

Employment First* (not only)

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The Origins of Employment First

Do you know your preferred employment outcome? Many of you reading this editorial may not have a disability, but if you do and you qualify to receive employment services, your options are being limited as you read this because of a policy known as Employment First. This approach sets “community-based, integrated employment – which pays at least the minimum wage – [as] the first option for employment services for youth and adults with significant disabilities” (Scaglione, 2015). Employment First is a federal policy that has been adopted in many states, and is currently being set in New York State after Governor Cuomo issued an Executive Order establishing an Employment First policy commission in September 2014 (Executive Order No. 136, 2014). To understand how this policy has come about, it is crucial that we understand its origins in the evolving definition of inclusion.

A landmark in the shift in disability¹ policy occurred on June 22, 1999, when the United States Supreme Court ruled that “unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the Americans with Disabilities Act” (United States Department of Justice Civil Rights Division, n.d.-b). This ruling became known as the Olmstead Decision, and it set a requirement that services for individuals with disabilities be provided in the “most integrated setting appropriate to their needs” (n.d.-a). It helped to construct a view of inclusion defined by participation in mixed-ability environments.

Though Olmstead specifically addressed a complaint related to institutional versus community treatment programs, media attention has since driven a shift in its application of inclusion through reports about terrible conditions and low pay in sheltered workshops. Among these reports have come criticisms of workshop employers such as Goodwill, of piece-meal workshops like Training Thru Placement², and of statewide practices that are alleged to exhibit abuse and neglect stemming straight from the institutional era (Adams, 2013; Barry, 2014; Denson, 2013).

This media focus is coupled with a policy catalyst in the form of the Workforce Innovation and Opportunity Act (WIOA) of 2014, an amendment and reauthorization of the Workforce Investment Act of 1998, aimed at helping American workers navigate employment in a recovering economy (Yashchin, 2014). The WIOA acknowledges the extremely high unemployment rate among individuals with disabilities and requires states to find ways to lower the barriers to employment (2014). This policy, and a wave of negative media attention, has shifted the concerns over segregation and inclusion that the Olmstead Decision magnified to the workplace, resulting in a policy known as Employment First.

Employment First is defined by the Office of Disability Employment Policy as “a concept to facilitate the full inclusion of people with the most significant disabilities in the workplace and community” (Office of Disability Employment Policy, n.d.). It holds competitive pay, inclusion in the community (meaning a community of mixed abilities), and the pride of holding a job as some of the reasons for pursuing employment ahead of other options. As a consequence of this prioritization, other service options – including

¹ Disability in this paper will be used inclusively to represent intellectual, developmental, mental, and acquired disabilities

² See “Rhode Island Settles Case on Jobs for the Disabled,” <http://www.nytimes.com>

sheltered workshops – will close. In New York State, funding for new placements in sheltered workshops already dried up in July 2013, and these facilities are mandated to close entirely by 2020 (Scaglione, 2015). As Employment First continues to grow nationwide and to be established here in New York, the time has come to question the definition of inclusion upon which it is predicated and to question whether Employment First truly achieves it.

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At its heart, Employment First seeks to expand the concept of inclusion into the workplace, but it does so at the cost of choice. To include all individuals fully in our society, *we have to start not with policies that we make on behalf of others, but with policies that allow for the same right to self-determination* that we understand in this country as a freedom that is constitutionally assured. To do this, we have to include those individuals in discussions of what inclusion means to them, how they want to live their lives, and where they want to work. For true inclusion to happen, we must amend Employment First. We must allow for a policy that pushes a population that has been historically sidelined and ignored to achieve new milestones and which accepts the idea that what this achievement looks like for each individual is his or her own choice. We must adopt Employment First* (not only), a title that will be used to reflect a policy that continues to set employment as a primary goal while allowing individuals to pursue work and activity options at their own discretion.

New York

We can start working toward greater inclusion of individuals by providing choice in New York State, where a task force announced last September by Governor Cuomo is currently determining Employment First policy (Executive Order No. 136, 2014). Presently, the Commission that will set this policy by March 2015 is heavily weighted with government officials, but lacks the individuals who will actually face the impact of this policy: the workers themselves (Scaglione, 2015).

If New York wants to establish a policy that honors true inclusion, it must start by practicing inclusion in the formation of employment policy. Individuals with disabilities, their families, advocates, friends, and supporters must have a say in how New York enacts policies of inclusion in the workplace and what options are made available to these workers. Without these voices, New York will adopt Employment First as a blanket policy that limits the paths of opportunity for this population. If, on the other hand, New York State includes people with disabilities and their friends and allies in shaping Employment First, New York could become a model state for a new element in this discussion — choice.

Sheltered Workshops: A Thing of the Past?

Sheltered workshops have constituted a dominant model of employment service for many years. In 2010, nearly 27% of the 566,188 individuals receiving employment services nationally worked in sheltered workshops (Butterworth et al., 2012). In 2011, that number totaled roughly 8,000 New Yorkers (Scaglione, 2015). Sheltered workshops come in many forms, but the most common is a piece-meal assembly shop where workers assemble items such as simple mechanical objects or provide packaging services for goods manufactured elsewhere. Workers are paid below minimum wage based on their production rates and work in a setting where their coworkers are other individuals with a range of disabilities, often both physical and developmental. The drive to eliminate this model is the result of a combination of low competitive employment rates for individuals with disabilities and the view that inclusion in the most integrated setting possible (as laid out in the Olmstead Decision) should take priority across all areas of living, including employment (Butterworth et al., 2012).

It must be acknowledged that some sheltered workshops have been the sites of gross neglect and abhorrent conditions. Conditions like those described in “The Boys in the Bunkhouse,” an explosive exposé published in *The New York Times* in March 2014, have been real for many people employed in sheltered sites, which receive little or no oversight. In this example, employees lived and worked on a farm that operated a turkey slaughterhouse. They worked long days slaughtering turkeys— a task that caused severe, and sometimes irreparable, injuries to some workers due to repetitive motions— while earning only enough to buy small indulgences and being forced to live in filthy and unsafe conditions.

For others, however, sheltered workshops have been an entirely different experience. They have allowed easy transition from school to work, provided a community with an undeniable and important commonality, and allowed people with disabilities the time and space to master tasks. Susan Constantino of Cerebral Palsy Association of New York State notes, “...lots of folks found they were doing meaningful work in these programs and getting a pay check” (quoted in Scaglione, 2015). Many individuals also choose to work in these workshops because they like being in a peer community where all levels of ability and behavior are welcome and normal. Another executive director of a New York agency affirms, “[t]hey have friends here...they come to work every day, see people they know, do work that they understand and feel valued” (Scaglione, 2015).

To fight against the maltreatment and dehumanization that some sheltered workshops have fostered is the right thing to do, but to broadly paint a work model that has been as beneficial for some as it has been awful for others denies individuals with disabilities the full spectrum of experiences. The lessons that we should take from the cases we read about are the importance of oversight and individual choice. Stories about workers who love what they do should be as valid as negative cases. Further, we must be sure that we have something better to offer to those who want it.

If not only to provide options for workers receiving employment services, we should keep other options available until it is clear that “there are sufficient community based, minimum wage paying jobs available for individuals and whether the State is prepared to fund the level of supports that individuals will need to get, learn, and keep those jobs” (Scaglione, 2015). New York State’s Office for People with Development Disabilities only aims to cover *half* of those individuals currently receiving sheltered employment services, if that many can even be placed (Scaglione, 2015). What we are doing is tearing down a system without either fully establishing another or consulting at an individual level with those who will be affected. Without this knowledge and these voices, Employment First could *exclude* workers from jobs and work communities in an attempt to create a more inclusive policy.

What’s Missing?

The relatively minute influence of voices’ against Employment First in the general conversation represents the problem with this policy: It represents only certain voices, who in turn support only certain choices. A case in which workers and families in New Jersey rallied together to successfully pressure legislators to keep sheltered workshops open barely received any press (Luberman, 2013). Another New York State executive director adds, “[i]f you asked individuals working in workshops if they want to give up that job and take a job in the community many would say no. But, the State and CMS aren’t asking!” (Scaglione, 2015).

Those voices that have been the primary drivers of Employment First have firmly backed this policy as a reaction to examples of exploitive sheltered workshops. Even advocacy organizations seem to have become caught up in the wave of negativity and are quick to dissociate themselves from the sheltered employment model. Some have gone as far as to create an Employment First guiding document, which, while an excellent

tool to guide creation and practice of employment services, does nothing to help those who want other options (Best Buddies et al., n.d.).

Arguments in favor of sheltered work, such as those presented in a study by de Urrías and Verdugo (2011) of the experiences of workers in these facilities, provide compelling findings that force us to question whether pursuit of the current definition of inclusion does not come at too high a cost. De Urrías & Verdugo (2011) found,

[t]he percentage of those who state that work satisfaction is very high (93.33%), singling out the task (41.76%) and their fellow workers (30.00%) as what they most like about work, and emphasizing that money is the least attractive feature³ (p. 159)

These figures suggest that there is an element of pride in work (seen in extremely high satisfaction rates) present in sheltered workshop workers and that their fellow workers, who also have disabilities, are among the major reasons for this satisfaction in this employment model. Given the high ratings of satisfaction and contentment with their work community, how can we continue to argue that other options must be pursued to achieve pride in work or inclusion?

Some of the few voices that dare to speak out against this policy even argue that framing inclusion around employment creates a valuation system (competitive employment is good; sheltered employment is bad) that is not necessarily accurate. As Donald Weikle, Jr. writes in “Achieving Community Membership Through Community Rehabilitation Provider Services: Are We There Yet?,” the assumption that sheltered employment is by definition bad is at best questionable (2008). In the article, Weikle (2008) asks the questions that this editorial suggests are not being asked:

Did anyone ask people working in facility-based or integrated work sites whether they liked those settings? Did anyone ask participants if they selected the work location from alternatives during their Individual Service Plan meetings? Did [anyone] investigate what I call ‘the boomerang effect’ in supported employment? That is, we help people move from congregate to integrated settings and many come right back. Are those individuals telling us something about their values and/or our services? In short, did anyone ask what consumers valued? (p. 58)

When It Won’t Fit, Push Harder

This dogged pursuit of adoption and adherence to Employment First, clearly, has prevented even the well-meaning from understanding that this policy does not and cannot work for everyone. It has come out of high-profile negative press and a search for a single solution. This causes us to forget that inclusion in the competitive job market may be inclusion for some, but will mean exclusion for many from the work they want, work they can do, and a community that many cherish. A policy that touts inclusion but defines it so narrowly that it limits an individual’s right to self-determination can only result in exclusion. A policy like Employment First is what happens when policymakers forget to include all stakeholders and decide, even out of good intentions, that they know better than the key actors affected by the policy.

New York is set to repeat this process by working with only select voices that will champion Employment First. Nowhere on Governor Cuomo’s commission is there a seat designated for workers who want to keep this option available, who like what they do and want to remain where they are, and for whom

³ The issue of subminimum wages merits greater discussion than can be afforded in this editorial. The author will simply note that equal pay should be the goal of any employment program, while also recognizing the difficulty in achieving this.

their work community represents an opportunity to feel safe and included in a group of similar individuals. There is no place for a counterargument or alternative voices.

In the same way that policymakers are ignoring those who wish to keep this model, they are ignoring this population's right to define for itself what they want their community to be. When did it become our choice to determine that an integrated community is the best option, if not the only option? While acknowledging that some may feel comfortable in peer communities because of lack of exposure to larger communities, how can we say with certainty that their desire to remain in their workplace communities is unjustified? If we cannot—and this editorial contends that this is the case—it simply does not make sense to mandate participation in one type of community to achieve a definition of inclusion determined by policymakers. None of us would accept a preferred employment outcome being forced on us so that we could achieve someone else's idea of inclusion, so why are we asking individuals with disabilities to do so?

Where Do We Go From Here?

Currently, Employment First is being developed in many states, including New York, and shows no signs of slowing. An Employment First action map created in part by the Association of People Supporting Employment First (APSE) shows that 32 states have some sort of formal policy action on Employment First and that 46 (including New York) have at least some activity related to Employment First happening (The Research and Training Center on Community Living at University of Minnesota, 2014). It will likely be adopted by each state over the next few years as media and advocates continue to push it as the preferred employment policy for individuals with disabilities.

This editorial makes no attempt to suggest that Employment First must be entirely dismantled. Employment First is here to stay for the foreseeable future, and in many ways it should. Community integration in terms of accessibility and acceptability has certainly not yet been achieved in the United States. Employment First puts pressure on states to find ways to foster inclusivity in the workplace, which in its current form continues to stand as a massive barrier to people with a range of disabilities due to demands for specific physical and mental abilities. Further, Employment First, as it is currently manifesting, will provide the support that many will need to find success in the workplace. As individuals are provided with job coaches and personal aides paid for by the funding that used to go toward sheltered workshops, many will be able to pursue dreams of competitive employment.

For too many, however, Employment First will take away a valuable option. With the closure of sheltered workshops, the option to move between competitive employment and sheltered employment will be lost. The opportunity to work among peer groups of other individuals with disabilities, and, consequently, to be a part of the norm at work, will be lost. The places that many have woven into their identities as workers and as people, where they have spent years or decades of their life, will be lost.

This editorial argues instead that Employment First should proceed with an asterisk: Employment First* (not only). Setting competitive employment as the preferred employment outcome for individuals with disabilities will help those who wish to pursue this avenue to do so and could serve as a supportive push for those who are shy to venture beyond what they have already experienced. It cannot, however, be the only possible outcome. Workers who try competitive employment and do not like it, workers who cannot retain such employment, and workers who do not wish to pursue competitive employment for any reason must still be given the option to work in other settings.

In an ideal world, funding should be reallocated to sheltered workshops, provided they meet criteria that should be created to review the quality of the workshops as a means to preventing the abuses that media has highlighted that occur in some settings. In reality, though, this continued financial support for sheltered

workshops is unlikely to happen. A compromise would be for workshops to convert to alternative models. Workshops could also pursue non-government funding if efforts could be made to change the public opinion of this model enough that it would be socially safe for private giving to occur. Finally, workshops could potentially splinter into smaller entities employing a small number of workers to get around the size limit that determines status as a sheltered workshop. With any of these options, it is imperative that workshops that employ workers in a safe, meaningful, and fulfilling way using proper oversights and find a way to remain open and remain an employment option for individuals with disabilities.

In order to make changes such as these, policy makers, the media, and the public will need to step back from the reactive loops in which they have been operating to reevaluate the prevailing interpretation of inclusivity and integration. For the typically-abled American population, our rights are often encapsulated by the single maxim, “the right to life, liberty, and the pursuit of happiness.” These rights, collectively, exemplify the right to choice. If this is the right that we as a country hold in highest regard, then an interpretation of inclusivity and integration must include choice as an integral part of these definitions. Inclusivity in this framework might mean inclusivity in whatever community that an individual wants to be a part. Integration might signify a society that creates ways for this population to participate in daily and community life if they so choose. An integrated and inclusive society founded on individual choice might not look like we think it should, but if we allow each individual to determine for him or herself what he or she wants in life, it will become a society that reflects each person’s wishes. We can start to move toward this by reimagining Employment First in New York by making a seat at the decision table for all stakeholders and by setting policies that allow maximal options for individuals. We can start by demanding Employment First* (not only).

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