

*The Journey to Self-Determination and Choice*

*A Brief History of Individualization*

*By*

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**Introduction**

The new century is bringing changes to both the generic workplace and to employment services for persons with disabilities. As the new decade unfolds, there is a confluence of the issues that affect the average worker in our country and also the non-traditional, aspiring worker with a significant disability. Within a week of being appointed as the Secretary of the U.S. Department of Labor, Elaine Chao characterized the changing face of the workforce in the United States:

“In one sense, the new economy is "deconstructing" work, with jobs that can't be pigeonholed into a traditional workday or workweek, and corporate structures that, in some cases, are eliminating the need for a workplace altogether. Workers themselves are demanding more autonomy, more freedom, more customization of the terms and conditions of their employment. As we invest in critical job training, we are giving workers the bargaining power they need to custom-design their jobs around their lives - - instead of the other way around." Secretary of Labor Elaine Chao January 24, 2001, Senate Health, Education, Labor and Pensions Committee

In her remarks, Ms. Chao not only articulated that employment is becoming more individualized and directed in terms of the everyday worker in our society, she also described the important changes that need to occur in the disability field. The issues of autonomy (self-determination), freedom (choice) and customization (individualized jobs) are consistent with emerging concepts in the disability field.

**From Individualization to Self-Determination**

The Rehabilitation Act of 1973 undoubtedly set the trend line towards a future in which services for persons with disabilities would be considered from an individualized perspective rather than from a group or macro point of view. This Act was the first in what has become a lineage of legislation that mandates an “I” in front of every “P”, every outcome, every programmatic response. By taking the bold step to require Individualized

Written Rehabilitation Plans (IWRP's), Congress recast the manner in which employment and, eventually, all disability-related services must be provided.

Next in line to feel the impact of individualization was education. When Congress passed the Education of All Handicapped Children Act of 1975 (P.L. 94-142), it mandated that education plans (IEP's) be individualized to meet the unique needs of each student. In addition to assuring that schools must be open to *all* students, this Act directed educator to individualize education outcomes and processes rather than merely provide single-size curriculum outcomes and planning.

The idea of individualized planning quickly spread to the broader disability field in the late 1970's and early 1980's. Georgia based advocates John O'Brien, Beth Mount and Connie Lyle suggested that in order to achieve true individualization, planning processes had to place the participant at the center of the planning process. Additionally, they suggested that the locus of power and decision-making shift from professionals to individuals and their families. Person-centered planning provided the foundation for the inevitable push towards individual control of resources.

In the late 80's, Congress added Part "H" to the Medicaid Act. This legislation targeted services for infants and toddlers with disabilities and their families. For years families had been asking that services for their children be available in an individualized manner, in their homes, instead of programmatically in centers or clinics. Many states implemented Part H services by allowing families to control the public funds once available only to agencies and other professional providers. Based on needs identified within a person-centered plan, families were able to access funding in an individualized manner. The experiences of these early efforts in individual control of resources

provided the foundation of what is now called the self-determination and choice movement within broader services for adults.

In 1992 Congress took the Rehab Act to a new level of individualization when it added the dimension of customer choice to the Act. The amended Act required counselors to offer users of rehab services choice in the “specific services [they needed] as well as choice in the provider of those services.” Clearly this requirement represented a significant shift towards a new definition of individualization. In addition to requiring counselors to use the participant as the starting point for employment, the changes in the 1992 Rehabilitation Act began to place real prerogative in the hands of the customer. Congress also adopted an amendment to the Act that required a major demonstration to explore customer choice in the area of employment.

During the ‘90’s the disability field also saw the rise of self-determination for adults with developmental disabilities in the areas of housing and non-employment, community services. The Robert Wood Johnson Foundation underwrote a major national initiative called Home of Your Own (HOYO). The demonstration broke new ground in the area of home ownership for persons with significant disabilities. The ownership of one’s home, including having the mortgage in one’s name, is perhaps the ultimate extension of self-determination in the area of housing. At the same time it funded HOYO, the Robert Wood Johnson Foundation also funded a national demonstration on self-determination for persons with developmental disabilities. This initiative was directed primarily towards securing individually-determined outcomes in the area of community living and participation using a personal budget strategy.

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The strategies associated with choice – vouchers, personal budgets, and participant control of resources – continued to grow across the employment field throughout the ‘90’s. In 1998, when Congress once again re-authorized the Rehab Act, it not only strengthened the choice requirements of the Act, it also built choice into the Workforce Investment Act of 1998 (WIA) through Individualized Training Accounts (ITA’s). ITA’s were designed to offer individuals interested in specific employment training increased choice through the use of an authorization that could be used with any of a variety of approved local providers. This approach differs from the traditional strategy that required individuals to use the specific provider(s) identified by the system.

### - From Individualization to Choice -

<b>Timelines</b>	<b>Catalysts</b>	<b>Changes in the Disability Field</b>
1973	The Rehabilitation Act	Individualized Written Rehab Plans
1975	PL 94-142	Individualized Education Plans
1970’s – 1980’s	Congregate programming	Person-centered Planning
1980’s (late)	Part H of Medicaid Act	Family control of resources
1992	Rehab Act of 1992	Informed choice
1993	RSA Choice Demonstration	Choice, vouchers, personal budgets
1994	Robert Wood Johnson Fd.	Home of Your Own
1994	Robert Wood Johnson Fd.	National Self-determination project
1998	Workforce Investment Act	Individual Training Accts., Choice

**Differences between Individualized/Self-Determined Services and Traditional Services**

<b>Traditional Services</b>	<b>Individualized Services</b>
1. Traditional assessment and evaluation methods typically highlight deficits.	1. Plans for services will be based primarily on non-competitive discovery methods that focus on strengths and interests.
2. Programs typically offer a set menu of services.	2. Outcomes for participants will be based on a person-centered planning process that creates clear blueprints for individualized services.
3. Families are asked to merely approve and support professional decisions.	3. Families and non-paid supporters will be welcomed into the employment process and will be expected to actively participate.
4. Professionals are the primary source of advice and information to participants.	4. Participants will have access to advice and information from outside the funding and service system such as from friends, family, advocates and other such sources.
5. Services are provided by disability specific providers.	5. Participants will have access to other more generic services, such as the One Stop Career Centers in addition to the typical, disability specific services.
6. Participants are often forced to rely on one provider of service regardless of their expertise in employment outcomes	6. Participants may select multiple providers to accomplish various employment outcomes, however, only one provider per discrete service.
7. Participants are assigned to providers for their general employment services	7. Participants will interview, choose, contract with and approve payment to service providers for distinct outcomes delivered

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| 8. Funds are obligated, transferred and managed from the system to providers with no input by the participant   | 8. Available funds will be blended at an individual level using a participant's personal budget based on the employment plan.   |
| 9. Funding limits and rates are pre-determined in negotiation with providers and funds are made available to the provider without input or say-so by the participant. | 9. Funding rates and limits will be based on individualized need as identified in the employment plan and final approval will result in negotiation between the participant and funding sources with input by the provider. |
| 10. Participants must conform to arbitrary, systemic indicators of quality  | 10. Participants will determine relevance of the outcomes received  |
| 11. Job site supports are determined solely by the provider   | 11. Job site supports determined by employers, employees and the participant.   |
| 12. Participants are limited to employer-based options.   | 12. Participants may pursue self employment as an employment outcome.   |