Choice: A Taxonomy of Responsibilities

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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.

Choice makes demands on participants, and sometimes on their families and friends. A circle contains descriptors what participants need to do and defines the purpose for undertaking the whole set of changes: as much as possible, each participant experiences ownership of both the process of moving into employment and its results by exercising mutual responsibility with investors, employers, and assistants.

To exercise mutual responsibility with a very broad range of different participants, programs need to make available a variety of different supports. A box with rounded corners contains a description of what needs to be available.

To allow participants and program staff to assume mutual responsibility for the process of moving successfully into employment, those with administrative responsibility for employment services must systematically invest in developing the capacities necessary to provide an adequate program response. A box with square corners contains descriptors of what needs to be available.

These three levels of change form a nested system. In each dimension of responsibility, capacity influences availability, and availability influences ability to exercise mutual responsibility. While programs can make conditions for choice available to at least some people in a system that neglects developing capacity, such an administratively weak system will exclude many more people from the benefits of choice.

*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 Zanne 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.

- 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 accommodation’s 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.
As much as possible, each participant owns both the process & the results by exercising mutual responsibility with investors, employers, & assistants. They take thoughtful risks, directly expend, make purchases, & manage assistants. They gather & use information & advice. They negotiate own job, assistance & accommodation. They mobilize own resources & contacts. They develop new skills, energy, people, & contacts. They engage in necessary planning & problem solving. They fit between working conditions & other concerns. They make & implement decisions about job fit with career interests & type of job. They make & implement decisions about necessary accommodation & on the job assistance. They gather & use information & advice.
Mutual responsibility means that people with severe disabilities join their contributions to the contributions of…

…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.
As much as possible each participant owns both the process & the results by exercising mutual responsibility, take thoughtful risks:

- Direct expenditures, make purchases & manage assistants
- Negotiate own job, assistance & accommodation
- Mobilize & develop own resources & contacts
- Make & implement decisions about own worklife, direct expenditures, make purchases & manage assistance
- Problem solving process, which allows consideration of work in context of whole life & career
- Availability of advice & decision making & negotiation skills
- Availability of sufficient individual budget under person's direction
- Availability of support from individuals & groups
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.
capacity to develop effective facilitators for planning, problem solving & negotiation

- availability of planning & problem solving process
- ability to negotiate own job, assistance & accommodation
- make & implement decisions about own worklife
- ability to manage direct expenditures, make purchases & manage assistants
- availability of individual budget
- ability to mobilize & develop own resources & contacts
- take thoughtful risks
- availability of responsive assistance
- availability of advice & skill building

capacity to develop service providers responsive to individual negotiation & direction

- capacity to attract, redirect existing public investments & attract new investment
- capacity to promote person’s control of expenditures
- capacity to allocate sufficient individual budgets
- capacity to blend funding sources by individual
- capacity to re-negotiate individual budgets based on changing circumstances
- capacity to learn, adapt, & disseminate innovations
- capacity to reduce disincentives to employment & earnings
- capacity to develop advisors
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 change 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.

Poor alignment within a level of the Choice system (represented by the rows on the facing diagram) 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**

**Person**
- make & implement decisions about own worklife
- mobilize & develop own resources & contacts
- take thoughtful risks
- direct expenditures, make purchases & manage assistants
- negotiate own job, assistance & accommodation

**Program**
- availability of planning & problem solving process
- availability of advice & skill
- availability of support
- availability of individual budget
- availability of responsive assistance

**Administration**
- capacity to develop effective facilitators for planning, problem solving & negotiation
- capacity to develop advisors
- capacity to reduce disincentives to employment & earnings
- capacity to allocate sufficient individual budgets
- capacity to develop service providers responsive to individual negotiation & direction
- capacity to learn, adapt, & disseminate innovations

*Choice Taxonomy* 9