

Twenty years of employment for persons with significant disabilities: A retrospective

Michael Callahan^{a,*}, Cary Griffin^b and Dave Hammis^b

^a*Marc Gold and Associates, Gautier, MS, USA*

^b*Griffin-Hammis Associates, Florence, MT, USA*

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Abstract. This article provides a retrospective of twenty years of employment for persons with significant disabilities detailing trends, short-comings and promising practices. The article coincides with the 20th anniversary of the *Journal of Vocational Rehabilitation*.

Keywords: Customized employment, supported employment, disability employment, employment first, rehabilitation, natural work supports

1. Introduction

In 2011 the *Journal of Vocational Rehabilitation* marked its twentieth anniversary. A good number of readers of the journal undoubtedly remember the first edition in 1991. It is interesting to reflect on how we thought the field of employment for persons with disabilities would change over twenty years. Certainly optimism was high, and for good reason. In 1990, President Bush signed the Americans with Disabilities Act in a memorable Rose Garden ceremony with hundreds of persons with disabilities in attendance, including Justin Dart. It was hoped that this new legislation would throw open the doors of the American workplace, that had been previously been shut, for job seekers with disabilities. For those working with individuals with more significant disabilities, 1991 marked five years of supported employment in federal statute, Congress added supported employment to the 1986 amendments to the Rehabilitation Act of 1973. In the five years leading up to 1991 tens of thousands of individuals previously thought to be not feasible for competitive employment

had entered the workforce. In the ensuing years following 1986, the federal government invested millions of dollars in changing traditional state systems to fund and embrace supported employment. The concept of natural supports had hit the field in 1988, extending access to needed supports beyond those available by a paid job coach. By 1991 previously un-served and underserved groups of people began to be granted access to supported employment services. Job carving was seen as a strategy to get beyond the demands of job descriptions that might be out of reach for some job seekers. Yes, there was, indeed, reason for optimism.

Beyond the optimistic indicators that had already occurred by 1991, the field of employment services for persons with disabilities was on the cusp of new and exciting changes just over the horizon. In 1992, Congress re-authorized the Rehab Act once again and made sweeping additions to the statute. Due to the impact of supported employment which proved that individuals once thought to be not feasible for employment could work, Congress directed VR counselors to generally consider that an eligible individual (any individual with a disability) should be considered as feasible regarding their ability to benefit in terms of a rehabilitation outcome [6]. This replaced the old “feasibility determination” that required counselors to assess

*Address for correspondence: Michael Callahan, Marc Gold and Associates, 4101 Gautier Vancleave Rd, Ste 102, Gautier, MS 39553-5152, USA. E-mail: MICALLAHAN@aol.com.

for one's feasibility for employment before offering services. Congress also added the concept of natural supports as source of on-going supports and required significant improvement in choice in the rehabilitation process for users of the system.

2. Decline in employment

It would be sensible to assume that the result of all this positive information unfolding over the next twenty years would be a time of continued growth of employment for persons with disabilities as well as a time of continuing innovation. However the reality was somewhat less than the anticipation. By mid-decade leaders in supported employment from each coast were sounding warnings of concern. Wehman and Kregel [19] and Mank [13] cited factors that might combine, unless clearly addressed, to cause a slowing of the growth and quality of supported employment services. Among factors referenced by these leaders were an underestimation of the strength of the traditional service system, limited incentives for agencies and systems to change, a leveling off of growth in the numbers of persons in supported employment, the attitudes of employers and conflicting policies and values within the systems associated with employment of persons with disabilities.

Indeed, the decline did occur over the next fifteen years. While the total numbers of individual with significant disabilities has remained somewhat consistent over the past ten to fifteen years, the percentage of people achieving an integrated employment outcome has gone down [1]. What is the cause of this stagnation after such a hopeful starting point that we enjoyed twenty years ago? Certainly there is no single answer. Indeed many of the concerns voiced by Wehman, Kregel and Mank in the mid-1990's came to be actual barriers over the years – decreased investment, lack of conversion of current services to integrated employment, little control by people with disabilities, an over-reliance on social systems for services, lack of incentives for services to change and a lack of service delivery strategies. To make matters worse, the needed financial boost to be provided by the anticipated conversion of funds from facilities to community employment did not happen.

In addition to these factors, it could be said that supported employment was a victim of its own success. As service agencies and funders scrambled to meet the early pent-up demand of supported employment in the early years between 1985 and 1995, many of the individuals who were more easily competitive in relation

to employer demands were likely employed first. Certainly the anecdotal evidence agrees with that outcome. By 1995, agencies and systems began to recognize that the individuals available for supported employment, particularly in services for persons with intellectual and developmental disabilities, were not nearly as competitive as those who came earlier.

During the 1990s the disability field saw an increase in a number of innovations that would impact the employment rate of individuals in supported employment. Consumer choice and self-determination received national attention starting in 1993 and continuing throughout the remainder of the decade. Professionals and parents supporting school inclusion for students with disabilities saw a conflict with the use of community work experiences during school hours. States began the overhaul to refinance services for persons with intellectual and developmental disabilities with federal Medicaid funding which favored services that were not employment focused. These factors created a perfect storm of slotting the individuals who might have been referred to supported employment services to other, alternative services such as *integrated community services, day programs without walls* or other substitutions for community, integrated employment. Early "leader" states in supported employment such as Connecticut, Wisconsin and Colorado experienced a shift away from employment to alternative services. And the decline was not just felt in the area of supported employment. The Presidential Task Force on Employment of Adults with Disabilities was empanelled by President Clinton in 1998 to discover the reasons for the general decline in employment for all persons with disabilities in an economic time of unprecedented job growth [5].

3. Hopeful trends and promising practices

Fortunately, the malaise of the late 1990s has given way to a decade of innovation and hopefulness. Although we might not be exactly at the place many thought we would be twenty years ago, the opening decade of the new millennium has provided a number of trends that bring optimism back into the employment field for persons with significant disabilities. Among these trends are:

- The Washington Working Age Adult Policy
- The concept of Employment First
- Customized wage employment

- Discovery as an alternative to traditional assessment
- Natural supports as a cultural concept of business
- Economic development as an approach to employers
- Job development focus on small business
- Social capital and parallel systems
- Stabilizing large scale social support systems

3.1. *The Washington state working age adult policy*

Perhaps the most sweeping initiative of the past twenty years emerged from Washington State. The Working Age Adult Policy represented a first of its kind stance for the nation when, in 2004, it stated that “supports to pursue and maintain gainful employment in integrated settings in the community shall be the primary service option for working age adults”. This innovation has proven to be a game changer for the field of disability employment. Embedded in the policy are a number of features that help to define the outcomes of any funding adult service [17].

Access to employment supports

Progress towards gainful employment

Work in Integrated settings

Targeting a “living wage”

Maintenance of gainful employment

Active pursuit of gainful employment

Resulting in supported employment (defined as: paid, competitive employment for people who have severe disabilities and a demonstrated inability to gain and maintain traditional employment. Supported employment occurs in a variety of normal, integrated business environments and includes: includes: minimum wage pay or better; support to obtain and maintain jobs; and promotion of career development and workplace diversity.)

The policy allowed for a two year ramp up for agencies to train staff, develop policies and communicate the direction to users of employment services and their families and supporters. With only five years of implementation since 2006, the results, in terms of employment outcomes, are astounding. Washington State is a positive outlier compared to the rest of the nation with 88% of individuals with developmental disabilities in integrated employment. Only two other states – Oklahoma (60%) and Connecticut (54%) have reached a level of at least 50% of these individuals in integrated employment [1]. Not only has this bold

policy re-configured the landscape in Washington, it also spurred the development of an “Employment First” policy for a near majority of states across the country. The critical importance of this policy is that it can no longer be said with any validity that the vast majority of individuals with significant disabilities cannot be successfully employment in integrated employment for at least the minimum wage.

3.2. *The concept of employment first*

The leadership provided by Washington State’s Working Age Adult Policy caused a ripple effect across the field of employment services for people with significant disabilities. By early 2011 twenty-one states had either developed or were in the process of developing a policy that would establish integrated employment as the primary service to be funded for individuals with developmental disabilities [12]. This shift has reflected a perspective that many felt needed to occur much sooner over the past two decades [13, 19]. It was clear to many leaders and researchers that funding a dual system of both community employment and facilities was not sustainable, financially, regardless of the values conflicts might exist. However, the use of facility based services continued to grow and drain resources needed for integrated employment over the past twenty years [1]. The Employment First Initiatives, led by the State Employment Leadership Network and supported by the Institute on Community Inclusion of the University of Massachusetts, is poised to reverse this trend. Indeed, of the twenty-one states with Employment First policies in place or in development, the average percentage of individuals in integrated employment is 32% compared to 20% for states that have not developed such a policy. In the data presented by states, the overall range of those in integrated employment is from 4% to 88% with six states at 10% or less. This indicates that a clear decision by states regarding both the importance and possibility of employment for individuals with significant disabilities will have direct impact on the outcomes of employment. At this point, twenty years after the first issue of the Journal, the trend lines look bright for the shift towards integrated employment to continue.

3.3. *Customized wage employment*

In the twenty years *prior* to the first edition of *JVR*, it was typical practice to expect that individuals with disabilities could become “job ready” through a

variety of services that provided training, evaluation and placement services. Of course, many individuals did not become job ready, as exemplified by their poor performance on comparative assessments and vocational evaluations. Countless others simply were not hired by employers following a competitive interview or, if hired, lost their job soon after due to an array of problems. One solution for this group of individuals was the venerable idea of supported employment. The concept was elegant in its simplicity; if support was provided *on* the job rather than *prior* to the job, many more individuals could become competitively employed. Supported employment grew from infancy in the early 1980's to a fully formed and federally funded concept by 1986. In modern terms, it went viral. But even with its popularity, supported employment was not working for everyone who might want to work. By 1998 the number of persons in supported employment with physical disabilities was 0.06% while the percentage of individuals with physical disabilities as a discrete category of all persons with disabilities was estimated to be about 20%, an under-representation by a factor of almost forty [2]. As the reach of supported employment was extended to individuals with increasing significance of disability, the supported employment, alone, was proving to be insufficient.

By 1991, in an article for the JVR, practitioners were recognizing the need to extend the reach of supported employment by tailoring the employment relationship between some employees and their employers [20]. Throughout the 1990's this approach was referred to unofficially as "individualized supported employment" in that the demands, and the barriers they created, of open jobs were by-passed through an intentional process that sought to identify specific needs and benefits rather than job openings. These efforts were to provide the foundation for the concept of customized employment that emerged from the newly formed Office of Disability Employment Policy (ODEP) within the US Department of Labor in 2001.

In the Spring of 2011, ODEP solicited proposals from across the country to implement services that would result in customized jobs for individuals with significant disabilities. ODEP defined customized employment as, "*individualizing the employment relationship between employees and employers in ways that meet the needs of both. It is based on an individualized determination of the strengths, needs, and interests of the person with a disability, and is also designed to meet the specific needs of the employer. It may include employment developed through job*

carving, self-employment or entrepreneurial initiatives, or other job development or restructuring strategies that result in job responsibilities being customized and individually negotiated to fit the needs of individuals with a disability. Customized employment assumes the provision of reasonable accommodations and supports necessary for the individual to perform the functions of a job that is individually negotiated and developed." [7] This definition was based on the experiences of the 1990's and would stand as the most important employment innovation since the development of supported employment fifteen years earlier. During the subsequent ten years, this innovation has provided a doorway to employment for any job seeker for whom competitive demand is a barrier to integrated jobs.

The important innovation of customized employment is that when the demands of open jobs create a barrier to employment for job seekers with significant disabilities, even with post-employment supports, it provides an alternative strategy to accomplish integrated, community employment with pay at or above the minimum wage. This is possible by negotiating with employers to target unmet needs of the workplace, tasks better performed by others at a lower pay grade (but still at or above minimum wage) and tasks that would benefit the employer in some discrete manner. This voluntary relationship goes beyond traditional job carving and restructuring and establishes a fundamentally new conceptualization of the employment relationship. Customized wage employment is a door opener for job seekers with significant disabilities.

4. Customized self-employment

The evolution of supported and customized employment includes the national adoption of self-employment or business ownership, as one means of accommodating an individual's ideal conditions of employment. Certainly many people with disabilities are motivated by the same spirit of ownership and independence found in many business owners, but more often that not, individuals with significant disabilities find that owning a business is another effective means of circumventing the traditional labor market competitiveness.

In this evolution, national projects again helped spur acceptance of the fact that anyone can own a company, when appropriate supports are available and affordable, and when an individual's talents are matched to the product, service and market. The Montana/Wyoming Partnerships for Careers project funded in the

mid-1990s by the Employment Training Administration with the U.S. Department of Labor, the Choice Access Projects funded by the Rehabilitation Services Administration of the U.S. Department of Education, and most recently the Start-Up-USA project funded by the Office of Disability Employment Policy, again at the Department of Labor, created enough examples of success and replicable information that every state today can share examples of individuals with the most significant disabilities starting and sustaining their own companies.

Today, numerous states and many community rehabilitation programs actively assist individuals in business ownership. While once most state Vocational Rehabilitation programs discouraged self-employment except for those enrolled in their blind business enterprise programs or for those without intellectual disabilities, states including Florida, Texas, Ohio, and others are pursuing customized self-employment through policy revisions and massive staff and vendor development programs (e.g., www.cbtac.org). Self-employment may not be the best option for all people, but as a customized employment option, it offers a substantive means for creating a unique job for one person at a time.

4.1. *Discovery as an alternative to traditional assessment*

Starting with the Rehabilitation Act of 1973, VR counselors were to determine predicted feasibility in terms of a rehabilitation outcome before services could be offered to an individual. The typical strategy to determine that feasibility has been comparative vocational assessment. As supported employment emerged in the 1980s many of the individuals entering employment had been evaluated and found not to be feasible for employment, many being denied VR services. By 1992, when over 100,000 individuals with significant disabilities had been successfully employed in supported employment, Congress changed the so-called “feasibility determination” and directed counselors to general presume feasibility in terms of a rehabilitation outcome, unless clear and convincing evidence indicated otherwise [6]. The basic question facing the employment field in 1991 was, “If an individual does poorly on a vocational assessment, how do we proceed optimistically toward a vocational goal?” The answer was, “Discover, don’t test”. Discovery evolved during the 1990s as an alternative strategy to comparative vocational assessment [2]. This approach utilized qualitative

research procedures rather than quantitative, comparative procedures to gather the information necessary to guide employment planning and services. Discovery is characterized by the following perspectives:

- Discovery seeks to identify **already-existing information** rather than developing information solely for the purposes of evaluation or diagnosis.
- Identifying a direction for employment is based on a **translation of typical activities of the person’s life** to employment possibilities rather than on a comparison of the individual with others or with standards and norms.
- The discovery process focuses more on **ecological validity** than **predictive validity**. It is more important that the direction to employment makes sense in relation to a person’s life than to attempt to predict success based on test performance.
- The information of discovery is used only as a **guide for matching and customization** and may not be used to exclude a person from employment.
- By implementing discovery, we try to **identify the real complexities** faced by the individual and attempt to negotiate and match employment that fits, rather than putting the burden of resolving complexities solely on the individual.
- The profile strategy seeks to **empower and involve applicants, their families and friends** rather than to exclude them. Natural, common sense approaches to employment are given priority over strategies which rely solely on professional judgment and service [4].

This process began in the mid-1980s as an aspect of employment services being provided at Syracuse University as was originally referred to as “the profile strategy”, referencing the narrative document that results from getting to know the individual [4]. The term “discovery” was added in the late 1990’s to shift the focus from the descriptive report to the process of learning about the person. Over the past twenty years discovery has evolved as the foundation of any person-centered, person-directed employment planning approach.

4.2. *Natural supports*

In 1988, three year prior to the first edition of *JVR*, Jan Nisbet and Dave Hagner [14] wrote an article for the professional journal for TASH, the advocacy organization that focused on employment supports for individuals with significant disabilities. In that article,

Nisbet and Hagner suggested that there had already become an over-reliance on the funded supports for supported employment and that more natural sources of support should be developed for individuals in SE. This idea added a new level of complexity and challenge to the concept of job coaching, a strategy still in its infancy in 1988. At this early juncture, it was already apparent that a sole reliance on human service supports would not only isolate supported employees from their typical co-workers and supervisors but that approach simply could not be sustained financially. The strategy of natural supports was an instant hit in the employment field during the following years. Four years later Congress added the term as a source of ongoing supports in the 1992 Amendments to the Rehab Act [6]. However, as popular and sensible as the concept was, there was also significant confusion, especially regarding the definition of “natural” as a modifier of supports offered to employees with disabilities.

In 1998 Paul Wehman and John Bricout [18] analyzed nine journal articles describing varying approaches and functional definitions of natural supports. Unfortunately, they found confusion brewing within the variation. Many of the early articles described ways to minimize the role of the job coach by finding innovative strategies to access supports from an array of sources such as mentors, parents, advocates, college students and workers from other shifts. These approaches shared the common feature of expanding the use of non-traditional supporters under the name of natural supports. As the concept matured during the mid to late 1990’s, there was a clear shift towards defining natural supports in terms of the workplace rather than in terms of alternatives to traditional job coaching. In 1997 West [21] and his colleagues suggested that natural supports “refers to the resources inherent in community environments that can be used for habilitative and supportive services”. In other words the “natural” in natural supports refers to the relative access to the support strategies available to all individuals rather than to an artificial source of support that might not actually be “natural” in some settings. Callahan and Garner [3] offered a roadmap for job coaches to follow based on the Seven Phase Sequence suggested by Marc Gold. This newly conceptualized sequence asks job coaches to start post-employment supports by analyzing the culture of each workplace as an aspect of the time-honored strategy of job analysis. This sequence provides a model that balances the features of naturalness within workplaces while addressing the individual needs of the supported employee.

4.3. Economic development as an approach to employment

Customized Employment may be best described as a set of techniques designed to make supported employment more powerful. Whether written in policy or procedures manuals CE represents a departure from the charitable approaches of job development used in the past. For an example of how CE is being embedded see <http://www.dars.state.tx.us/drs/providermanual/guidance/SupportedEmploymentandSupportedSelf-EmploymentComparisonDiagram-ImageVersion.png>. Hearing the phrase “I wish the business would just give her a chance” or entertaining the thought that “employers just need to be educated” signals the use of traditional methods CE eschews. The Discovery process hones an individual profile that leads the job search to companies “where the career makes sense” [11]. From there an interest-based negotiation occurs that not only emphasizes the natural fit of the individual to the work culture and the tasks to be performed, but it also illuminates the contribution the person will make to the business, not the least of which is economic.

Wearing cost savings on one’s sleeve is probably not the savviest approach to job development, but through the negotiation certainly a clearly highlighted advantage to hiring will be that this new worker will never cost more than they generate through their productivity. Wages, after all, are the residue of profit, and with most companies in the United States being undercapitalized, the addition of employees that generate income are crucial to survival.

Certainly most business owners do not rise in the morning and wonder who will make them money this day, but the fact remains that an employee must earn their keep if their employer is to remain solvent, and that performing tasks and using skills that contribute to the effort nestles one into the fabric of even the smallest company, bringing respect, enhanced job security, and opportunities for advancement. CE emphasizes the work culture-skills/tasks-work conditions match between worker and company, which is polished through the negotiation.

4.4. Job development emphasis on small businesses

Clearly CE can and has worked in very large corporations, but in daily practice, it appears more attuned to the needs of small companies. Today this is also where opportunity and job growth are most pronounced. CE

is best implemented in the ubiquitous small companies that populate the countryside and contribute over 85% of all new jobs. The Kaufman Foundation for Entrepreneurial Leadership reports that big business generated no new net jobs in the past 4 years [16]. With over 22 million single owner-operator firms out of a total 37 million businesses in the United States, and only 17,000 of these businesses having more than 500 employees, small business is the place for job development for the following reasons:

1. Most small business is under-capitalized, which means they could use talent that helps them generate more revenue.
2. Most small businesses do not have Human Resource managers or written job descriptions that have to be changed or circumvented as in larger companies.
3. In smaller companies it's much easier to reach the decision maker.
4. Small business owners and managers gravitate towards job seekers with similar interests, whereas in bigger companies the HR manager, who likely does not have a shared interest or social connection with the job seeker, often stands between the applicant and the production floor. Hiring is personal in a small company. And, people with similar interests are more likely to mentor and coach one another, augmenting natural support facilitation. Artisans, after all, own and operate most companies in the world, not business school graduates. Artisans have and share skills that help employees learn new skills, leading to better jobs in the future [9, 10].

4.5. *Social capital and parallel systems*

The job development search for small companies exposes an unexpected and welcome consequence of implementing Customized Employment. In order to find an array of employment options, and those that fit a specific individual, one can no longer look for job openings or employers who "are hiring". "Retail Job Development," that is, investigating job options from the perspective of anyone else entering an establishment's front door, will no longer suffice. The tasks performed, and the equipment used, in the back rooms, away from the customer or casual observer, are where the action is for the CE job creator. The back room is where the magic of the company often occurs. Where obscure proprietary processes and unique technologies

convert raw materials into finished products; where co-workers assemble sub-component parts; where the bread is baked, and where the lathes are turning. Yes, there are still plenty of jobs opening boxes at the big retail stores, but how is that customized? How does that sort of job derive from Discovery? How does that job concretely teach skills that lead to the next job advancement? How does it match who the worker is today?

The good news is that we are overwhelmed with opportunity. There are unlimited ways to make a living. And, all employers are hiring 24/7; they are hiring people who can contribute to their company's bottom line, their quality, their culture. The challenge CE poses is ripe with the exploratory opportunities of every community. And with millions of companies in the country with just a handful of employees, and few bureaucratic hiring hurdles, the odds favor a CE approach.

Leaving Main Street, or the Box Store Strip, where most job developers are far too comfortable [9] takes us to new sections of town; to garages without neon signs; to single owner or Mom and Pop companies; or even enterprises with several dozen workers, where there are no HR managers; few job descriptions to modify; no computer kiosks ready to accept applications for employment; no CRP classes to pass or State credentialing to investigate. Instead, one finds an assemblage of just regular folks, and skilled artisans, and day laborers making a product or delivering a service, feeding their families and paying their rent, often in relative anonymity of even their neighbors and the local Chamber of Commerce. And while the chore of locating these little companies is daunting, the effort reveals the rich commercial life of even the smallest rural communities or fast-paced inner city neighborhoods, and evermore opportunities to make an employment or social connection.

The vast U.S. disability service system had the wealth to construct parallel universes, within sight, but just out of reach of our communities. We built our own housing, our transportation, and our own employment. The CE process takes us into the heart of communities, starting with Discovery, right through the negotiated employment process. In order to do CE vigorously and correctly, searching out the companies that need help to grow is essential to finding individualized job fitment. To exploit these opportunities, families and neighbors re-engage and leverage their social capital to make connections; rehabilitation staff have to meet new people, unlearn the language of recruitment and elevator speeches and instead know how to converse in the

common, respectful language of small business, of supply chain leveraging, and of neighbors helping neighbors. CE has the potential to reintegrate people, programs, and commerce and reduce the separation so intrinsic to our broader system.

4.6. *Beyond equilibrium – destabilizing large scale social support systems*

On a macro-large numbers scale in the billions to trillions of dollars, thousands of studies, reports and data indicate the potential that some progress in employment outcomes over the past 20 years can be attributed to legislative changes and efforts to resolve the complex interactions and work disincentives of multiple social systems' financial, medical, nutrition, housing and daily living supports for individuals with the most significant disabilities. The long term impacts of legislation enacted across social support systems continues to predict to resolve to cost neutral or slightly better potential cost savings as calculated results to the government/tax payers needed to pass legislation designed to improve the continued low employment rates of Social Security Disability Insurance Beneficiaries and Supplemental Security Income Recipients.

Such analyses and records could go on from this point for another 100 hours or 1,000 pages. Yet they barely scratch the surface of the large scale economic research studies, reports, financial analyses and demonstration field studies designed to reduce system level barriers and expand opportunities for individuals with the most significant disabilities to enter the paid work world. New systems that level federal and state supports are in place and expanding into areas such as system information supports and planning services to navigate the complex social systems surrounding individuals with complex disabilities to work at higher earnings levels, including new opportunities for increasing wealth through higher assets and resource thresholds. Many of the legislative changes to Social Security, Medicaid, housing subsidies, supplemental nutrition programs, and energy assistance, have changed in ways not even imagined 20 years ago, and hold a current and future potential for supporting employment at earnings much higher than federal poverty levels. Improvements in the area of benefits planning assistance, and multiple options for continued Medicaid or extended Medicare at much higher levels of earnings, have been, and continue to be, conceived, researched, proposed and enacted into law both at the federal and state level across the country.

Yet, to be fair, the improvements and new potentials noted above, over the past 20 years, are balanced by large scale systems that seek to return to status quo, and the positive systems changes have had their issues and similar to continued improvements, continued issues are expected in the future also. To quote a report from the somewhat famous, or in some circles infamous, Ticket to Work and it's Advisory Panel's final sunset report to the President and Congress, on 12/17/2007 the panel asked: "Are we better off?" [23] (referring to the result of the Social Security Ticket to Work program the advisory panel was developed to support). The panel proceeded to address the premise of a series of multiple answers at great length over many pages of the final report, yet at one point wrote: "For the Panel, the greatest disappointment has been in implementation of the Ticket to Work program" [23].

Reports from Social Security data, raw numbers, and research studies before 1990, and throughout the past 20 years continue to yield a large scale outcome of: "less than one half of 1% of Social Security Disability Insurance (SSDI) beneficiaries return to work and leave the SSDI roles". That was the case 20 years ago and is still the case. With all the legislative changes and new opportunities the statistics continue to play out the same. It seems to be a reasonable conclusion that there's still something missing and quite a bit of work to be done at the larger levels of social systems change.

Occasionally, a systems level anomaly, created out of the personal genius of one person conceiving an approach that ends up in legislation and infecting a large system, begins to show huge potential for increasing employment outcomes. When that occurs, the prior stable system, parallel universe, becomes unbalanced and seeks equilibrium (balance) desperately as any system would, by resisting such changes and using all possible measures to force itself back to status quo. One such instance in the past 20 years in the employment supports systems, was the rise and fall of SSA's Plans for Achieving Self-Support (PASS). Below is a chart from the Ticket To Work Advisory Panel from 1990 to 2006 [23].

Initially a few employment seekers and some local support staff learned about PASS in the late 1980 s. As they began to use PASS, employment seekers with disabilities began telling other employment seekers and local agency staff began to spread the word. Within a few years PASS spread across the country from about 900 PASSes approved and funded by local SSA staff in 1988 to over 10,000 in 1995. PASS clearly became

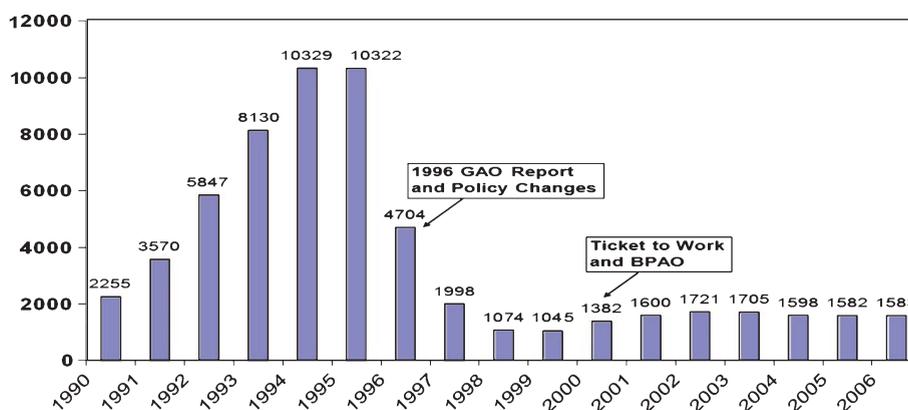


Fig. 1. PASS utilization.

a statistically significant employment support anomaly in the prior stable SSA system, rapidly increasing far beyond all the predictable flat charts of large scale systems, and well beyond any shadow of a statistician's doubt in process of radically changing the SSA system. PASS was (and even continues to be) a self-directed funding tool used by individuals with disabilities to support their own employment goals. Eligible individuals receive SSI or SSDI in order to access PASS funding for a self-directed work goal. SSI recipients and SSDI beneficiaries by SSA's definition of disability are individuals with the most significant disabilities.

In 1995 PASS was clearly headed into an exponential growth curve the SSA system had never seen before nor has since with any employment support system tool, rapidly approaching a point of an actual potential massive systems level change that incurred the full force of the system to audit, critique, interrogate, and as quickly as possible punish all involved, or in systems terms "refine and improve PASS, clarify policies and reorganize by appointing new internal experts," in 1996 and 1997. Once the good deed was punished (no good deed goes unpunished) the system was able to quickly bring the system back into balance/equilibrium to a flat line "no growth" status within 2 years by wiping out all the gains, canceling 9,000 PASSes almost overnight, resulting in a low power very limited macro system compatible tool now that has no significant impact on employment status and no potential to rock the systems boat in the future.

There's some lessons to be learned from the rise and fall of PASS. It was a system level tool for a while that was approved locally at local SSA office by neighbors who worked for SSA (now it's approved by an expert

regionally who generally never meets the employment seeker). The PASS approver prior to 1996 was not an expert, and yet was a neighbor working in a local SSA office who trusted the local employment agencies and local neighbors with disabilities to do what was best. Now, the more non-local interpretations of PASS policies encourage indirectly the mistrust of all parties involved in writing a PASS, and especially the PASS participants/users. PASS had been something anyone could write and understand, a one page simple form, where the person involved could fairly easily figure it out or the entry level employment support staff could figure it out with the person. Now it's a 14 page form with warnings of punishment embedded in the last 3 pages of the form. There's much more to be learned in the details of what occurred during those years with PASS at SSA, yet mainly PASS was local, simple, and trusting and in each case a celebration when someone's PASS was approved. It was, as described in prior sections of this paper, a community working together and trusting each other.

Whatever solutions in large scale systems await us in the future, the ones that potentially hold promise are those that give power back by the systems becoming destabilized and out of balance. If the systems can be destabilized long enough and not allowed to return to the prior equilibrium/status quo, they could end up with a radical new strength and support by being local, neighbors, simple and trusting. In each local community the capacity exists for us and our neighbors working in social systems to do what we can do best by reengaging and dissolving the system barriers back into a single community to the point of vibrantly adding to the local single universe.

5. Conclusion

Although it may be said that the twenty years following the inception of the *Journal of Vocational Rehabilitation* did not fully live up to the promise that many felt was possible two decades ago, there is much to be hopeful about. For the first time in the field of employment for persons with disabilities, we are hearing the phrase *employment for all* being uttered in the same breath as *employment first*. Customized employment has emerged as a strategy that is compatible with the venerable concept of supported employment to make employment for all a real possibility. In 2011 policy makers, practitioners and persons with disabilities met for the second Alliance for Full Participation gathering in Washington, DC, where the focus was solely directed at assuring full access to employment for all individuals with disabilities. We are confident that the *JVR* will continue to offer cutting-edge strategies and policy direction for the next two decades that will help make our future visions a reality.

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