of uncertainty and the stress they experience from working through the tangled and often emotionally charged problems that come up as people with disabilities move from exclusion into the work place.

At their best, the Choice Demonstration projects show some of the ways these capacities generate. Project staff generated system capacities by reaching out to people with disabilities who have been marginal to rehabilitation process and enlisting them as co-producers of broader capacity. By themselves choosing to adapt as far as possible to the differences the people they enrolled presented, staff put themselves and their system in a position to learn. Given the size and complexity of the systems involved, it is not surprising that the rate of learning for the people most involved was considerably higher than the rate of learning for the system as a whole.

The diagram below represents some important differences in the ways the ten people I interviewed remembered themselves when they joined the Choice Demonstration project.



As the positions of the dots relative to the coordinates suggest, half the people had a good idea of what they really wanted to do, though two of them waited until they trusted the project before being willing to move their idea from the category of “someday, maybe, in my dreams” to “why not work toward it now.” One of these five people knew where she wanted to work and what she wanted to do but felt unable to make contacts and negotiate for accommodations from an employer. One knew how to do the work that

would become her business and one knew exactly what steps she needed to take to complete her training, but neither of these people knew anything about starting-up or operating a business. One person knew exactly how she wanted to contribute, but was not sure what shape a job might take. One person had completed professional training but did not know how to go about getting re-engaged after five years away due to disability.

The other half of the group I met wanted work of some kind but needed help to discover both what job would suit them, and how to learn to do the job when they found it.

As the shading in the dots representing each person's position suggests, people also differed in the social support available to them and the degree to which the people who were their active supporters aligned with the goal of competitive employment for them. Three people reported feeling isolated and seven has strong support from family and sometimes from other allies. Of those with strong support, three had people who were already aligned with their working and four were unsure about the possibility for a number of different reasons.

Eight people were recipients of either SSI or SSDI. Four people had held jobs in competitive employment and two had held jobs in sheltered workshops. Three people had post-high school education and two had completed degrees.

Many origins and many destinations create the opportunity to build capacity by exploring many paths. The projects expanded their capacity to assist people into the workforce by learning from five kinds of situations that people brought to them: stretching the sense of feasibility, saying no to a project procedure; experiencing a setback that challenged one of the project's assumptions; discovering important resources among family members and other allies; and discovering the power of personal mission. Projects functioned within three sorts of boundaries: purpose, system policy, and project design and participants tested each of these boundaries in ways that made the project more adaptable to the variety of individual circumstances.

At each point the difficulties and anxieties of learning might have been avoided by simply declaring the journey over. The projects learned because excluding people was less acceptable to them than enduring the difficulty of change was.

Stretching the sense of feasibility. Purpose was not negotiable. Participants had to be interested in work and they had to be able to define a way in which VR services could help them attain that goal. With some people, the

project may have been willing to tolerate more uncertainty about whether a reasonable goal might emerge than the counselors might usually tolerate. Remembering one participant, a counselor said,

“I remember meeting her and hearing about the profound extent of her disability and thinking, ‘There is just no way under heaven that this person is going to be employed.’ I am thankful we kept going because I learned so much from being involved.”

Projects defined their task as changing system policy. They might fail to win a change that would benefit a participant, but in general they did not fail to try.

Adapting to participants’ saying “no”. Around project design, project staff faced tough choices and therefore good learning opportunities. Some examples:

- Three participants put a very high value on controlling the personal information available to the project. Each of the counselors involved remembers being concerned about the level of uncertainty this introduced. The issue became a point for negotiation with each participant, and in two instances the participant remembers this as their first signal that they could trust the project. These two participants negotiated a compromise that was not completely comfortable for either party: participants shared more disability related information than they had wanted to and counselors moved ahead with much less documentation of the extent of participant’s disabilities than they were used to having. The third participant was never willing to negotiate the issue of disclosure openly and he successfully attained his goal without project staff ever feeling he had been honest in his reports about his disability.
- One project put a high value on people assembling a team to help with planning and problem solving and to provide practical help and emotional support. When a participant objected and requested a waiver of this project requirement, the project coordinator was caught between two values. She knew that a team could make a substantial difference. And she knew that the participant touched a real contradiction by asking why, if the project was about individualization and choice, participants were all required to have a personal team whether they wanted one or not. In the event, the counselor chose flexibility over the project design and this went another step toward cementing a strong relationship which the participant was able to use as a source of guidance and coaching as she moved toward her goal.

- Dave* refused to participate in person-centered planning until the staff involved accommodated his preference as to the place, time, agenda, and procedure of the meeting. Graphic recording was unacceptable to him and he wanted to run the meeting himself. Making room for Dave took the person-centered planners on an uncertain journey. In this instance, it was a productive journey. Once he knew he could be in charge, Dave began to accept coaching about how to make his meetings work for everyone.

Projects learned when they had a clear design and the willingness to question and adapt their design in light of the “no’s” that participants brought them. The opportunities for learning were particularly fruitful when project staff experienced a dilemma and had the support they needed to work their way through it. Every adaptation brought its own potential problems along with a broader repertoire and a better understanding of what Choice implies.

Adapting to setbacks from outside. Setbacks that challenged the projects assumptions about how Choice would affect its environment stimulated a deeper understanding of the rehabilitation system and what it takes to change it. As noted above, the fact that service providers responded sluggishly to the opportunity to test their performance against the judgements of individual customers with money to spend opened a thread for discussion among project coordinators which continues to deepen until today.

Supporting the contribution of family and allies. Purposely seeking and supporting investment from people’s families and other allies disclosed an important resource. People with disabilities and their families can co-produce supports that service providers seem reluctant or unable to supply. Steven’s father and a trusted employee were able to assist him to achieve a level of performance that changed the way his family sees his potential and the way he sees himself.

Tapping the energy of personal mission. Five of the people I interviewed talked about—or seemed to people who know them and care about the to manifest—a sort of deep satisfaction with their work. This is different from the work-related satisfactions of making a profit or having a high status. Indeed, while I am sure that a number of self-employed Choice participants choose this path primarily as a way to make money, three of the four self-employed people I met seemed to rank making money below expressing a sense of personal mission. They fulfill this mission by offering a service for which they sense a coincidence of their talent and their community’s need. For two other people, satisfaction seemed to come from feeling themselves to be working in the right company: both Mike and Steve find relationships with their bosses and co-workers their greatest source of satisfaction at work.

* Drawn from a profile prepared by a project.

Project staff who experienced people finding this sense of fit learned to look and listen for the possibility among other people they met.

Many people I have listened to talk about their work feel a disconnection between their job and what matters deeply to them. Some people who work in rehabilitation even broadcast a sort of curse on people with disabilities, railing that it is naïve to expect work to be satisfying and telling people with disabilities that they should be grateful to have any sort of job at all. These disaffected workers might envy half the people I interviewed for the depth of their sense of connection between task and place and talent. Cynics could pounce on their small incomes and the insecurity and tentativeness of their enterprises, but I don't think this would dilute their sense of doing the right thing in the right place. The sense of envy at a well-fitting job might make an interesting metric against which to measure Choice, if someone could calibrate a meter to measure it. Perhaps further research on an envy indicator would be useful.

Choice as an emergent property of the rehabilitation system

There is a helpful, if abstract, way of understanding choice as an emergent property of the whole system rather than as a discrete policy or practice. That is to say, we can look at choice not as one more property that makes up the employment and workforce development system but as a quality that emerges from the way the parts of the system work together. Missing parts, not much choice. Poor relationships among the parts, not much choice. Strong forces pulling the parts this way and that, not much choice. Greater alignment and harmony among the parts, more choice. Thoughtful development of new parts, more choice.

To bring this idea a little closer to the planet's surface, and to summarize and finish this report, I take refuge in this story from my visits.

Carol, a Choice participant who lives in a small Eastern Vermont village, tells me a story she has repeated more than once about the founding of the daycare center that happens all around us as we talk and I try to resist the offer of a second fresh cinnamon roll so I can keep up with my notes. Like all good storytellers, she gives us an image through which to remember the story's lessons. The image is a concrete object in the playroom of the Hidden Rainbow Daycare. It is a sandtable in the big room behind Carol's kitchen at which, when I visited, two small boys were making roads for little cars whose occupants kept having loud and horrible accidents at the hands of imagined monsters and being rescued by even louder pretend superheroes. Carol says,

I had a car accident when I was 50. My husband was killed and the doctors said it was a miracle that I lived. They also said I would never walk, but I proved them wrong. Nearly dying was a reminder to me that I have to utilize whatever time I have to make this world a better place. I knew I wanted to get back to work. I was not given my life back just to let things lie. I have to do what's most important to me and not waste time or talent.

I hate waste in any form. Worst of all I hate the waste of people's lives. And for me, the most important thing for me to fight is the waste of children's lives and children's talents.

My first experience with rehabilitation didn't work out so well. They assessed me and the provider told me he had put it all together for me. He had set up for me to have a job in a nursing home, doing for old people. I said, "No!" Doing that would have been a waste of my talents. My gifts are with helping children grow up to look out for themselves

and each other. So I decided rehabilitation was a waste of my time.

I moved that sandtable the kids play with in the back room with me from place to place for all the years since my own kids were little. It was the key to what I really needed to do, make a living giving kids a good place to play and learn together, but it hadn't really come clear to me that I could really do it. And that first assessment just completely missed that sandtable. In all the questions they asked me, it just never came up at all.

Then the Choice project came along and I decided to give rehab another chance. The second time though the sandtable did come up. We talked about it quite a lot. I got encouragement and information and help to make what I knew needed to be to really happen. And there it sits today in the middle of a bunch of kids whose moms don't have to worry about their care while they go to work.

I understand this as a story about the way a system's capacity grew. It took a substantial growth in the system's capacity for the sandtable to come to be in its present position. The rehabilitation system had to reverse its bias against self-employment and its counselors had to develop good contacts among business consultants and micro-enterprise specialists so that they could broker necessary help in business planning and learn themselves how to form well reasoned opinions about people's business concepts and the business plans people used their money to buy help in preparing. The system had to find a way to make direct payments to participants so that they could leverage system dollars into a better credit rating, which meant developing new ways to think about and implement controls on expenditures and new ways to issue checks.

What is important is that Carol did not have to wait quietly until the system developed these new procedures and relationships. She and her commitment to her village's children were a part of the design of the system's changes, a part of the rationale for making the changes. And this is at least partly because Carol's counselor was able to be intrigued with the sandtable. He did not have a way of assessing her geared to the quickest possible closure. He was willing to drink coffee with her in her home, with her grandchildren running around. He was willing to puzzle with her over all those years of lugging the sandtable from place to place. He was willing to encourage her to take the practical steps to find out where that sandtable wanted to be and who needed to be playing around it and what it would take to make it part of a going concern. He was willing to acknowledge what he didn't know and to find people who knew it. He was willing to take personal responsibility for making room in

his system for what his system could not yet do. Or at least that's how I interpret Carol telling him,

You came and you kept coming back. You listened and you didn't run away from what you heard from me or let me run away from it. You did what you said you would do. You stuck with me through some difficult times and some hard meetings. You took me to talk to your bosses about what I wanted to do and what I was doing. You were glad about every step forward I took."

Carol's business has its vulnerabilities. She works a long day with beautiful kids, some of whom have more than their share of difficulties. She counts on many of their families to pitch in as they can, and some of the families she assists have more than their share of difficulties. She puts her commitment to keep her price at a point where families earning eight or ten dollars an hour won't end up paying a major chunk of their wages for childcare above growing her own business's cash reserves. But for now she is working hard not just at making a living but at making a difference to the children and mothers of her village.

I wonder if she, in the midst of the sometimes happy, sometimes angry, sometimes frightened noise of the children and mothers she serves, could be a kind of model to counselors and administrators in the rehabilitation system. She says,

I have heard some dreams and I have had to hear some terrible stories from the kid's parents. But I figure the least I can do when someone comes in is put on a pot of coffee and listen hard.

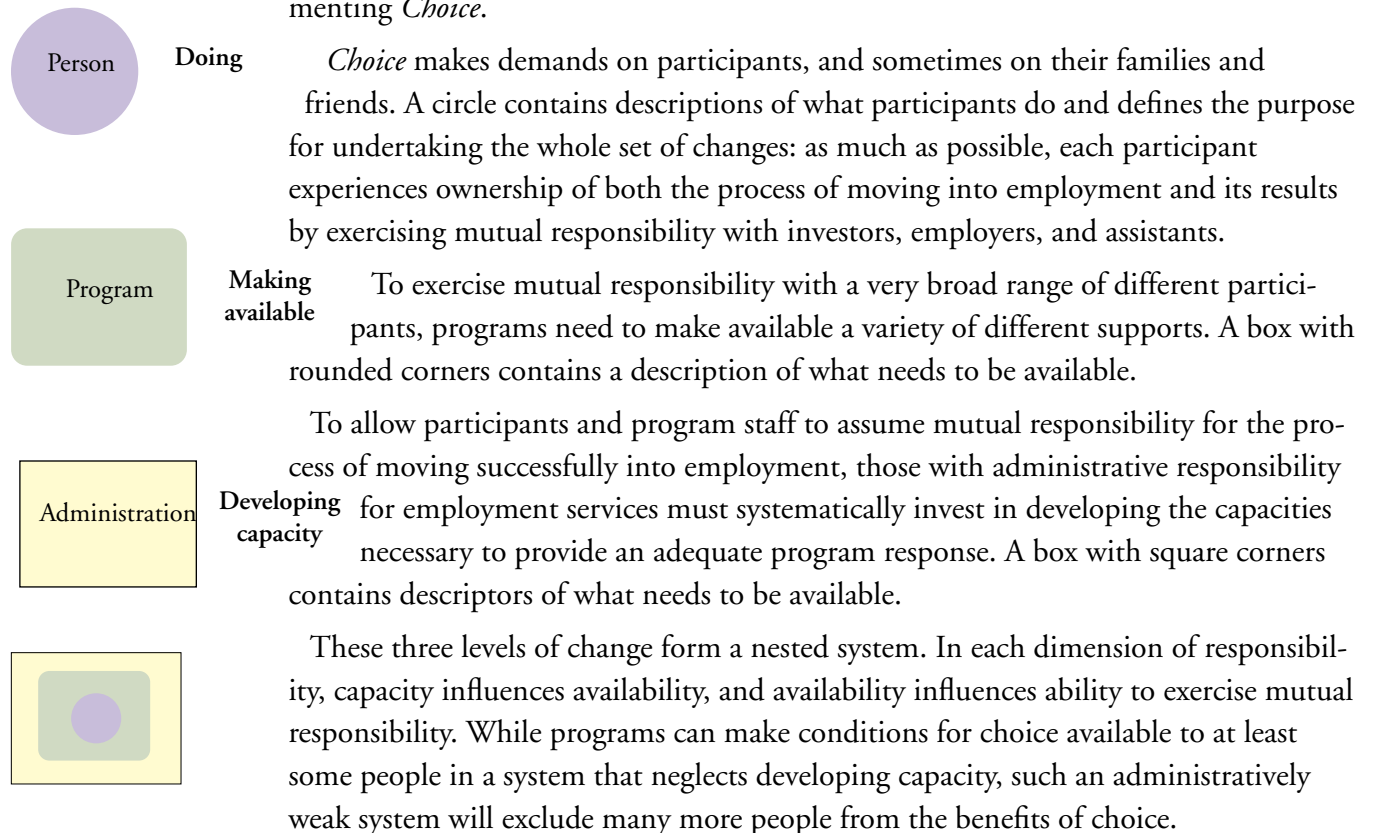
It takes some strength to be emotionally available to someone who decides on a new career at 50 plus after major trauma with no track record as a business person. It takes some imagination to look at the place where Carol lived and see a licensed day care center in an acceptable relationship with a banker. It takes some maturity to participate in moving the story of the sandtable along until that sandtable occupies its current place of honor in the playroom. This strength, imagination, and maturity must be prized and cultivated by any organization that is to have a hope of significantly increasing the proportion of working-age adults with disabilities who are at work, doing jobs that are satisfying to them.

Appendix A

*Choice: A Taxonomy of Responsibilities**

This taxonomy abstracts the conditions for offering people with severe disabilities the opportunity to experience a sense of ownership of the process and results of their involvement with services aimed at assisting them to employment.

The taxonomy reflects the learning of four of seven *Choice* projects funded by the US Rehabilitation Services Administration to demonstrate a variety of approaches to improving access to employment by increasing the choice available to participants. Within this focus, the four projects differed in sponsorship, design, and participant demographics. However, when project directors met to share the lessons from their work, substantial agreement emerged around the dimensions of change necessary to offer people a meaningful opportunity to direct their employment support services. This taxonomy expresses my understanding of this agreement in an orderly fashion that identifies the set of interrelated, multi-level responsibilities involved in implementing *Choice*.



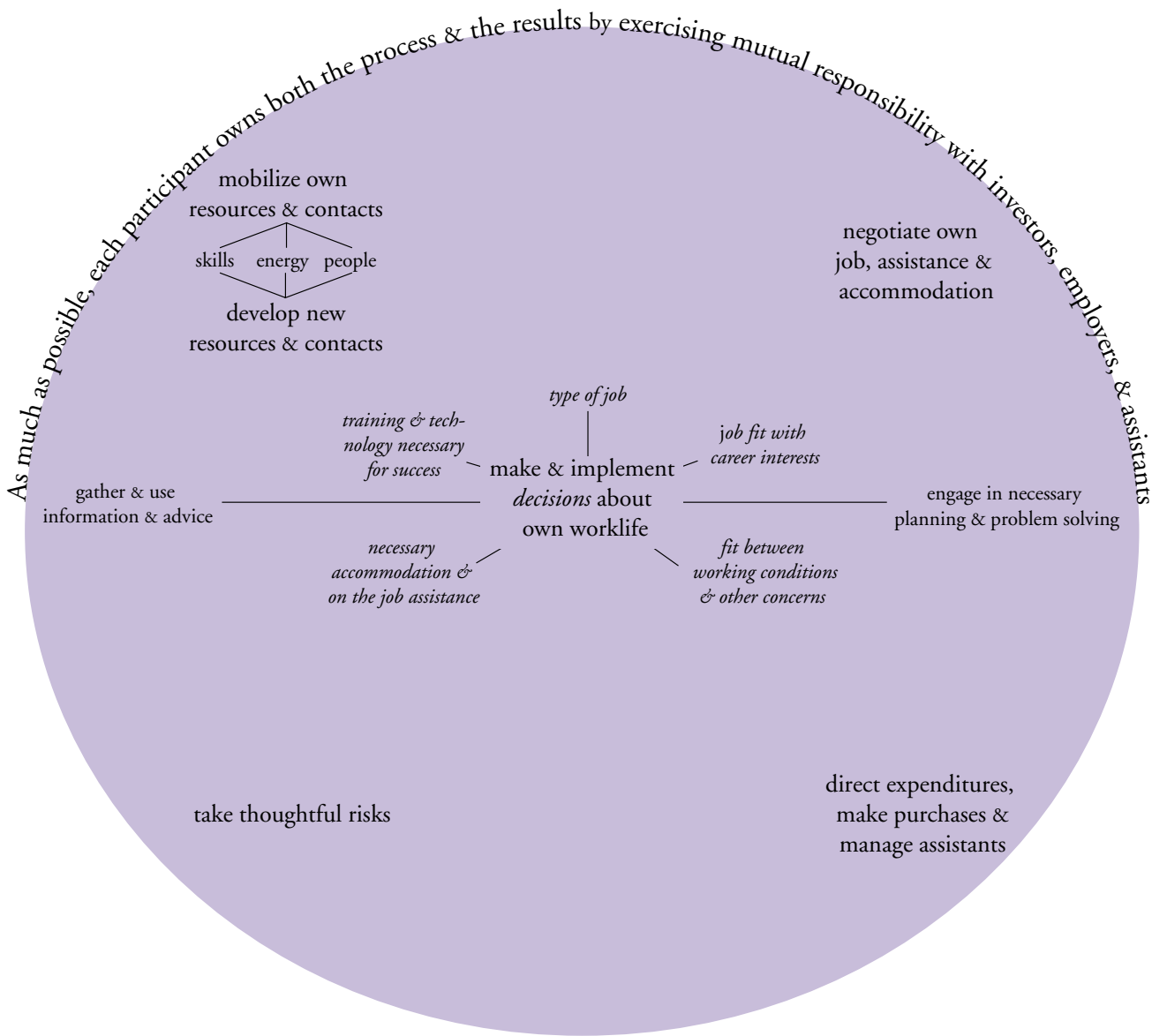
*I prepared this taxonomy is based on discussions at a think tank on “The Meaning of *Choice*” organized by Mark Gold & Associates for the Presidential Task Force on Employment of Adults with Disabilities. The group met in New Orleans, LA on 14-15 February 2000. Participants included Nancy Sullivan (Arkansas Commitment to Client Choice Project); Michael Callahan, Susan Linders, and Norciva Shumpert (UCPA Choice Access Project); Michael Collins (Vermont Consumer Choice Demonstration Project); Abby Cooper and Rosemary Gallagher (Washington State Participant Empowerment Project) and Christopher Button, Joe Skiba, and Suzanne Tillman. The taxonomy expresses a structure that emerged for me from reflecting on the group’s discussion: other participants may not necessarily see things the same way.

Choice engages and supports people with severe disabilities in exercising mutual responsibility for successfully defining, directing, and pursuing a search for employment that suits the person and makes a productive contribution. *Choice* participants accept as much personal responsibility as possible for five sorts of action.

Doing

- Making and implementing decisions about their own worklife, gathering and making use of information and advice and engaging as necessary in an organized planning and problem solving process. The informed decisions people or their substitute decision makers need to make include...
 - ... the type of job they want to do
 - ... the way they will discover the type of job they want to do if they do not know
 - ... the fit between the job they choose and pursuing or discovering their career interests
 - ... the training and technology necessary for their success on the job
 - ... the accommodations and on-the-job assistance necessary for their success
 - ... achieving an acceptable fit between working conditions and other concerns, such as the potential negative consequences earnings may have on benefits
- Mobilizing their own resources and contacts and actively working to develop new ones. Resources include...
 - ... skills necessary both for success on the job and for planning, problem solving, negotiating, and directing required assistance
 - ... energy necessary for effective performance, which is affected by personal habits and capacity to deal with difficulties and barriers
 - ... people who can provide help, ideas, contacts and leads, and encouragement
- Taking thoughtful risks in such matters as seeking a form of employment that fits high personal aspirations rather than settling for any available job or taking charge of defining and directing the process rather than being the object of other's efforts
- Actively directing expenditures, making purchases, and managing necessary assistance
- Playing a central role in negotiating their own job, the assistance they require from service providers to get and succeed at work, and the accommodations their employers or investors and their co-workers need to make

People with severe disabilities differ considerably in their ability to exercise these responsibilities without assistance and support. Some people arrive with a plan for themselves and some people require a great deal of assistance to discover their employment interests. Some people can negotiate confidently and others start out discouraged or without information or skills. Some people like managing an individual budget and others find it a major problem. *Choice* calls for a program that makes available the flexibility to respond to differences according to the principle that each person gets the help they need to decide and do what's necessary: not more, not less.



Program

Mutual responsibility means that people with severe disabilities join their contributions to the contributions of...

**Making
available**

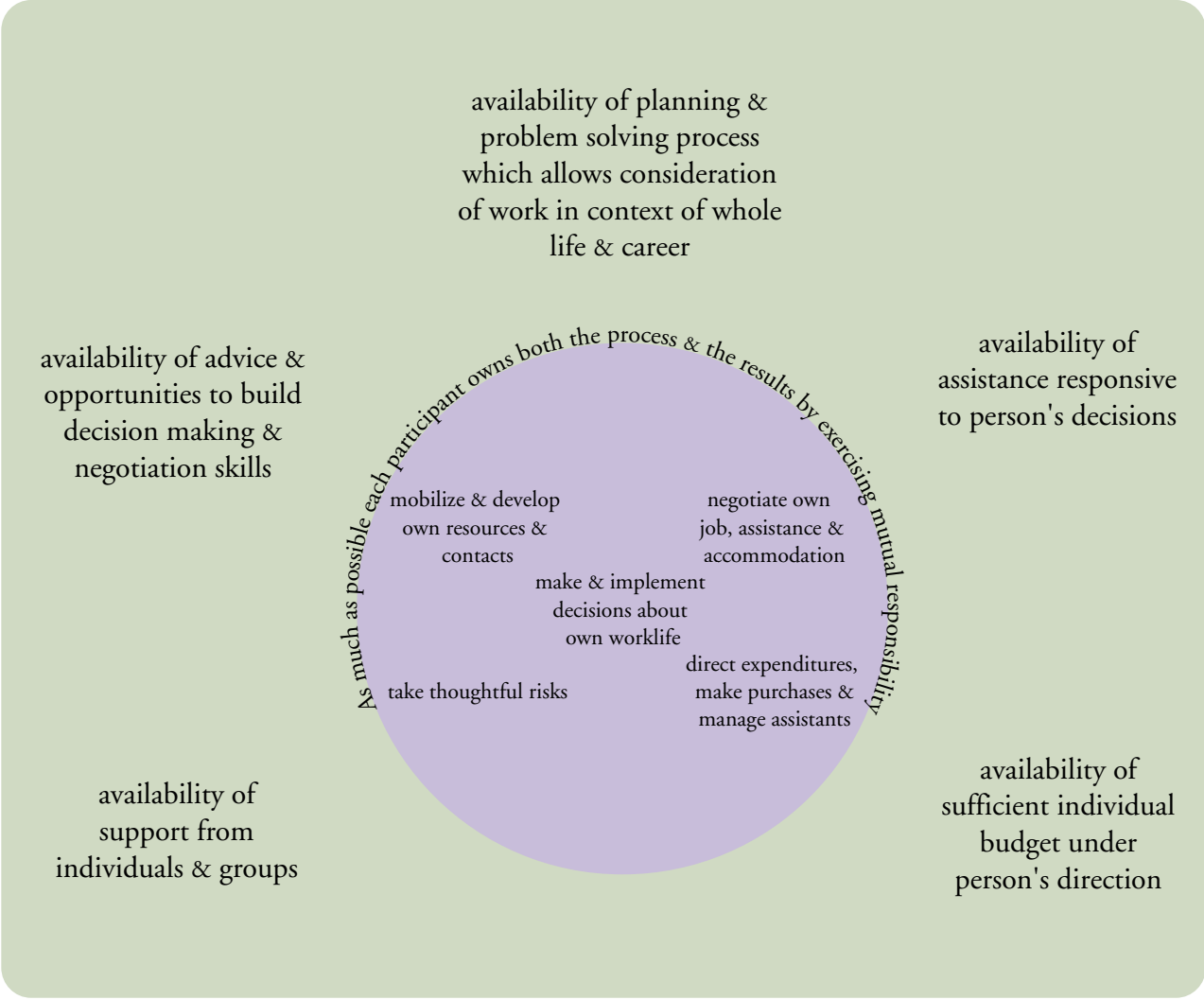
...investors: people who donate help, representatives of public agencies, banks and other financial investors if a person is self-employed

...employers and co-workers or suppliers and customers if a person is self-employed

...assistants: people and agencies who provide services, including both disability related assistance and employment related assistance

Programs function to make available a variety of ways to complement or supplement what people do themselves. A program can make its contribution available by brokering a connection with a provider outside the program or offer needed help directly. In either case, the program negotiates its approach with the person.

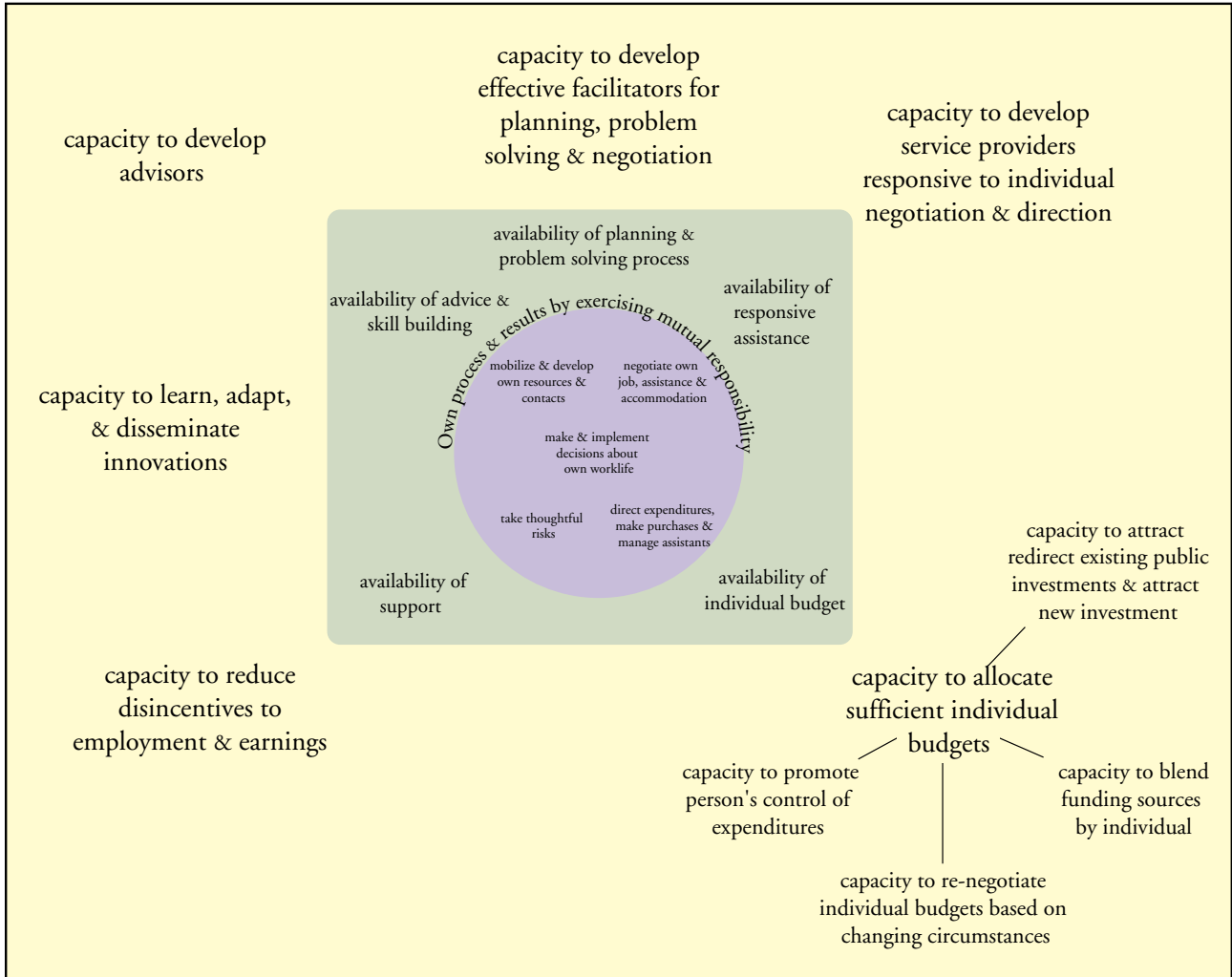
- To support decision making, programs make available planning and problem solving processes
- To support people in mobilizing and extending their resources, programs make available information in accessible formats and advice from people who combine knowledge and expertise with respect for the person's choice and responsibility
- To help people underwrite thoughtful risks, programs make available ways for people to organize supports and back-ups
- To support people in directing expenditures and managing assistance, programs make available alternative forms of money and personnel management and assistance, consultation, and training in managing money and people
- To support people in negotiating directly for assistance and job opportunities, programs make available a variety of leads, and training, consultation, and assistance.



Developing
capacity

To promote *Choice*, public administrators have responsibility for assuring sufficient capacity:

- To assure the availability of necessary planning and problem solving processes, administration creates the capacity to develop and support effective facilitators and teachers
- To assure the availability of advice and skill building, the administration creates the capacity to...
 - ...provide information in a variety of useful formats
 - ...design training formats and materials
 - ...offer opportunities for a variety of people, including people with disabilities and family members, to develop their ability to serve as advisors and organizers of support and skill building groups
- To assist in underwriting risks, administration increases the capacity to reduce disincentives to employment and earning through advocacy, support groups, and insurance and back-up strategies
- To assure the availability of individual budgets, administration develops capacity to flexibly allocate individual budgets sufficient to allow people to achieve their objectives by...
 - ...redirecting existing investments from services that do not support *Choice*
 - ...attracting new investments
 - ...increasing the extent to which individual budgets blend funds from different sources (e.g. Vocational Rehabilitation, Medicaid, Small Business Administration, Special Education)
 - ...actively promoting the individual control of expenditures through direct cash grants and vouchers
 - ...re-negotiating individual budgets based on changing circumstances
- To improve the supply of responsive assistants, administration develops capacity to increase the number of service providers willing to negotiate with individuals around the design and price of services and accept individual's role in managing and directing their work. This entails...
 - ... offering incentives for the re-design of existing service organizations in terms of *Choice*
 - ... lowering barriers to entry for new providers designed around *Choice*
 - ... offering assistance to service organizations that want to design or re-design around *Choice*
 - ... assuring that pre-service and in-service training supports values and practices consistent with *Choice*
- To guide the deep changes required by *Choice* requires that the whole system develop its capacity to learn from the experience of *Choice* participants, adapt to the opportunities and barriers emerging from rapidly changing work environments and a changing policy environment, and disseminate the effective practices that people and programs originate



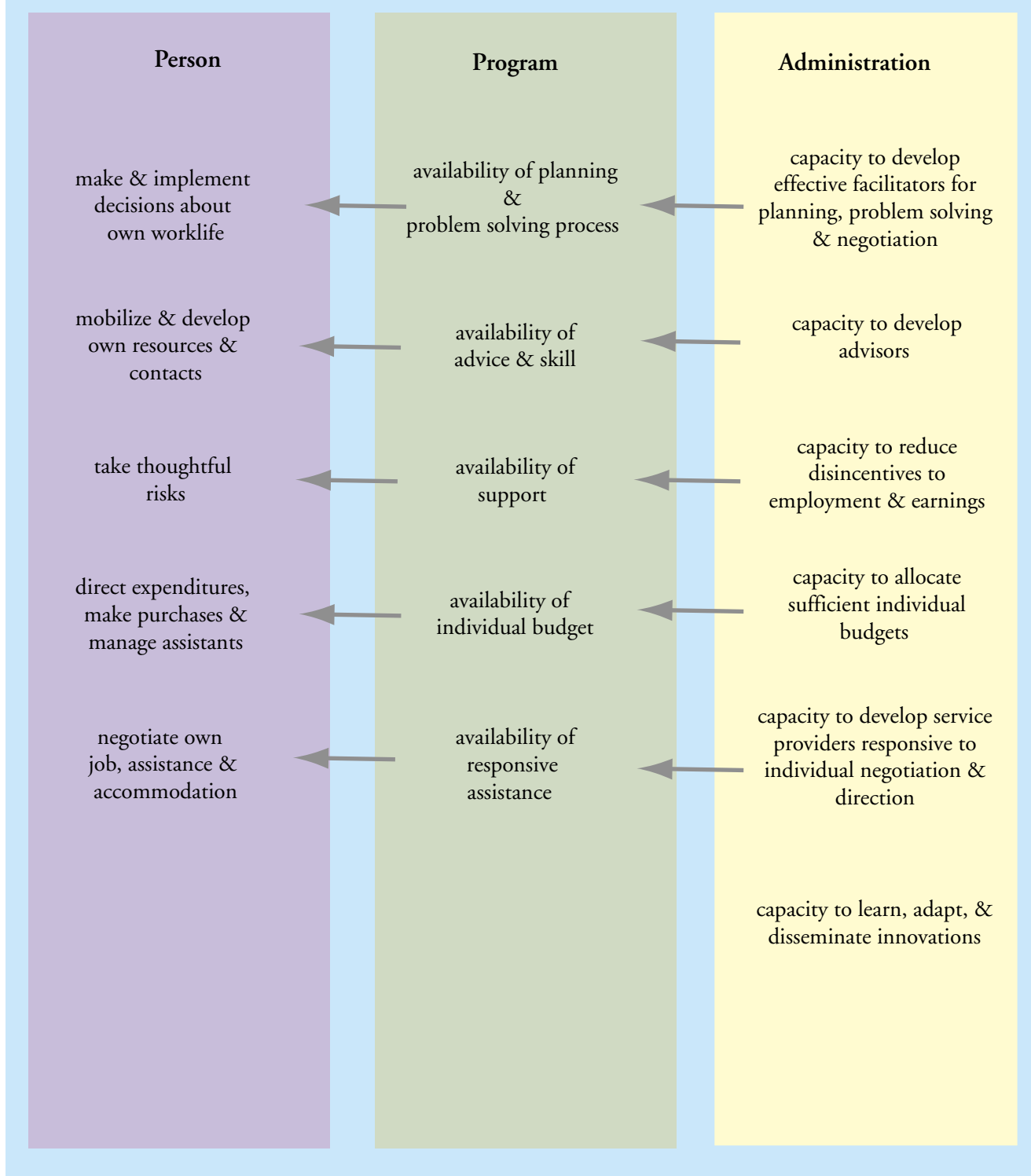


Choice functions as a system serving the purpose of continually increasing the number and variety of people with severe disabilities who own both the process and the results of their move into employment. Ownership implies more than satisfaction with a service consumed. Ownership means investing significantly in discovering and realizing both a job and the unique combination of accommodation, assistance, and personal support necessary to successful performance.

Poor alignment across the levels of the *Choice* system (represented by the columns on the facing diagram) limits both the extent to which people can achieve their purpose and the number of people who can achieve their purpose. Administrative weakness in developing the mechanisms through which people can easily direct expenditures detracts from the *Choice* system's ability to engage people in taking charge of the process. But even in the presence of such administrative flexibility, programmatic weakness in assisting people to work out the particular way in which they will exercise control will deprive people of the opportunity to own their worklife.

The rows on the facing diagram summarize the levels of the *Choice* system and depicts them in harmony. Poor alignment within or across levels compromises both the quality and the reach of the effort. A program attached to a particular planning technique will impose a drag on some people's efforts. A person unwilling to mobilize other people will have a thin network producing job leads and thus fewer options. An administration under-invested in developing more responsive service providers will frustrate the efforts of people who want to spend some of their budget on assistance.

The *Choice System*



Appendix B

Abstracts of the Four Choice Projects Reviewed for This Report

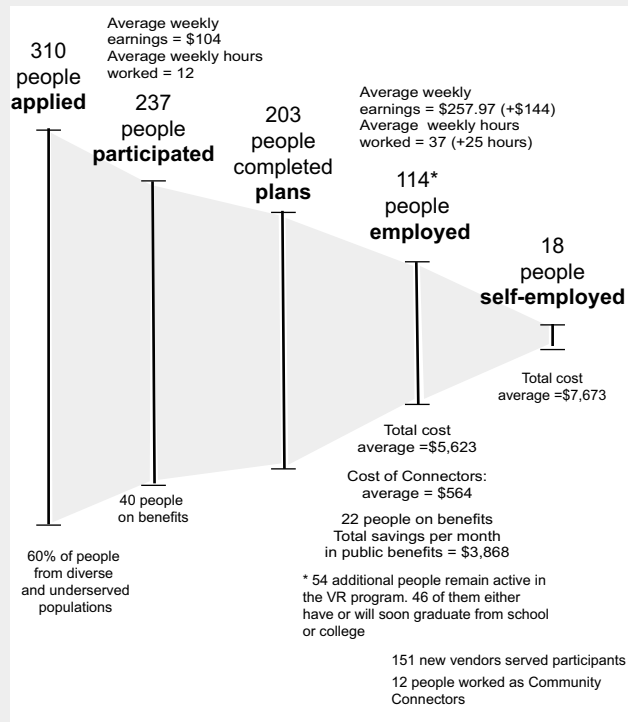
Commitment to Client Choice – Arkansas Rehabilitation Services

Goals

- Create an agency environment that supports choice
- Increase opportunities for informed choice in definition of vocational goals, selection of needed services, and service providers
- Expand positive employment outcomes for people with severe disabilities
- Increase cultural diversity of people with severe disabilities who have positive employment outcomes
- Support replication of policies and practices that support choice

Strategies Implemented

- Work in a rural culturally diverse part of the state where unemployment is high and services are not abundant
- People set direction through a person-centered career plan, created with the help of an experienced, independent facilitator
- People had the support of a Consumer Connector, chosen by the person, responsible to link the person with community resources and support people in making and implementing choices toward their career goals.
- People encouraged to attend Go for the Gold: Empowerment for Life, a 6 hour training course to develop attitudes and skills
- Increase individual control of vouchers for services
- Guide the project through feedback on consumer satisfaction



" For true choice to occur, individuals must be empowered. They must have control over resources and support in the development of creative career paths, innovative services, and atypical providers. Informed choice requires more than a few alternatives on a narrow menu and the menu must allow flexibility for the individual to design unique possibilities. Informed choice requires ample information about options including the chance to experience alternatives. It depends on a career planning process that is driven by individual's interests, skills, and desired future and through which trusted advice can be sought. Money must be flexible so that highly individualized options are readily available. Weight must be given to consumer satisfaction and direction in evaluating rehabilitation services. The list of lessons about choice goes on and on."

Source: *Final Performance Report and personal communication with Project Consultant*

UCPA Choice Access Project

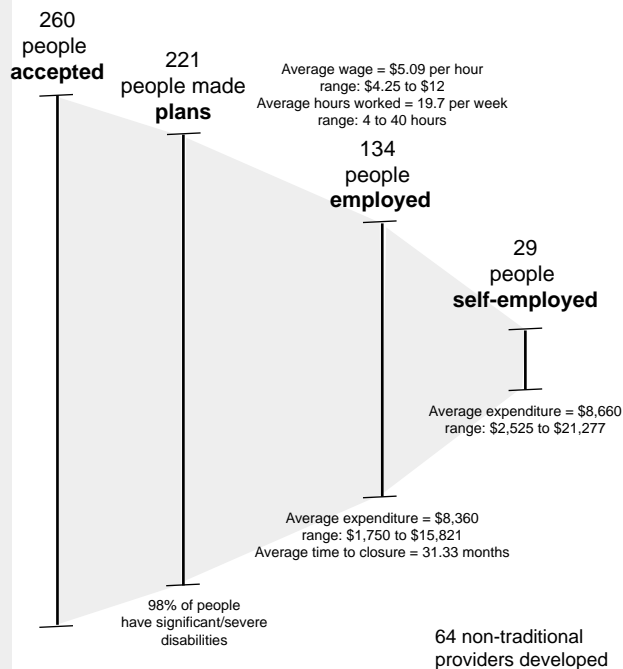
Goals

- Build on demonstrated effective approaches to facilitate implementation of individualized Choice Plans for people who experience severe physical disabilities which affect mobility and communication and manipulation.
- Identify individually desired employment outcomes and employment related services and supports using a validated Vocational Profile Process.
- Ensure customer selection, purchase of and access to desired employment related services and supports which result in meaningful, integrated employment for all participants.
- Evaluate outcomes, cost-effectiveness, feasibility and replicability of the customer choice process in terms of achievement of desired employment goals.
- Disseminate findings and practices in user-friendly ways

Approaches Implemented

- Focus on people with severe physical disabilities, for whom rehabilitation services have not typically been successful. Assume employability given an appropriate process. Follow an individualized discovery process; no tests or evaluations allowed.
- Project employs local Choice Coordinator for project activities such as supporting the local committee, recruiting participants, assisting in developing individual Futures Plans for Employment, developing local advisors and providers, and handling project paperwork.
- Each participant recruits an Employment Advisor, paid or volunteer, to assist in negotiating with service providers to achieve planned outcomes.
- Local Referral Committee, representing different stakeholders, selects participants, decides on individual budget exceptions, and assists in conflict resolution.
- Technical assistants from national project support local projects and offer regular training to qualify providers in using the project's process and to prepare Employment Advisors.
- Assign each participant a budget, held in individual accounts, with UCPA acting as fiscal agent.
- Think of participants as "customers with money to spend." Model project relationships on the relationship between a citizen and his or her attorney or architect. Providers work by contract for individual customers and are paid by customer authorization when they have delivered an agreed result to the customer's satisfaction. Pay for results at each step in the process and develop incentives to expedite the process.
- Follow a proven process, implementing a sequence of five Core Employment Services:
 1. Develop a Vocational Profile based on a person-centered process
 2. Link planning to job development through a Profile Planning Meeting
 3. Implement Individualized Job Development, targeting the exact type of job the customer wants
 4. Once a job is located conduct a Job/Technology Analysis of the specific job site and job duties.
 5. Develop and implement an Employer-Directed Support Plan which defines all the support needed to assist the customer to successfully do the job with the most possible support from their employer and co-workers.
- Develop new providers if existing providers are unwilling to implement an individualized process or accept the terms of customer control.

Projects implemented in three cities and, in addition in the final year, with 30 individuals in locations remote from project sites



"We have learned that virtually everyone is employable, given clear expectations, sufficient resources and quality supports... However, money alone is not enough to assist people who are truly significantly disabled to become employed. It also takes effective support strategies and a firm expectation of success."

Source: Project Final Report

Vermont Consumer Choice Demonstration Project

Goals

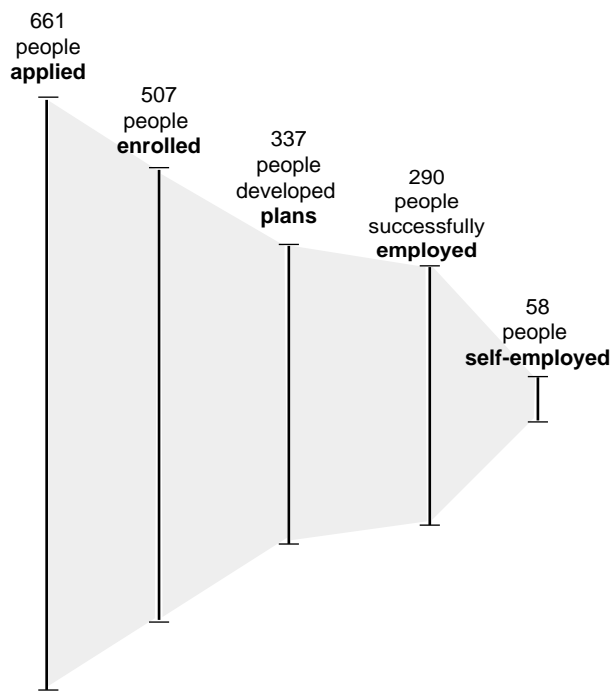
- Enhance the ability of DVR consumers to make decisions by teaching them relevant skills.
- Provide an approach that encourages personal responsibility within the rehabilitation process.
- Remove barriers within the DVR system which inhibit consumer choice and the timeliness of service delivery.

Basic Belief

An individual provided with sufficient information, resources and support will become better able to make informed decisions which will lead to the achievement of their vocational goals.

Position Assigned by DVR Management

The project is a "living laboratory" to discover and test ways to improve the whole system of service delivery.



"The mindset used to be 'we know best', but we are opening up to the possibilities and we hear from the consumer about possibilities. We help give the empowerment to figure out where they want to go. We used to think it was our job to find the resources. Now we realize it is our job to show the individual how to do it themselves."

– Counselor in regular VR program after Choice Project

Changes Implemented Throughout System

- Review DVR policies and procedures against this criterion: "Does this make it easier for the system or better for the consumer?" and discard or change rules that have no basis in expediting consumer services.
- Empower counselors to expedite eligibility determination, decide on "fast track" planning for people whose needs are specific and clear, authorize immediate direct cash payments to consumers.
- Increase availability of funds and authority to make decisions in local offices.
- Create a more consumer focused and welcoming environment.
- Shift the counselors role from a clinical to a primarily educational approach. Counselors use their judgment to assess skill levels and to develop individually relevant teaching strategies.
- Use independently collected consumer feedback as the primary basis for improving service delivery and as a major factor in evaluating program and staff performance.
- Expect consumers to use or develop their skills in selecting, negotiating for, and assessing the suitability of the services they need.
- Increase consumer responsibility, dignity, and privacy by providing consumers with cash to purchase services. Expect counselors to offer consumers support as necessary in taking responsibility for cash purchasing.
- In response to consumer interest, provide better supports for self-employment.
- Offer consumers the opportunity to learn and find support in group sessions that match consumers interests, skills, and needs for support.

Factors in changing the system

- Top management commitment and wide opportunities for participation: "We are definitely going in this direction but how we get there can be up to you."
- Positioning the Choice Project as a living laboratory within the system. Recruiting current counselors to work full time on the project, locating the project in local offices, looking to peers and managers for help in solving problems.
- Implementing a Division wide long range planning process involving staff from all levels and consumers and using the plan as a medium for assessing and incorporating learning from Choice.
- Investing in many training and sharing activities.

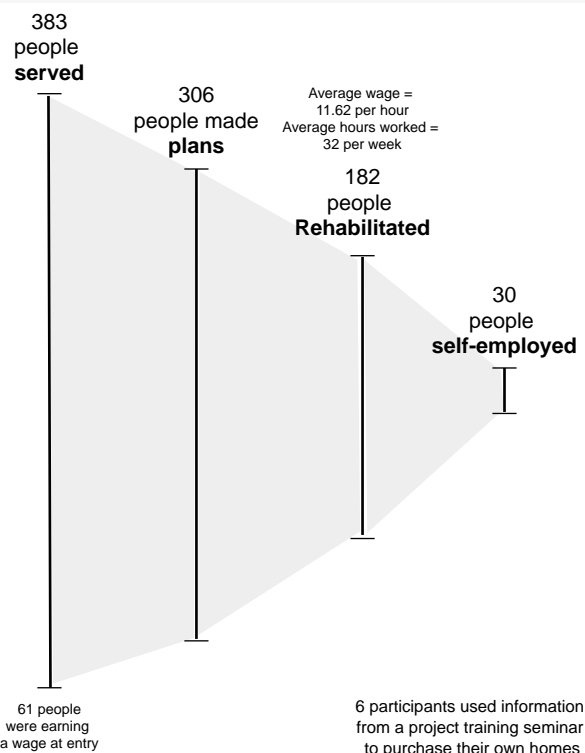
"Providing a sense of **ownership** has become the battle cry of the project. When an individual can pay for services themselves, it becomes their money, their responsibility... They become proud of their accomplishments because they did the locating, arranging, purchasing and decision making... [Consumers] can evaluate 'with their feet'."

Source: *Project Final Report*

Participant Empowerment Project – WA DVR

Assumptions

- Participants need to have real choices and be in control of decisions in all phases of their rehabilitation.
- Participants who receive information understandable to them make decisions that make sense in their lives. Participants and their significant others need accurate information in a format they understand.
- The rehabilitation process needs to be holistic.
- Participants need control over money.
- Participants will get the most from services if they have control over those services.
- The project needs freedom from the rules and norms of the current system. It needs to function



"The traditional rehabilitation system values a linear approach where the professional is expected to provide the solution... Implementing informed choice is complex and non-linear."

Approaches Implemented

- Value a developmental approach, expect learning and change, question, and adapt practice to fit individual requirements and preferences.
- Redefine the counselor's role from expert to advisor/mentor with responsibility for offering the balance of support each participant needs to be in control.
- Authorize counselors to enroll people immediately based on the information provided by participants.
- Invest counselor time in getting to know each participant in order to build a relationship and get to know how the participant processes information.
- Support participants to figure out the types and sources of information best for them and to analyze and apply the information they gather.
- Make peer support groups available as a source of support and information.
- Offer a wide variety of training seminars based on what current participants want to know and involve participants in presenting them.
- Assist each participant to develop a rehab team that includes people chosen by the participant. Provide a facilitator for team meetings so that the counselor can be a member. (A few participants choose not to have a rehab team.)
- Assist participants to develop a futures plan with the support of their rehab team. Develop several installments of the plan with timelines short enough to allow participants to make adjustments based on experience.
- Provide participants with individual budgets under their control with rehab team support. Give participants monthly expenditure reports and require participant authorization for all payments.
- Assist participants to select providers, negotiate how providers will assist them, hold providers accountable for performance, and deal with conflicts. Require providers to bill participants directly.
- Influence providers to accept direction from participants. If necessary, develop ways to do what providers are unwilling to do.

"...participants achieved outcomes at the same or better rate than the traditional [VR] program. Generally, participants did not ask for or spend more money than they needed to achieve their goals. When participants controlled the process and had ownership of their rehabilitation decisions, they were committed to their plan."

PEP Participants* (79)	State VR Participants* (79)
38 different job types	19 different job types
\$12.55 average wage	\$7.42 average wage
41 closed rehabilitated	23 closed rehabilitated
420 average days in service	401 average days in service
\$1,552 average overall cost	\$1,786 average overall cost

* Matched for location, age, disability, and ethnicity

Source: Project Final Report