The role of informed choice in advancing competitive integrated employment

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Abstract.

BACKGROUND: Recent laws, regulations, court cases and policies have included the requirement that people with disabilities be provided the opportunity to exercise informed choice in decision-making to promote inclusion and integration into society. These contemporary developments build on principles established in the early deinstitutionalization litigation, including rights to habilitation and to community settings as a remedy for unnecessary institutionalization.

OBJECTIVE: This policy paper examines these regulatory, legal and policy changes to better understand the legal mandate for informed choice and its application to promote competitive integrated employment.

METHODS: This policy paper analyzes the foundation of informed choice as presented in the Workforce Innovation and Opportunity Act (WIOA), the Home and Community Based Services (HCBS) Settings Final Rule, two landmark Department of Justice (DOJ) court cases (Oregon and Rhode Island) regarding sheltered workshops, the Olmstead decision by the Supreme Court and recent interpretations of the Americans with Disabilities Act. The paper includes interpretations of informed choice from key civil rights lawyers in key court cases, reviews of case law, statutes, regulations, policy initiatives, executive orders, state Employment First initiatives and landmark settlement agreements.

RESULTS: It is the authors’ finding that, in combination, these laws, regulations and policies form a mandate for informed choice and create an affirmative obligation on the part of government entities to provide opportunities for people with disabilities to experience competitive integrated employment outside of sheltered workshops and other segregated settings as integral to making informed choices.

CONCLUSIONS: The article posits that informed choice and the resulting affirmative obligation it embodies has not been sufficiently implemented by governmental and other private entities, and additional affirmative steps are needed to fully secure the legally mandated right to informed choice regarding employment services.

Keywords: Employment, self-determination, supported employment, competitive integrated employment, employment services, vocational rehabilitation, Olmstead, Pennhurst, informed choice

1. Introduction

Societal change is all around us. From how we communicate using cell phones, email and the Internet to the way we have rapidly adopted Uber and Lyft car sharing rides, change is moving faster and faster. Government and the disability service systems have been slow to adapt to these changes. Over the past
several years, significant changes have occurred at the Federal level that promote inclusion and integration of people with disabilities into society. These include the Supreme Court Olmstead decision, the Workforce Innovation and Opportunity Act (WIOA), the Home and Community Based Services (HCBS) Settings Final Rule, and several key Department of Justice (DOJ) cases that further interpret the Americans with Disabilities Act (ADA). These changes largely reflect law, policy and regulation. The alignment of these game changers creates unprecedented opportunities for employment for people with disabilities.

Today, we find ourselves poised at almost the same place we were fifty years ago when the field successfully confronted institutionalization. In 1969, the number of people with Intellectual and Developmental Disabilities confined in state institutions peaked at about 194,000. Since that time, more than 150,000 people moved out of institutions into small community integrated settings and gained lives that were better in virtually every way we know how to measure (Downey & Conroy, in press). Today, the number of people remaining in state institutions is down to about 22,000. Eleven states have become institution free (AK, AL, DC, HI, IN, ME, MI, MN, OR, NH, NM, RI, VT, WV), with several additional states on their way in the next two years.

Yet, having made tremendous gains in reducing segregation in state institutions, we now find ourselves addressing segregation in the community in the form of day services.

This policy paper focuses on employment and discusses how this new framework can be used to significantly advance competitive integrated employment for people with disabilities much as occurred in residential services over the last 50 years. The term “Informed Choice” is being used here because it is codified in most of current law, policy and regulations. It is included in each of the current landmark cases interpreting the ADA (for additional information on the ADA, see www.ada.gov). Informed choice is a term that is part of “supported decision-making”2 and also includes a duty for affirmative efforts on the part of government (for additional information on Supported Decision-Making, see www.supporteddecisions.org).

Despite national and state policies promoting competitive integrated employment, a large percentage of adults with significant disabilities remain in facility-based sheltered workshops or non-work programs – also often segregated – even though a majority of individuals would either like employment outside sheltered workshops or to be able to at least consider it an option (Butterworth, et al., 2013). The National Core Indicators data brief of February 2014 indicates that 74% of those who indicate their desire for a job do not have community employment as a goal in their service plan (Hall et al., 2011).

Often people are employed in sheltered workshops earning less than minimum wage with little chance of advancement because of a lack of understanding and experience of the range of employment options or because they have not been given the opportunity and support to choose employment (Beckwith, 2016). Cimera found that “the relative value of what sheltered employees earned actually decreased by 40.6% since the 1980s while the relative value of wages earned by supported employees increased by 31.2%” (2012, p.3).

Even when given a choice, many people with disabilities often have not had the opportunity to experience competitive integrated employment, or, the choices offered are framed by professionals, or well-meaning family members who do not think the person can succeed in integrated employment, or that the perceived costs of doing so are too high. In other words, people have not been given the opportunity to make an informed choice.

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1Informed choice is part of “supported decision making” as an alternative to guardianship. The Statement of Principles by the Coalition on Alternatives to Guardianship says, “Every person can make choices and has a right to make decisions. People who have a cognitive or intellectual disability may express those choices/decisions in non-traditional ways. Any legal system or proceeding which deprives an individual of his/her right to be accommodated and supported in choosing and making decisions and which appoints a substitute decision maker based on tests of competence, makes that person vulnerable and deprives him/her not only of his/her right to self-determination but also of other rights which should be inalienable.” Informed choice is used here because it is codified in current law, policy and regulations. It is included in each of the current landmark cases interpreting the ADA (for additional information on the ADA, see www.ada.gov). Informed choice as part of supported decision making, includes a duty for affirmative efforts on the part of government (for additional information on Supported Decision Making, see www.supporteddecisions.org).

2Supported decision-making is “A process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult (Texas Legislature, 2015).
“Informed choice” is something that all people require. It is based on the principle of presumed competence, that every person has the ability and the right to make choices and act on those decisions. It encompasses the Dignity of Risk that Perske (1972) enumerated in his ground-breaking article. Individuals who have significant disabilities may express their preferences in non-traditional ways and it is the responsibility of people closest to the person and systems providing services to support individuals well in making decisions and to provide access to quality employment in accordance with that decision. The absence of these requirements deprives the individual of his or her inalienable right to self-determination, and more fundamentally, to access lifestyle options that provide fair compensation and full participation in community life.

Evidence suggests that individuals who have full information and the opportunity to experience different options are likely to choose an integrated option (Migliore, Mank, Grossi, & Rogan, 2007). The DOJ has given additional guidance for what the obligations are when someone has ostensibly chosen segregation; recognizing that when provided decent opportunities with support, people with disabilities rarely choose segregation or socially devalued status.

“Public entities that have traditionally relied on segregated work settings should take affirmative steps to remedy this history and to ensure that individuals have a real opportunity to make an informed choice to work in integrated settings. Affirmative steps may include providing information about the benefits of working in integrated employment settings; providing vocational and situational assessments, career development planning, and discovery in integrated employment settings; arranging peer-to-peer mentoring; facilitating visits, conducting job exploration, interest inventories, and work experiences in integrated job settings; and providing benefits counseling, and access to benefits plans, to explain the impact of competitive work on an individual’s public benefits.”


Informed choice grew out of the recognition of peoples’ rights being violated and perverted during the early deinstitutionalization cases e.g. Halderman v. Pennhurst (1977), Wyatt v. Stickney (1977), People First v. Arlington Developmental Center (1995). In each of these cases, affirmative steps were taken to ensure that people were making an experientially based informed choice about living in the community after they had been segregated from community life. In the earliest presentation, to fuse the emerging legal principles with the understandings in human services, Civil Rights Attorney, David Ferleger, considered what he called “the place of choice” and articulated questions to be asked on “each occasion where we believe we are providing, presenting or witnessing a ‘choice’” (1995, p. 5). He also highlights how families may want something different from what the Individual may want and suggestions for how to reconcile this.

In People First v. Arlington Developmental Center, Federal District Court Judge McCalla found that even Individuals under Tennessee Guardianship “…retain the rights of other citizens and that parents and guardians lack the power to waive the fundamental rights of their children and wards.” (1995, p. 12).

In what became a landmark case, the Federal Court in Oregon put a spotlight on the common misunderstanding that providing informed choice is as simple as waiting for the person to initiate or express what they want, without having a frame of reference for doing so. “Due to their disability, many individuals with [intellectual or developmental disabilities] may not ask for supported employment services because they are not aware of them or because they are not aware that they have any choices as to services that they are entitled to receive” (Lane v. Brown, 2012).

The term, informed choice, now appears in laws and regulations governing Vocational Rehabilitation,

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3These questions are:
- What frame of reference is being used?
- How do we assist people in obtaining access to a better frame of reference when making choices?
- What is life like for other people of the same age, interests and goals? How do the prospective choices enable that life?
- Is the suggested choice likely to invite, risk or perpetuate neglect or other harm?
- Who is the most vulnerable in the situation? Who is at risk if particular choices are made? Who will be left out?
- Who is the chooser? Why is this the chooser in this situation? What voice does the subject of the choice have?
- Why does he or she not have a greater or determinative choice?
Medicaid, Workforce Development, and Education programs. The concept has often been included in State Employment First initiatives and in legal decisions based on the Americans with Disabilities Act and the US Supreme Court *Olmstead v. L.C.* decision.

The presumption that informed choice will lead to competitive integrated employment is now reflected in many State laws and regulations. The term appears around Employment First, a national systems-change effort to align policies, practices, and funding to prioritize competitive, integrated employment and other community-based services that lead to optimal inclusion and socioeconomic advancement of people with disabilities as the priority outcome of day and employment services.

Nevertheless, the construct of informed choice has not been well defined and many states, providers, and direct service professionals misinterpret or even ignore the importance of informed choice altogether. This is often complicated by the lack of skillful person-centered planning, and the impoverishment of experiences that people with disabilities have been subject to. If the individual has greatly limited life experiences, it is not an informed choice to only tell the person what his/her options are.

The following sections of this policy brief will guide state policy makers in using the informed choice framework as they attempt to transform their service systems to comply with recent mandates for competitive integrated employment. Section 1 is the Introduction, Section 2 defines Informed Choice, Section 3 describes the mandate for states to facilitate informed choice in laws, regulations and court decisions, and Section 4 details the characteristics of an employment system to ensure informed choice. The Appendices further describe these features.

2. Defining informed choice

Informed choice in employment entails knowledge and experience with appropriately high expectations for full community integration, valued social roles, normative routines and rhythms appropriate to the individual’s age. Real choice requires multiple options that reflect the integration mandate of the ADA. The term “choice” refers to decision between multiple meaningful viable options.

Being provided the choice of either McDonalds or Burger King is not informed choice. ‘Viable’ alone is not enough – both McDonalds and Burger King are ‘viable’ but essentially equivalent. The term “choice” refers to a meaningful decision between multiple, *significantly distinguishable* viable options. Choice incorporates the importance of autonomy, control, self-determination and having a variety of options to choose from.

The Department of Justice (DOJ) has taken a strong position about what is required for someone to be able to make an “informed choice.” It is not just simply asking a person (or their guardian/family) if they want to leave a segregated setting. It requires affirmative action on the part of government. It includes active engagement, in-reach and providing experiential opportunities (like opportunities to visit integrated settings, to meet with providers of integrated services, to speak with peers and other families who have had loved ones supported in integrated settings the community, etc.). In their 2011 statement on integration, DOJ defines these requirements as follows:

> Individuals must be provided the opportunity to make an informed decision. Individuals who have been institutionalized and segregated have often been repeatedly told that they are not capable of successful community living and have been given very little information, if any, about how they could successfully live in integrated settings. As a result, individuals’ and their families’ initial response when offered integrated options may be reluctance or hesitancy. Public entities must take affirmative steps to remedy this history of segregation and prejudice in order to ensure that individuals have an opportunity to make an Informed Choice. Such steps include:

1. providing information about the benefits of integrated settings;
2. facilitating visits or other experiences in such settings;
3. offering opportunities to meet with other individuals with disabilities who are living, working and receiving services in integrated settings, with their families, and with community providers.
4. making reasonable efforts to identify and addresses any concerns or objections raised by the individual or another relevant decision-maker.4

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4Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.* Retrieved from [http://www.ada.gov/olmstead/q&a_olmstead.htm](http://www.ada.gov/olmstead/q&a_olmstead.htm)
Informed choice is generally considered to have the following components:

- **The Individual is the focal point and the driving force**: The Individual’s career goals and paths drive the employment service process. The Individual has control of resources, selecting providers, targeting outcomes and deciding what is relevant. In addition, the Individual determines the degree of privacy, disclosure, outside participation, and personal effort they want to embrace in order to be employed. (Callahan, 2000). This also means that the primary focus is on the individual and not the guardian.

- **The choice must be offered in a manner that the Individual understands**: information about possibilities and opportunities must be available and understood. It must be: (1) presented in the person’s preferred language, including the use of Assistive Technology when needed, (2) address the capabilities of the individual involved in the choice making process, (3) be experientially based for people who need concrete experiences for learning and (4) presented by someone who is trusted by the person.

- **The Individual has information, knowledge, and experience**: The Individual has accurate information and knowledge to weigh the possible values and consequences of various choices. This means that the Individual has the opportunity to experience different types of work. This is true for everyone, but particularly critical for individuals who have difficulty with abstract concepts. The individual must be exposed to the reality of work (vs. non-work or segregated work). If someone has greatly limited life experiences, it’s not informed choice to tell him/her what the options are without being able to experience and understand the offered choices. And the experiences offered as a foundation for decision-making should be varied in terms of types of work/jobs, and based on discovering what is important to the person using a person-centered assessment.

- **The Individual has a meaningful choice**: A choice is meaningful only if (1) the individual is choosing among a range of feasible options and new options are created as needed; (2) service providers are willing to accept the choice and the reasonable risks associated with the choice; and (3) resources are available to support the choice and the choice is accepted and implemented. For example, if an agency has the capability to serve only a limited number of individuals in supported employment and keeps others on waiting lists or in segregated programs, the individual may have an “illusion of choice” that a menu of services is theoretically available but there may be no choice but to take the only existing option.

- **The Individual has the power, confidence, and authority to make a decision**: “There are a variety of factors that can diminish individual’s ability to exercise control in their lives and achieve personal empowerment. Low societal expectations, lack of opportunity, learned helplessness, employers’ misperceptions, institutional bias and unresponsive bureaucracies all present challenges to consumer empowerment.” (Institute on Rehabilitation Issues, 2003). Nevertheless, law and regulations have made it clear that clients are the decision-makers of their rehabilitation.

- **The Individual has the appropriate supports to make decisions**: Person Centered Planning (PCP) forms the backbone of current planning and decision-making (O’Brien & Blessing, 2012). It is a central requirement of the new HCBS Final Settings Rule. According to the National Parent Center on Transition and Employment, “In person centered planning, groups of people focus on an individual and that person’s vision of what they would like to do in the future. This ‘person-centered’ team meets to identify opportunities for the focus person to develop personal relationships, participate in their community, increase control over their own lives, and develop the skills and abilities needed to achieve these goals. Person Centered Planning depends on the commitment of a team of individuals who care about the focus person. These individuals take action to make sure that the strategies discussed in planning meetings are implemented” (Pacer, n.d.).

- **The Individual has the right to choose people to support their decision-making process**: Just like people without disabilities, people with intellectual disabilities have the right to receive assistance from one or more trusted friends, family members, professionals or advocates – to help them understand the situations they face and choices and options they have, so they can
make their own decisions. This process mirrors what happens for most adults when they make decisions such as whether to get car repairs, sign legal documents or consent to medical procedures: they seek advice, input and information from friends, family or professionals who are knowledgeable about those issues, so they can make their own well-informed choices. (Terrill, Campanella, & Melda, 2014).

- **Informed choice is a part of Supported Decision-Making:** The Supported Decision-Making movement developed as an alternative to Guardianship and now has broader application. It is a means “...through which people with disabilities use friends, family members and professionals to help them understand the situations and choices they face, so that they can make their own decisions without the need for a guardian” (Blank & Martinis, 2015). Informed choice as a part of Supported Decision Making has legal mandates beyond providing a framework as an alternative to Guardianship. It includes an affirmative right to be provided meaningful experientially based choices to enhance self-determination, independence and improved life outcomes.

- **The Individual receives ongoing advice and support and has the opportunity to modify the choice:** It is important that the Individual is in the driver’s seat and that they have the opportunity to make mistakes and to learn from that like everybody does.

- **The Individual is free to decide without undue pressure:** No part of the service delivery system should be able to use its power or influence to persuade the individual to make a certain decision. The individual has the right to leave one provider and be served by another. Every opportunity should be made to minimize conflicts of interest, particularly on the part of the person who is helping the Individual make the decision. This is often unconscious on the part of human service providers (Gordon, 2014).

- **Reasonable Accommodations:** “A reasonable accommodation is any change in the workplace or the way things are customarily done that provides an equal employment opportunity to an individual with a disability” (U.S. Equal Employment Opportunity Commission, n.d.).

For a person with a cognitive or intellectual disability, it might require giving the person a bit longer to learn the job, or structuring the task or the environment to make it easier to learn the job tasks. For a person with a psychiatric disability, a flexible schedule may be required in order to see a therapist or to go to doctor’s appointments, to support the person in their recovery. Sometimes people need time off for hospitalizations, which presents similar challenges to the employer as non-disabled employees who go on family and medical leave or who have other reasons for being out of the workforce on a temporary basis.

In the end, employers are accommodating people who are labeled and not labeled all the time…. In fact, everyone needs performance enhancements. Employers make accommodations for skilled individuals who have no obvious disability; it’s not very different from accommodating a person with a disability. An employer wants as much functionality out of an employee as possible. This is true for all employees.5

### 3. Mandates for states to facilitate informed choice in laws, regulations, court decisions and employment first initiatives

The focus on informed choice was a logical extension of remedies for rights restrictions and violations of people’s civil and human rights. For instance, in *Halderman v Pennhurst* (1977), the Hearing Master was appointed to provide the opportunity for individuals and their families to consider and object to specific proposed community settings. The process included participation in planning, visits to the proposed home, and meeting potential roommates. This additional safeguard was provided in the context of the federal court’s groundbreaking constitutional decision that “given appropriate community facilities, all the residents at Pennhurst, even the most ‘profoundly retarded’ with multiple handicaps, should be living in the community (*Halderman v. Pennhurst* (1983)).

In the long running Federal Court case, *Wyatt v Stickley*, the Judge ruled that “An ‘informed choice’

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might include the opportunity to visit community sites, talk with the providers, talk with the other consumers, visit community workshops and jobs, and have a trial placement in the living arrangement. Habilitation and normalization require that the plaintiffs have this choice” (1997). These cases were the frontrunners and became the standards of what constituted informed choice.

3.1. Statutory

Over the past few decades the concept of informed choice has emerged in other laws, decisions and regulations that underpin the type of services and supports provided today. Recent guidance issued by the U.S. Department of Justice clarifies the meaning of the ADA and Olmstead as a framework for promoting true social integration and meaningful choices that are reflective of cultural norms.

In 1990, Congress enacted the ADA “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.” In passing the ADA, Congress recognized that “historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.” Therefore, the ADA and its Title II regulations require public entities to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” The preamble to the “integration mandate” regulation explains that “the most integrated setting” is one that “enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible...”

In Olmstead, the Supreme Court, interpreting the ADA and its integration mandate, held that Title II prohibits the unjustified segregation of individuals with disabilities. The Supreme Court held that public entities are required to provide community-based services to persons with disabilities when (a) such services are appropriate; (b) the affected persons do not oppose community-based treatment; and (c) community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of others who receive disability services from the entity.

Statement of the Department of Justice on Application of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C. to State and Local Governments’ Employment Service Systems for Individuals with Disabilities.


Since first appearing in the 1992 amendments to the Rehabilitation Act of 1973, the concept of informed choice has been closely linked to competitive integrated employment outcomes. For example, the U.S. Department of Justice relies on informed choice to determine if an individual wants integrated employment. The Rehabilitation Act ties informed choice to individual dignity and the pursuit of meaningful careers (29 U.S.C. §701 (c)(1)). Informed choice is embedded in the person-centered planning process for Home and Community Based Waiver Services under Federal Medicaid policy guidance, where recent requirements clearly indicate competitive integrated employment is the preferred outcome (42 CFR 441.301(c)(2)(i)).

3.2. Workforce innovation and opportunities act (WIOA)

In 2014 Congress passed the Workforce Innovation and Opportunities Act (WIOA) establishing competitive integrated employment for people with disabilities as a national priority. The explicit goal of the law is to increase competitive integrated employment. The law defines employment for people with disabilities as Competitive Integrated Employment (CIE). It redefined competitive employment as fully integrated, in synch with what was required by the Lane case. The law requires that people with disabilities be paid the same wages and have the same benefits as people without disabilities, and to interact with coworkers and get the same opportunities for career advancement as coworkers without disabilities. It substantially restricts the use of subminimum wages, especially for youth. WIOA requires state agencies such as Vocational Rehabilitation, Medicaid, Departments of Education, and State Developmental Disability Authorities to work together and to prioritize CIE and to address disincentives to employment for people with significant disabilities.

States have already made positive changes consistent with WIOA. Vermont has eliminated the use of sheltered workshops (Stockton, 2014) and Mas-
sachusetts has stopped funding sheltered workshops as of August 2016 (NASDDDS, 2016).

New Hampshire was the first state to ban sub-minimum wage employment in 2015, Senate Bill 47 (Carlson, 2015). The Maryland General Assembly followed this example on May 19, 2016 with the Ken Capone – Equal Employment Act (2016), eliminating the use of subminimum wage. The bill was named after Ken Capone, a former worker in a sheltered workshop and a Board officer of Maryland’s Protection and Advocacy agency (Grunberger, 2016).

### 3.3. Legal action

In recent years, the DOJ has brought additional ADA/Olmstead cases to further clarify the application of the ADA to non-residential settings, employment and transition from school to work services (see Appendix B). Two such cases are described below: *Lane v. Brown* and *U.S. v. Rhode Island.*

For states to authentically offer real choice, often systems change is necessary to build the capacity to support the choices people actually want (real homes, real jobs, unpaid relationships, friends). Regarding employment, the Department of Justice has advised states: “to continue to avoid unnecessary segregation for the long term, states addressing a history of segregated employment should engage in affirmative efforts at system transformation” (U.S. Department of Justice, 2011, p. 12).

**Lane v. Brown.** *Lane v. Brown* is a class action that challenged the unnecessary segregation of over 3,000 individuals with intellectual and developmental disabilities who were in sheltered workshops in Oregon. The complaint alleged that many of these individuals would prefer to receive supported employment services that would allow them to work in integrated employment settings if these individuals had the opportunity to receive experientially based choice and realistic opportunities to receive such services.

In addition, many youth with Intellectual and Developmental Disabilities in public schools were not offered timely and adequate services to allow them to make informed choices about transitioning to work in integrated settings after graduating from or exiting secondary school. The State also frequently failed to ensure that transition-age youth with Intellectual and Developmental Disabilities were informed of alternatives to working in segregated sheltered workshops.

The State’s failure to prepare youth with Intellectual and Developmental Disabilities to make an informed choice about postsecondary work in integrated settings was exemplified by the fact that some schools operated sheltered workshops on school premises or had students perform activities that were similar to those performed in sheltered workshops. Few schools actually exposed students with I/DD to, or prepared them for, typical jobs in the community. The State’s failure to prepare students with I/DD for integrated employment resulted in these students’ acculturation and training in segregated sheltered workshops, and often led to permanent placement in segregated sheltered workshops.

This case was the first in the nation to directly hold that the ADA applies to employment settings and requires States and other public entities to provide employment services in integrated settings rather than in segregated sheltered workshops. In crafting the remedy, the vision for all people with developmental disabilities in Oregon was to have access to the same opportunities and choices as Oregonians without disabilities.

In 2015, the Plaintiffs and the United States entered into a Settlement Agreement with the State of Oregon, as well as other named state officials to resolve all violations of the Americans with Disabilities Act (ADA), and the Rehabilitation Act of 1973. The Settlement Agreement incorporated an Oregon Executive Order to “improve Oregon’s delivery of employment services with the goal of achieving competitive integrated employment for individuals with intellectual and developmental disabilities, consistent with their abilities and choices.”6 The Agreement provides that all individuals with I/DD will be provided a Career Development Plan, that all those who prefer integrated employment will be provided supported employment services, that over 1,100 individuals will receive Competitive, Integrated Employment, and that at least 4,900 youth will be offered employment services in an integrated setting. The Agreement also raised expectations for people with disabilities to work in real jobs for real pay, by requiring that integrated employment be compensated at minimum wage or better, that individuals have supports that allow them to work at least 20 hours/week, and that they receive the same pay, benefits, interactions with co-workers, and opportunities for advancement as people doing the same or similar work who do not have disabilities.

**US v. Rhode Island.** The U.S. Department of Justice (DOJ) issued findings about the State of Rhode

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6See *Lane et al. v. Brown et al. Settlement Agreement at 8.*
Island’s unnecessary segregation of individuals with intellectual and development disabilities in sheltered workshops and facility-based day programs in violation of the ADA and Olmstead. The DOJ found that Rhode Island significantly and unjustifiably relied on segregated settings to the exclusion of integrated alternatives such as supported employment and integrated day services. In 2014, the United States and Rhode Island entered into a consent decree to resolve the violations (U.S. v. State of Rhode Island, 2014).

The Rhode Island Consent Decree also underscores the importance of informed choice and provides clear evidence that, although most of the Olmstead litigation is focused on residential settings, its requirements also apply to employment and day settings: “...individuals with I/DD will be offered meaningful options for postsecondary Supported Employment and Integrated Day Services...” and “(s)uch individuals and their families must be provided information through the person-centered planning process sufficient to make a meaningful informed choice between such services and remaining in school” (2014, p. 6).

The Consent Decree makes it clear that competitive, integrated employment is the preferred option. Segregated settings such as facility-based work (e.g. sheltered workshops), group enclaves, mobile work crews, time-limited work experiences or facility-based day programs are permissible only after an individual has: 1) participated in at least one vocational or situational assessment, 2) completed one trial work experience in an integrated work setting, 3) received outreach, education, and support services, and a benefits counseling consultation. Individuals in segregated settings must be reassessed twice a year to ensure that they have a meaningful opportunity to choose Supported Employment Services in an integrated work setting.

Significant changes in Federal Policies and Regulations further support people with disabilities having access to the same choices and opportunities as people without disabilities, and to have the chance to live full lives in the community. Two important examples are: 1) HCBS Final Settings Rule and 2) WIOA.

While these landmark DOJ cases were being litigated, important regulatory and policy changes were occurring that contained the elements of self-determination, informed choice, independence and integration to fully implement the proposed remedies of the cases on a national basis.

The combination of the legal cases and changes in public policy present unprecedented opportunities to significantly advance competitive integrated employment for achieving true community integration and a full life.

3.4. Regulatory

Centers for Medicaid and Medicare – Home and Community Based Services In March 2014, the Home and Community Based Services (HCBS) Final Settings Rule, issued by the Centers for Medicaid and Medicare (CMS) became effective. The Final Rule explicitly set affirmative obligations to States to come into compliance with the ADA and Olmstead through community integration and divesting from segregated programs.

The Final Rule requires that people receiving services through Medicaid HCBS waiver programs have full access to community life and services in the most integrated setting. (https://www.federalregister.gov/articles/2014/01/16/2014-00487/medicaid-program-state-plan-home-and-community-based-services-5-year-period-for-waivers-provider).

The Final Rule required the States to come into compliance within 5 years (March, 2019). While integration was already required under the ADA and Olmstead, for the first time, States were obligated to take the following specific action steps:

1. Develop a Transition Plan to divest from segregation and those services that are isolating from the broader community. The plan must:
   1. Evaluate all of the HCBS funded services to determine those that are integrated or segregated according to the newly released HCBS standards detailing isolating services. The people receiving services have to be included in the assessment process and can challenge the assessments. These processes and tools have to be open, public and transparent.
   2. Address building capacity to ensure every Individual be given an option of a non-disability specific setting (like employment in a competitive job).
   3. Share the plan widely with the broader public and obtain public input from a broad range of constituents into the Plan.
   4. Be submitted to CMS for review and feedback.
   5. Be revised based on CMS feedback.
   6. Be approved by CMS in order to continue to receive federal funds.

Since issuance of the Final Rule, CMS has provided additional Implementation Guidance to
the states (Incentives to Fund Outcomes). The Reviews of the Transition Plans by CMS have been comprehensive. To date, only Tennessee has received final approval of its state Transition Plan. To learn more about the Final Rule and/or track its implementation, see HCBS Advocacy website www.hcbsadvocacy.org.

The Final Rule expectations include the following:

1. Supporting people with disabilities to have lives similar to people without disabilities.
2. Providing opportunities for true integration, independence, choice, and self-determination in all aspects of life – where people live, how they spend the day, and real community membership.
3. Ensuring quality services that meet people’s needs and help each person to achieve goals identified through person-centered planning.

The Final Rule provides an unprecedented opportunity to:

1. Expand capacity of more integrated and individualized services.
2. Move state systems away from outdated, segregated service models.
3. Help states comply with their obligations under Olmstead.

The Final Rule also:

1. Supports access to the greater community.
2. Provides opportunities to seek employment and work in competitive integrated settings, engage in community life, and control personal resources.
3. Requires settings are selected by the individual from among setting options, including non-disability specific settings.
4. Optimizes individual initiative, autonomy, and independence in making life choices.
5. Facilitates individual choice regarding services and supports, and who provides them.
6. Individuals must be given an option of a non-disability specific setting (like employment in a mainstream job).
7. States can require all day services (including pre-vocational services) to be community-based.

States are required to assess the following questions regarding employment settings:

1. Do they “provide individuals with the opportunity to participate in negotiating his/her work schedule, break/lunch times and leave and medical benefits with his/her employer to the same extent as individuals not receiving Medicaid funded HCBS?”
2. Is the individual receiving the “right service” if competitive integrated employment is the desired outcome?

Some day settings will need to be closely examined as potential day “settings that isolate” – sheltered workshops, facility-based day habilitation, adult day health, and day treatment programs.

Employment First State Initiatives. “Employment First,” the idea that competitive employment in an integrated setting should be the priority outcome for people with disabilities, is a national movement. Currently 32 states have Employment First Legislation, executive orders or official policies. Another 17 states have employment first-type initiatives but no official policy. Informed choice is a key component of Employment First. For more information see http://employmentfirst.leadcenter.org/

4. Systems that support informed choice

The concept of informed choice is often confused by professionals and sometimes even used by the service system to support segregation.

Most supports are administered by state Intellectual/Developmental Disability agencies with funding from Medicaid, as part of Medicaid Home and Community-Based Waivers, Vocational Rehabilitation programs, local education agencies and, to a lesser extent, state workforce agencies.

These supports are provided by a network of over 8,000 community rehabilitation providers (CRPs) (Butterworth, et al., 2013). The CRPs are staffed with direct support professionals (DSPs) often referred to as employment specialists, job developers, job coaches, or employment consultants who identify the job seekers’ preferences and needs, identify employers, negotiate job descriptions, facilitate the transition, and provide follow-up supports.

For people to be successful in obtaining CIE, the funders, the CRPs, and the DSPs need to engage in affirmative steps to facilitate the individual’s ability to make an informed choice.

In order to do this well, systems that tend to be more effective in supporting people include the following characteristics (See Table 1):
Table 1

<table>
<thead>
<tr>
<th>Objective</th>
<th>Role of the system</th>
<th>Role of provider</th>
<th>Role of counselors and direct service professionals</th>
<th>Role of individual</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual is the focal point, the driving force, and the decision maker</td>
<td>- Has a unified vision of preferred employment outcomes and informed choice across payers, providers, and DSPs and choice</td>
<td>- Committed to informed choice&lt;br&gt;- Relinquishes power in favor of the consumer.&lt;br&gt;- Recognizes the need to make the client happy&lt;br&gt;- Solicits input/feedback from the client about services</td>
<td>- Has expertise but relinquishes power to the individual&lt;br&gt;- Facilitates the individual’s ability to identify their own preferences&lt;br&gt;- Makes appropriate accommodations to support the individual’s meaningful participation in meetings and other aspects of the decision-making process</td>
<td>- Directs the Person Centered Planning process&lt;br&gt;- Chooses who will be involved in which decisions&lt;br&gt;- Makes choices known with necessary support</td>
</tr>
<tr>
<td>Individual has information, knowledge, and experience</td>
<td>- Ensures that each individual has access to information including opportunity to experience alternatives</td>
<td>- Uses discovery to help person see the options, develop preferences, and articulate the choice&lt;br&gt;- Sets up trial work opportunities&lt;br&gt;- Participates in the process where individual chooses provider</td>
<td>- Ensures that the individual understands the options by (1) creating experiential opportunities and (2) uses appropriate modes of communication and other support services</td>
<td>- Shares hopes, dreams and aspirations with the support necessary to do so.</td>
</tr>
<tr>
<td>Individual has appropriate supports to facilitate choice</td>
<td>- Invests the process of helping people to understand their options and moving further along the continuum of independently making decisions</td>
<td>- Identifies and addresses barriers that might interfere with the individual’s ability to make an informed choice&lt;br&gt;- Teaches self-determination&lt;br&gt;- Looks closely at a person’s life for indicators of preference</td>
<td>- Identifies trusted people to assist with decision-making</td>
<td>- Identifies trusted people to assist with decision-making</td>
</tr>
<tr>
<td>Individual has meaningful choice among multiple options and can create new options</td>
<td>- Funds are assigned to people rather than programs&lt;br&gt;- The system has a range of service options from traditional and non-traditional providers&lt;br&gt;- System has allocated funds in such a way as to ensure there is adequate capacity to accommodate individual’s choice.&lt;br&gt;- Funds from multiple agencies are seamlessly integrated to fund services for each individual&lt;br&gt;- Funding mechanism reflects policy priorities</td>
<td>- Is flexible in the type of services it provides&lt;br&gt;- Honors the preferences of the person</td>
<td>- Creatively looking at options—expertise&lt;br&gt;- Find or design new possibilities based on individual’s dreams desires and experience</td>
<td>- Identifies non-negotiables&lt;br&gt;- Actively participates&lt;br&gt;- Experiences multiple options based on preferences, skills and capacities.&lt;br&gt;- Has a trusted person (navigator) to support you to express your concerns, issues and worries.</td>
</tr>
<tr>
<td>Objective</td>
<td>Role of the system</td>
<td>Role of provider</td>
<td>Role of counselors and Direct service Professionals</td>
<td>Role of individual</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
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</tr>
<tr>
<td>Individual has right to choose people to support them</td>
<td>-Uses family members, support system and expertise of the provider appropriately without pressure</td>
<td>-Encourages and values the input from others.</td>
<td>-Chooses people to help make decisions</td>
<td></td>
</tr>
<tr>
<td>Individual has the right to leave one provider and be served by another</td>
<td>-Funding is tied to individual rather than a program so the money moves with the individual to another provider</td>
<td>-Support Coordinators solicits person's wish and desire and facilitates changes when necessary</td>
<td>-Exercises right for provider choice, right to leave one provider and be served by another</td>
<td></td>
</tr>
<tr>
<td>Individual receives ongoing advice and support and opportunity to modify choice</td>
<td>-System to reassess the placement at will or periodically</td>
<td></td>
<td>-Exercises right to make choices</td>
<td></td>
</tr>
<tr>
<td>Individual has control of resources, selecting providers, targeting information and deciding what is relevant</td>
<td>-The funding mechanism gives the individual a maximum amount of control while maintaining accountability and responsible stewardship of public funds</td>
<td>-Participates in the process where the individual chooses the provider.</td>
<td>-Exercises autonomy and control. Focuses on most important pressing needs</td>
<td></td>
</tr>
<tr>
<td>Individual is free of undue pressure</td>
<td>-Conflict free independent Support Coordination/case management</td>
<td>-Is responsive to the person’s desires and overcoming the status quo. Safeguarding against staff convenience</td>
<td>-Starts all planning and interactions with an agenda that is free from system and program assumptions</td>
<td>-Exercises autonomy and control</td>
</tr>
<tr>
<td>Individual has control--Is empowered to make decisions</td>
<td>-Conflict free independent Support Coordination/case management</td>
<td>-Invests in the process of helping people to understand their options, independently making decisions and taking pride for those decisions</td>
<td>-Supports the job seeker to make decisions, even those that might not be the ones you might have made for the person</td>
<td>-Exercises autonomy and control</td>
</tr>
<tr>
<td>Other issues that need to be discussed but are not directly tied to the definition</td>
<td>-Safeguards against exploitation and retaliation</td>
<td>-Credential and certification issues</td>
<td>-Have the right to change their mind and exercise dignity of risk.</td>
<td></td>
</tr>
</tbody>
</table>
• Adequate capacity to offer choices consistent with the law and contemporary practice in CIE
• Opportunity to experience a diversity of jobs based on individual interest: In terms of choosing a type of job, it is not sufficient for the state to merely describe the options to the individual. The individual must have an opportunity to experience the job for their choice to be considered “informed.”
• Access to information: The system provides information in a manner that the person genuinely understands job options in choosing a type of job.
• Meaningful choice of provider: Competent and skilled providers must be available to offer diverse possibilities for real competitive integrated employment. They should utilize employment practices that are culturally typical and consistent with good practices in supported employment. Choice is a hollow promise if the necessary supports for employment are not available (Callahan & Mank, 1997).
• Divestment from segregation: If a large amount of money is expended to keep people in segregation, this restricts funds available for meaningful choices of integrated options. A common misunderstanding of the Olmstead decision is the belief that the State has an obligation to provide and fund segregation, which they do not.
• Conflict-free case management: To safeguard against the conflict that exists because providers naturally prefer that individuals choose goals and paths that fit within their agencies’ existing service menus, and that the goals can be achieved with their agencies’ current resources, CMS formalized the concept of “conflict-free” case management in its Balancing Incentives Program (BIP) and defined additional components including monitoring, oversight, grievance procedures, and stakeholder engagement.
• Individuals are supported to communicate their preferences: Some people with significant disabilities have difficulty understanding or communicating their choices. If an individual can only understand and make yes/no choices then choices should be offered in a yes/no format. For individuals who have limited communication ability, it may be necessary to provide Assistive Technology and use strategies that utilize resources and supports such as

family members, friends, advocates and others through person-centered planning strategies. (Storey, 2005).
• Service options are available from traditional and non-traditional providers: Established providers need to expand their menu of services to meet the needs of participants. At the same time, non-traditional providers may be needed to meet the choices of some individuals. This creates a challenge for the system. In an effort to ensure that services are of high quality and meaningful, government funding agencies require that providers use “qualified personnel.” However, these formal qualification requirements favor traditional providers and may exclude others from providing services thus limiting the range of options available (Callahan, 1998).

Finally, states that effectively support informed choice structure funding in ways that drive outcomes. Such funding systems must allocate funds in a way that does not restrict choice, gives individuals a maximum amount of control, and supports a full range of options in the community. In practice this means the following:
• Funding is tied to people rather than programs: The Individual must be able to leave one provider and be served by another if they wish and the money should follow them to the provider of their choice. This contrasts with the traditional funding mechanism where the funding agency contracts with a provider to offer a certain set of services. If the individual leaves the program, there are no changes in the program’s level of funding because the money is assigned to the program not the person (Callahan & Mank, 1997).
• The funding mechanism gives the individual a maximum amount of control while maintaining accountability thereby fulfilling the requirement for responsible stewardship of public funds: Personal budgets or individual accounts are the funding mechanism most aligned with the concept of choice. In these approaches, an individual is given access to a pool of funds and is free to spend it on any configuration of employment supports, even non-traditional providers of service. This places the individual with a disability in the same position as people without disabilities when it comes to their status in the buyer-seller relationship.
Other funding approaches can enhance informed choice. For example, the state may have an outcome-based funding arrangement where at least some of a provider’s compensation is contingent upon reaching agreed-upon outcome performance measures. This approach creates an incentive for swift achievement of employment goals, and reinforces the principles of rapid job placement, consumer choice, and retention through natural supports. (Hall, Freeze, Butterworth, & Hoff, 2011). A funding structure that pays providers on a day rate is completely incompatible with informed choice and should be avoided.

- **Funding mechanisms reflect policy priorities:** States with policy and funding alignment pay more for desired outcomes (a community job), and less or nothing at all for outcomes that are not a priority. Funding rates are based on the real-world costs of providing high-quality integrated employment, and do not solely rely on the typical approach of revising funding based upon historical costs.

- **The system has relevant performance measures:** Traditionally employment indicators look at the number of hours worked, wages earned and other factors such as paid vacation leave. Systems should also be measuring the degree to which the outcome matched the participant’s desires (WIOA Advisory Committee, 2016).

### 4.1. Practices that support informed choice

A number of states have instituted creative practices that support informed choice and leverage quality employment outcomes. These range from creating financial incentives to peer mentoring of case managers, vocational rehabilitation counselors and other gatekeepers, strategies for guiding career aspiration, and building capacity so that real choice can be offered in all the communities where people live. Equally, some states have been more aggressive in eliminating segregated day service options (See Appendix A: Examples of Good Practices Supporting Informed Choice from the States).

### 5. Conclusion

As we have described throughout this Policy Brief, we are in a time of rapid change. There is unprecedented alignment of law and policy and regulation that aim to create a mandate and affirmative obligations for state and federal systems to support people with disabilities to have the same choices and opportunities as people without disabilities. A window of opportunity has opened to exploit these changes and for the vision of full participation and inclusion in community life to be realized for people with disabilities. But that window could close. Or we could have what Burton Blatt once called a “reform to sameness” (Blatt, 1970).

We need to have appropriately high expectations for people with disabilities. Also, a respect for the exercise of what famed author and advocate Bob Perske called “the dignity of risk” (Perske, 1972). This includes opportunities for people with disabilities to exercise the right to make informed choices – big and small in life – from big things like working and contributing in life and who to live with, to the smallest things that can often make all the difference in a person’s life.

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### Conflict of interest

The authors have no conflict of interest to report.

### References


BOSTON, Institute for Community Inclusion (UCEDD), Boston, MA.


Lane V. Brown (283 F.R.D. 587, 600 (D. Or.) 2012).


APPENDIX A: Examples of Good Practices
Supporting Informed Choice from the States

Iowa:

Iowa has developed a model with a facilitated process to assist people with disabilities to leave sheltered workshops for integrated work. Providers are given 34 hours of an enhanced rate for Pre-Vocational Services to follow a step-by-step process to support informed choice and smooth transition to integrated work:

1) Attend work service planning meeting covering topics such as, “What is Supported Employment?” and “Why Work?” People are supported to express any preliminary concerns regarding going to work and any concerns about leaving the sheltered workshop.

2) Participate in a “Bridge” Discovery Process (not the full-blown formal Discovery Process), but enough to initiate and guide career exploration.

3) Access basic information on benefits.

4) Meet to discuss summary report (what strengths, gifts, and interests were found, the basics of Supported Employment and how it works, and address frequently asked questions).

5) If the individual still indicates “no” to competitive, integrated employment, s/he is referred to a different service than pre-vocational/subminimum wage work in a workshop. People looking for work can stay in the program. (This eliminates any incentives for provider to encourage the person to say no to work.)

Tennessee:

The State has made a significant commitment to rebalancing its day services, phasing out sheltered workshops, and building capacity for Competitive Integrated Employment (CIE), so that real choices are available across the state.

There is a new waiver for Discovery. If people are “not interested in employment,” they must complete a Discovery process before they can continue in Day Habilitation or Pre-Voc. If after Discovery, they are still not interested in working, they must find other program services. The State will not continue to fund Pre-Vocational or “Work Training.”

Maine:

The State of Maine funds Discovery through Developmental Disabilities Services with the caveat that VR will open a case – direct linkage and no refusals- for Supported Employment Placement Services.

Wisconsin:

Wisconsin addressed the critical role of case managers as “gatekeepers” to employment opportunities and supports. They recruited case managers who had the highest placement rates in the state. (They found that many had VR, Transition, or SE experience). Then the State: 1) Convened a focus group; 2) Did a panel training for other case managers; 3) Promoted these case managers’ approaches and touted successful outcomes for people on their caseloads; and 4) Are considering tying annual job placement/job acquisition percentages to annual performance evaluations and compensation.

APPENDIX B: Informed Choice in Law and Regulation

• Americans with Disabilities Act and Related Cases
  
  i. Olmstead Decision
  
  In 1999, the Supreme Court held in Olmstead v. L.C. that unjustified segregation of people with disabilities constitutes discrimination in violation of the 1990 Americans with Disabilities Act. The Court held that public entities must provide community-based services to persons with disabilities when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated.

  In 2011, the Department of Justice (DOJ) established that informed choice should be the arbiter of whether an individual does “not oppose an integrated setting.” In its statement on the enforcement of the Integration Mandate, DOJ wrote:

  Individuals must be provided the opportunity to make an informed decision. Individuals who have been institutionalized and segregated have often been repeatedly told that they are not capable of successful community living and have been given very little information, if any, about how
they could successfully live in integrated settings. As a result, individuals’ and their families’ initial response when offered integrated options may be reluctance or hesitancy. Public entities must take affirmative steps to remedy this history of segregation and prejudice in order to ensure that individuals have an opportunity to make an informed choice. Such steps include providing information about the benefits of integrated settings; facilitating visits or other experiences in such settings; and offering opportunities to meet with other individuals with disabilities who are living, working and receiving services in integrated settings, with their families, and with community providers. Public entities also must make reasonable efforts to identify and address any concerns or objections raised by the individual or another relevant decision-maker.

Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.7

In response to claims Olmstead does not require that states impose community services on people who do not want them, Courts have found, consistent with DOJ’s interpretation, that the ADA and Olmstead require states to provide services in integrated settings but does not obligate the states to provide them in institutions or segregated settings.

ii. U.S. v Rhode Island

In 2014, the U.S. Department of Justice entered into a settlement agreement with the State of Rhode Island for unnecessarily segregating individuals with intellectual and development disabilities in sheltered workshops and facility-based day programs rather than providing and promoting integrated alternatives such as supported employment and integrated day services.

The Rhode Island Settlement Agreement reiterates the importance of informed choice and provides clear evidence that, although most of the Olmstead litigation is focused on residential settings, its requirements also apply to employment and day settings:

“...individuals with I/DD will be offered meaningful options for postsecondary Supported Employment and Integrated Day Services …” and “(s)uch individuals and their families must be provided information through the person-centered planning process sufficient to make a meaningful informed choice between such services and remaining in school.”

The settlement agreement makes it clear that competitive, integrated employment is the preferred option. Segregated settings such as facility-based work (e.g. sheltered workshops), group enclaves, mobile work crews, time-limited work experiences or facility-based day programs are permissible only after an individual has: 1) participated in at least one vocational or situational assessment, 2) completed one trial work experience in an integrated setting, 3) received outreach, education, and support services, and 4) a benefits counseling consultation. Individuals in segregated settings must be reassessed twice a year to ensure that they have a meaningful opportunity to choose Supported Employment Services in an integrated work setting.

iii. United States v. Virginia

Under the settlement agreement reached between the United States and the State of Virginia following the results of an investigation which determined that Virginia failed to provide services and supports to individuals with I/DD in the most integrated setting appropriate to their needs as required by Olmstead and the ADA, discharge plans must be developed with the input of the individual with I/DD through a documented person-centered planning process. Through a person-centered planning process, there is a greater likelihood that the individual makes a meaningful informed choice as to where they live and work.8

During the discharge planning process, individuals with disabilities and their families must be provided with the opportunity to speak with community providers, visit community placements and programs, and facilitate conversations and meetings with individuals currently living in the community and their families prior to being asked to make a choice regarding community options. Family-to-family peer support programs will help facilitate this process.9

In addition, training centers must have knowledge about community services and supports in order to propose appropriate options regarding how an individual’s needs could be met in a more integrated setting, present families with specific options for

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9Id. at 16.
community placements, services, and supports, and together with providers, answer questions asked by individuals and their families about living in an integrated community setting.

a. Medicaid

Medicaid’s Home and Community Based Services waiver program (HCBS) is the largest Federal source of funds for employment services for people with intellectual and developmental disabilities. Although states have flexibility in designing their waiver programs, the Centers for Medicare and Medicaid Services (CMS) require that all HCBS waivers include a person-centered planning process.

Although the term is not always used, the concept of informed choice is deeply embedded in the person-centered planning process. CMS specifies that the individual will lead the person-centered planning process where possible; that necessary information and supports are available to support the individual to provide this leadership; the process will include other participants chosen freely by the individual; it will be based on the strengths, preferences, needs, and desired outcomes of the individual; and the process will identify a mix of paid and non-paid services and supports that will assist the individual to achieve those outcomes in the most inclusive community setting; and that the individual can make an informed choice regarding the services and supports they receive and from whom. The plan must be reviewed and revised at the request of the individual or at least every 12 months. 42 §441.301(c)(1)-(3)

b. Workforce Innovation and Opportunity Act (WIOA)

The Workforce Innovation and Opportunity Act (WIOA) amended the Rehabilitation Act to add Section 511 which places limitations on the payment of subminimum wages by entities holding special wage certificates under section 14(c) of the Fair Labor Standards Act. It specifies that an individual cannot begin working in a subminimum wage job unless it can be shown that “the individual has been provided career counseling, and information and referrals to Federal and State programs and other resources in the individual’s geographic area that offer employment-related services and supports designed to enable the individual to explore, discover, experience, and attain competitive integrated employment.” 511(a)(2)(B)ii(I) Furthermore, an entity “may not continue to employ an individual, regardless of age, at a subminimum wage unless the individual is provided counseling, and information and referrals...delivered in a manner that facilitates independent decision making and informed choice, as the individual makes decisions regarding employment and career advancement.” PL113-128 §511(a)(2)(B)ii(I)

The Workforce Innovation and Opportunity Act (PL 113-128) specifies that consumers, with and without disabilities, must have an “informed customer choice in the selection of training programs.” PL 113-128 §108(b)19. To facilitate the choice, the system should “ensure there are sufficient numbers and types of providers of career services and training services (including eligible providers with expertise in assisting individuals with disabilities and eligible providers with expertise in assisting adults in need of adult education and literacy activities) serving the local area and providing the services involved in a manner that maximizes consumer choice, as well as providing opportunities that lead to competitive integrated employment for individuals with disabilities.” PL 113-128 §107(d)(10)(E)

The legislation guarantees that the customer has a choice of providers but neither the legislation nor the proposed administrative rules include any language about the role or responsibility of the system to ensure that the individual has the appropriate information to make this choice.

c. Vocational Rehabilitation

Informed Choice is a key concept in the rules and regulations operating the Vocational Rehabilitation System. The first section of the Rehabilitation Act declares:

> 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: (1) respect for individual dignity, personal responsibility, self-determination, and pursuit of meaningful careers, based on informed choice, of individuals with disabilities.

Rehabilitation Act: 29 U.S.C §701.

The importance of informed choice is reiterated in the regulations guiding the implementation of the Rehabilitation Act. It states that the purpose of the statewide grants to assist states in operating programs are “Designed to assess, plan, develop, and provide vocational rehabilitation services for individuals with disabilities, consistent with their strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice, so that they may prepare for and engage in gainful employment.” 34 CFR §361.1 (b). The phrase
consistent with an “individual’s strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice” is repeated 14 times in the regulations.

Since first appearing in the 1992 Amendments to the Vocational Rehabilitation Act of 1973, the term “informed choice” has been clarified in subsequent amendments, regulations, and policy directives and now include the following requirements for Vocational Rehabilitation system and service providers funded by that system:

**Eligible individuals must have the opportunity and support to exercise their informed choice throughout the employment process.** The IPE must “be developed and implemented in a manner that affords eligible individuals the opportunity to exercise informed choice in selecting an employment outcome, including the employment setting; the specific VR services needed to achieve that outcome; the entities that will provide the service; service providers, and methods for procuring services.” 34 CFR §361.45(d)(2). The choice of procurement methods must be accompanied by flexible procurement policies that afford individuals meaningful choices. 34 CFR §361.52(b)(3).

**VR agencies must help individual acquire the information they need to exercise informed choice and provide appropriate support for individuals who need assistance in exercising their right to an informed choice.** Congress specifically recognized that importance of “providing individuals with the disabilities with the tools necessary to make informed choices and decision.” 29 U.S.C §701(a)(6)(A). This includes using appropriate modes of communication to ensure each individual receives information concerning the availability and scope of informed choice, the manner in which it may be exercised, and the availability of support services for individuals with cognitive or other disabilities who require assistance in exercising informed choice. 29 U.S.C §722(d)(1).

**VR must document the presence of informed choice in the process.**

The VR agency must encourage integrated employment prior to referring an individual to a sheltered workshop. Individuals must be offered information, experience and support to exercise informed choice before they can be placed or remain in a subminimum wage job and that the information must be provided by an entity without a conflict of interest. (P.L. 113-128 §511)

### APPENDIX C: Informed Choice in Regulation

The mandate to afford people with significant disabilities the opportunity to have an informed choice in determining their employment appears in regulations, and guidance at the Federal and state levels.

Informed choice is required in the services that the following Federal agencies fund and deliver:

- **Services administered through State Vocational Rehabilitation agencies, as guided by the Rehabilitation Services Administration:** The Rehabilitation Act requires agencies to ensure that eligible individuals have the opportunity to exercise informed choice in selecting an employment outcome, including the employment setting; the specific VR services needed to achieve that outcome; the entities that will provide the service; service providers, and methods for procuring services. 34 CFR §361.45(d)(2). The choice of procurement methods must be accompanied by flexible procurement policies that afford individuals meaningful choices. 34 CFR §361.52(b)(3).

- **WIOA Section 511**

Through amendments to Title V of the Rehabilitation Act (which is effective on July 22, 2016), Section 511 of WIOA prioritizes, and places heightened emphasis upon, the provision of services that maximize opportunities for competitive integrated employment for individuals with disabilities, including those with the most significant disabilities, consistent with their unique strengths, resources, priorities, concerns, abilities, capabilities, interests, and informed choice. 34C.F.R. §397.

The purpose of proposed part 397 is to set forth requirements that designated state units and state and local educational agencies must satisfy to ensure that individuals with disabilities, especially youth with disabilities, have a meaningful opportunity to prepare for, obtain, maintain, advance in, or regain competitive integrated employment, including supported or customized employment. WIOA requires that the designated state unit provide career counseling, and information and referrals to federal and state programs and other resources in the individual’s geographic area that offer employment related services and supports designed to enable the individual to explore, discover, experience,
and attain competitive integrated employment in a manner that facilitates informed choice and decision-making by the youth, or the youth’s representative as appropriate. 34C.F.R. § 397.

- **Services provided by State Medicaid agencies under the Centers for Medicare and Medicaid Services through Home and Community Based Waivers and State Plan Options:** CMS requires that all HCBS waivers include a person-centered planning process that guarantees that individuals can make an informed choice regarding the services and supports they receive and from whom. 42 § 441.301(c)(1)-(3)

- **HCBS Settings Rule in defining the parameters of the choices offered:** Although the term is not always used, the concept of informed choice is deeply embedded in the person-centered planning process. CMS specifies that the individual will lead the person-centered planning process where possible; that necessary information and supports are available to support the individual to provide this leadership; the process will include other participants chosen freely by the individual; it will be based on the strengths, preferences, needs, and desired outcomes of the individual; and, the process will identify a mix of paid and non-paid services and supports that will assist the individual to achieve those outcomes in the most inclusive community setting; and that the individual can make an informed choice regarding the services and supports they receive and from whom. The plan must be reviewed and revised at the request of the individual or at least every 12 months. 42 § 441.301(c)(1)-(3)

- **The Final Rule of the Medicaid Home and Community Based Services (HCBS), 1915(c), 1915(i) and 1915(k), was enacted to ensure that individuals receiving long-term services and supports through HCBS programs under the Medicaid authorities have full access to benefits of community living and the opportunity to receive services in the most integrated setting appropriate. The Settings Rule establishes an outcome oriented definition that focuses on the nature and quality of individuals’ experiences, the requirement to maximize opportunities for individuals to have access to the benefits of community living, and the opportunity to receive services in the most integrated setting. The HCBS Settings Rule defines the person-centered planning requirements. Person-centered service plans document the options based on the individual’s needs, preferences; and for residential settings, the individual’s resources. Final Rule CMS 2249-F and CMS 2296-F; Medicaid Program; State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, and Home and Community-Based Setting Requirements for Community First Choice (Section 1915(k) of the Act) and Home and Community-Based Services (HCBS) Waivers (Section 1915(c) of the Act).**

- **Job Development and Training Services provided by America’s Job Centers within the workforce investment system as funded by the U.S. Department of Labor’s Employment & Training Administration:** The Workforce Innovation and Opportunity Act (PL 113-128) specifies that consumers, with and without disabilities, must have an “informed customer choice in the selection of training programs.” PL 113-128 § 108(b)19.

- **Social Security Administration’s Ticket to Work program:** The Ticket Act specifies that the Employment Network shall “develop and implement each individual work plan in partnership with each beneficiary receiving services in a manner that affords the beneficiary the opportunity to exercise informed choice in selecting an employment goal and specific services needed to achieve that employment goal.” PL 106-170 § 101(g)(1)(B)

At the State level, at least 32 states have some form of Employment First initiatives (ICI 2013) many of which specify informed choice as a guiding principle. Since first appearing in the Rehabilitation Act of 1992, the concept of Informed Choice has been closely linked to competitive integrated employment outcomes. For example, the U.S. Department of Justice relies on informed choice to determine if an individual wants integrated employment. The Rehabilitation Act ties informed choice to individual dignity and the pursuit of meaningful careers. 29 U.S.C. § 701 (c)(1). Informed choice is embedded in the person-centered planning process for Home and Community Based Waiver Services under Federal Medicaid policy guidance, where recent requirements clearly indicate competitive integrated employment is the preferred outcome 42 CFR 441.301(c)(2)(i).