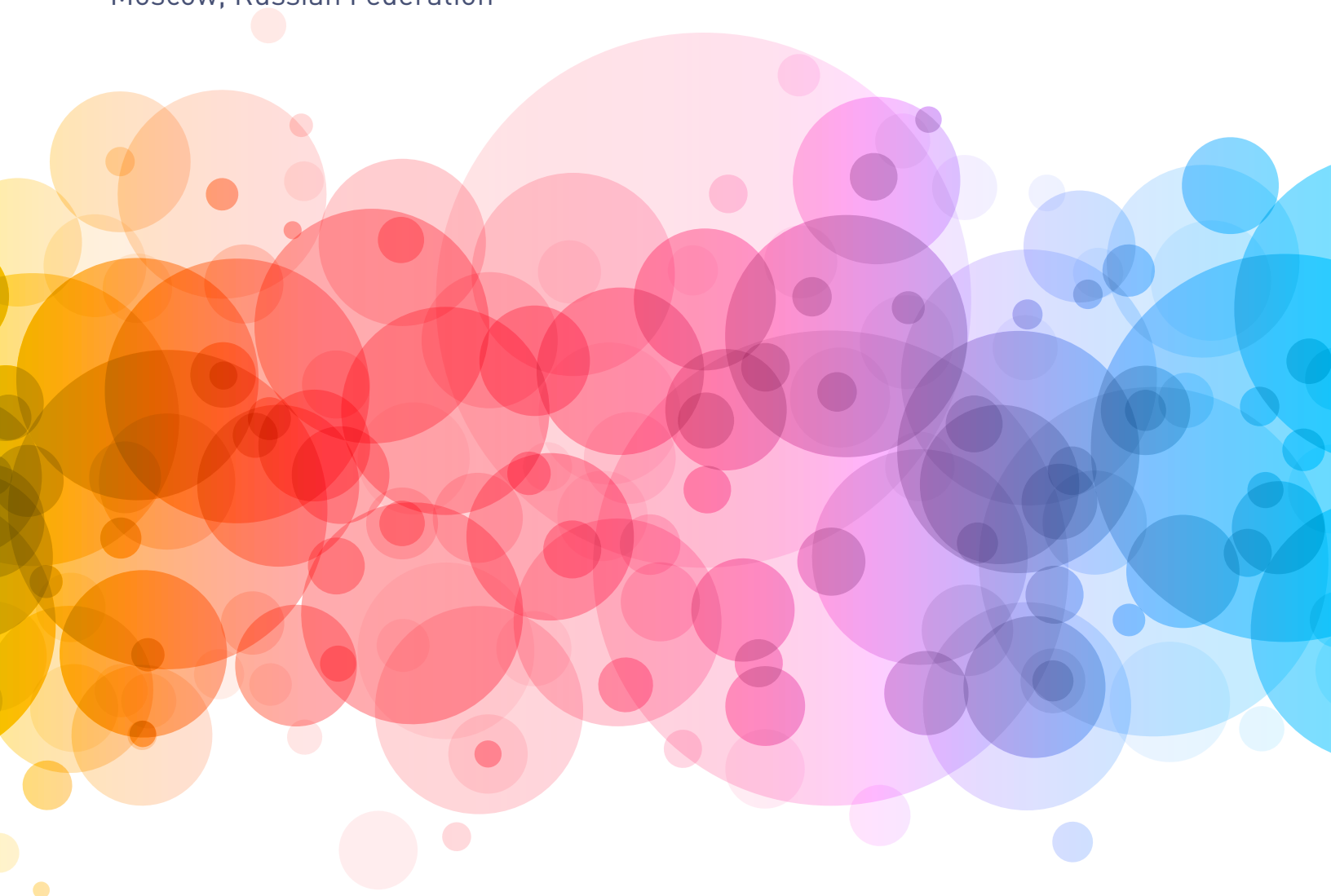


# Handbook on Community Living and Employment

Institute on Community Integration  
University of Minnesota, USA

Life Route Foundation  
Moscow, Russian Federation



Handbook on Community Living and Employment

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## INTRODUCTION

# Concepts, Challenges, and the Support of Community Living and Employment for People with Disabilities

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## Living a valued and meaningful life

Every adult with or without a disability is entitled to live in the community of their choice, develop and maintain friendships based on their preferences, establish intimate relationships, have access to healthcare and other needed services and supports, and the opportunity work in a job that matches their interests, skills, and talents. These are not only outcomes toward which all societies and cultures should aspire on an ethical basis, but are codified as basic human rights under the United Nations Convention for the Rights of Persons with Disabilities (CRPD, 2006).

Over the past several decades, many nations have made significant progress towards providing greater opportunities for inclusive community living to their citizens with disabilities. Within these countries: (1) young adults with disabilities have access to transition programs to prepare them for the move from school to work or other activities; when culturally appropriate, from living with their families to living in the community; to developing their own social networks; (2) a range of opportunities are available for adults with disabilities to reside within the community with supports provided in a person-centered manner; (3) people have the option of directing their own supports, including determining those areas in which they desire services, who will provide them, and how these will be delivered; (4) alternatives to guardianship are available for people who experience challenges making informed decisions, including supported decision-making; (5) self-determination is both explicitly and implicitly supported; (6) the community has become more accessible in both physical and other ways to persons with a wide range of abilities and support needs; and (7) people with disabilities are supported to obtain and maintain employment within inclusive community settings in positions that are consistent with their interests and that provide career paths.

While some countries have already made progress toward creating societies that are more inclusive and supportive of persons with diverse abilities and support needs, others are just embarking on this journey. Given the differences we observe across countries with respect to cultural perspectives and attitudes about disability (e.g. viewing disability from a medical as opposed to a social model), the resources that are available to support inclusive community living and employment; differences in the roles of local, state/territorial, and federal authorities; an emphasis on evidenced-based (i.e. research-based) versus theoretically-based practices, and the myriad of other challenges faced by persons with disabilities, the simple application of approaches used in one country to another is unlikely to be successful. As a result, models and programs for community living and employment need to be developed for each country specifically, evaluated for their effectiveness and subsequently shared in order for all of us to learn from each other's innovative practices, successes, and challenges.

## The multiple components of community living

Figure 1. Components of community living



Supporting positive community living outcomes for persons with disabilities is a multi-faceted process. There are many components to successful community living (see Figure 1). In the U.S., these outcomes have been identified by the National Quality Forum (NQF, 2016), a not-for-profit, nonpartisan, organization that works to catalyze improvements in human services as critical aspects of community living. These outcomes are important to measure for all people with disabilities. This framework for community living, that includes community-based employment, has been validated with large groups of persons with disabilities, family members, providers of community support services, and program administrators (Abery, Tichá, & Goodnight, 2019). Implicit with-

in this model is the idea that experiencing each of these outcomes in a positive manner supports an individual in leading a high *quality of life* - an outcome to which *all people* regardless of ability are entitled (CRPD, 2006).

### Quality of life

The World Health Organization (WHO) defines quality of life (QOL) as “the individual’s perception of their position in life in the context of the culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns” (WHOQOL, 1997). Over the past three decades, this concept has been increasingly applied in efforts to enhance community living of persons with

disabilities. The QOL construct has been a tool that policy makers, including the World Health Organization (WHO, 1997), have used in an effort to move persons with disabilities out of institutions and into community living arrangements. Schalock makes the argument that QOL “concerns the very essence or essential aspects of human existence.” (Schalock et al, 2002, pp. 458). As Schalock and his colleagues report, international consensus studies suggest that, across cultures, QOL shares a number of common features, including general feelings of well-being, positive social involvement, and opportunities to work toward achieving one’s personal potential. The core dimensions that lay behind the concept (see Table 1) include personal well-being of a physical, psychological, and material nature, interpersonal relations based upon one’s own decisions as to whom to affiliate, opportunities for personal development, self-determination, and social inclusion all considered within the context of an ecological-lifespan perspective.

The indicators included in Table 1 are based on a synthesis of the international QOL literature (Schalock & Verdugo, 2002) and indicate the multidimensional nature of the QOL construct. For individuals with disabilities, living a high quality of life in all cultures has been a challenge. Dozens of studies across multiple cultures dating back to the 1960s document that institutional life is essentially devoid of most, if not all of the domains of quality of life.

### Movement from institutions into the community

Few groups of people have been subject to the same levels of encroachment on their human and legal rights as well as to abuse and neglect as people with disabilities. Despite the fact that people with disabilities are entitled to the same rights as other citizens (CRPD, 2006) and the United Nations Convention on the Rights of Persons with Disabilities (CRPD) has been

**Table 1. Quality of life conceptual and measurement framework**

Domain	Indicators
Emotional well-being	Contentment, positive self-concepts, low levels of stress
Material well-being	Financial status, employment with competitive wages, affordable housing
Physical well-being	Health and health care, leisure & recreation activities, activities of daily living
Personal development	Education, personal competence, performance
Self-determination	Autonomy & personal control, choices, goals and person values
Social inclusion	Community inclusion and participation, community roles, reciprocal relationships & social supports
Interpersonal relations	Interactions with others, social relationships, & supports
Rights	Human (respect, dignity, equality) and legal (citizenship, access, due process)

Adapted from: Schalock, Verdugo, Gomez, & Reinders, (2016).

signed and ratified by all but a few countries, it is still considered acceptable in most parts of the world to deny people with disabilities access to society and confine them in institutions that in many cases are unfit for any human being.

The institutions of today are the last vestiges of past ideologies in which societies were viewed as having the right and power to label people with some type of disability as less than fully human, separate them from their families, friends and the rest of the community, and severely restrict their self-determination, legal and human rights, and freedom. As evidence has accrued since the deinstitutionalization of people with disabilities began in most Western countries two to three decades ago, it is clear that no person with a disability needs to live in and institution, regardless of the intensity of their support needs. Overall findings across a multitude of countries indicate more positive outcomes for people living in smaller community-based settings than in institutional settings in almost all areas of life including: everyday functioning, health, behavior, social inclusion, family and friend contact, self-determination and choice-making, degree of autonomy, and perceived life satisfaction (Brown, Raphael, & Renwick, 1999; Emerson & Hatton, 1996; Felce & Perry, 1995; Hamelin, Frijters, Griffiths, Condillac, & Owen, 2011; Young, Sigafos, Suttie, Ashman, & Grevell, 1998; Tichá et al., 2012). These results include both direct observation and interviews with individuals with disabilities who have moved from institutions to small community settings as well as reports of family members (e.g., Griffiths, Owen & Condillac, 2015).

Although research clearly indicates the benefits of community living for persons with disabilities, it is also clear that this typically requires the supports of others, be it family members or professional direct care staff. This presents challenges for all societies as poli-

cies must be changed, alternative funding and financial systems developed, new staff trained, and attitudes of the public towards persons with disabilities become more positive.

## **Movement from sheltered workshops to competitive integrated employment**

The Americans with Disabilities Act (ADA) of 1990 has mandated public places, including employment sites, to be accessible for people with disabilities and to provide reasonable accommodations in order for them to be able to perform essential functions of a job. Despite these positive changes since the days when people with disabilities lived in institutions, there is still a higher percentage of people with disabilities who are unemployed or underemployed compared to people without disabilities. Employment has been shown to relate directly to improved standard of living and social inclusion, important indicators of quality of life.

In order to assure that more people with disabilities are working in community-based competitive jobs, it is not only necessary that people with disabilities have access to education and training to gain the knowledge and skills they desire and require, but to also educate the employment sector about the importance and benefits of employing persons with disabilities (Blanck, Adya, Myhill, & Samant, 2007).

Equivalent to people with disabilities moving from institutions to living in the community, there has been a movement from participating in pre-vocational activities in sheltered workshops (facility-based employment) to working in supported-community based and customized employment. Similarly to institutional restrictions and limitations of independence, choices and other freedoms of people with disabilities, sheltered workshops provide very limited opportunities not only in the choices of jobs (mostly pre-vocational activities), but also



in the level of compensation (sub-minimum wage). The next step in the evolution of employment for people with disabilities has been to provide guidance and support to enter competitive workforce in the community, starting with hiring, to onboarding and sustained employment by vocational rehabilitation personnel and supported employment job developers. This type of employment is known in the U.S. as competitive integrated (supported) employment. Most recently, the approach to employment of individuals with disabilities has become more person-centered and individualized, leading to customized employment. Customized employment is based on the premise that each job seeker is an individual free to make choices about his or her life course, is treated with dignity, is presumed to have competencies that are either obvious or will emerge with time, and has access to community-based settings, where he or she is provided with high quality employment opportunities and supports (Szoc & Harvey, 2011). Customized employment was added to the U.S. Workforce Innovation and Opportunity Act (WIOA) as a type of competitive integrated employment in 2014. This approach to employment is based on a blended model of services and supports, on flexible strategies, and individually negotiated and developed job opportunities (Inge, Graham, Brooks-Lane, Wehman, & Griffin, 2018).

Employment First policy has acted as an impetus in many U.S. states for people with disabilities to move from sheltered workshops to a fair-wage employment in the community alongside people without disabilities.

### **Challenges and needed changes to better support community living and quality of life (QOL)**

People with disabilities experience a myriad of challenges to living within the community and experiencing a high quality of life. These chal-

lenges can result from a lack of available supports for inclusion, negative attitudes persons with disabilities experience in their neighborhoods or workplace, feelings of loneliness, and/or not feeling valued for who he or she is as a person. The past several decades have witnessed great progress being made internationally toward increasing the number and quality of community-based services and supports available to persons with disabilities, providing the opportunity for a greater number of choices in community living and employment, facilitating self-determination, and changing public attitudes and perceptions about disability for the better. Every society, however, still faces challenges in assuring that all of its citizens, including persons with disabilities, feel valued, accepted and included and have the resources to live either independently or with supports in the communities of their choice. Progress, however, is being made as people with disabilities, their families and supporters have found their voices and demanded that outdated, unresponsive service systems change their practices.

In many countries, in spite of the ratification of the CRPD (2006) and a slow but sure movement toward the greater educational inclusion of children and youth with disabilities, people with all types of disability are still viewed from the lens of a medical model. Members of these groups are seen as having defects and deficits with little attention paid to their gifts and capacities. Members of the medical profession, many of whom were trained in the distant past and have scarcely heard of a social model of disability, control funding and both the access to and the type of services people with disabilities receive. As societal perspectives on disability have changed and institutions and segregated schools started to close, professionals with outdated views and values have tenaciously attempted to hold onto their power, continuing to dispense treatment and advice based on outdated theory and practices

with little to no research evidence to support their utility. Persons with disabilities and their families, however, are demanding more. People with disabilities and their family members have become advocates for new ways of thinking, opportunities for living and working in inclusive settings, increased funding for services and supports, and changes in societal attitudes.

The work of Bertoli et al. (2011) points out that in many countries, while significant efforts have been made to support the inclusion of students with disabilities in school, these individuals face a sudden abandonment when they leave the educational system as there are far fewer, if any in some countries, support services for adults with disabilities. In Bertoli's research, young adults with intellectual disability spent much of their free time involved in little to no activity. Participation in employment, including sheltered work, was extremely limited. The authors hypothesized that the lack of employment opportunities was likely, over time, to contribute to a loss of acquired skills and suggested that a policy of work inclusion for all on a daily basis was needed. Over the last 15 years, however, efforts have been made in many countries to implement transition programs for youth with disabilities to prepare them for an adult life that includes living independently or semi-independently in the community, working in inclusive employment settings, having their own social networks, and recreating with their fellow citizens.

In the U.S. as well as other Western countries, the concepts of community-living and quality of life are considered to be very personal for each individual and require careful consideration when providing services and supports. This individualized approach needs well trained and knowledgeable direct support staff, who have the necessary background and professional competencies to effectively support people with disabilities in community settings (see Chapter 8). Unlike the caregiver employed

at an institution, community living staff require the training and knowledge to experience a shift in their value orientations, so that they no longer view themselves as caregivers, but professionals and advocates whose role is to support people with disabilities they serve for them to experience personally defined desired life outcomes. There is a shortage of direct support staff in the U.S. and in most countries as they are poorly paid, receive insufficient training and education, and have no career paths (Nye Langerman & Hewitt, 2019). Burn-out among direct support professionals who provide daily services is quite common (White, Edwards, & Townsend-White, 2006), with many people with disabilities experiencing complete turnover of their support staff in as little as 6-12 months. In many countries today, however, these challenges to the system are starting to be addressed as efforts are being made to better equip and support those professionals who provide services to people with disabilities. Realistic job previews, improved online, and in-person, training, and professional credentialing systems are all slowly, but surely improving the quality of supports people with disabilities receive.

Kozmo et al. (2009), among others, has found that the prevalence of health risk factors, such as inactivity and obesity, among people with disabilities is quite high and that less restrictive living arrangements potentially increase the probability of smoking, poor diet, and obesity. Martinez-Leal et al. (2011) conclude that people with such disabilities need tailored primary health programs that guarantee their access to quality health, health promotion and preventative health actions. Universal health care systems that have taken hold in many countries now provide greater access to health care. The *Medical Homes* movement in the U.S. and Canada, in which specialty health practices are developed that are staffed to specifically cater to the needs of persons with

various disabilities have increased access to personal care and health. In addition, a number of health promotion programs for persons with disabilities have been developed (e.g., *14 Weeks to a Healthier You*, *Partnerships in Health and Wellness*, *The HealthMatters™ Program*), the results of which have been very encouraging.

In many countries, the complexity of providing high quality supports to persons with disabilities in community living settings have stretched regulatory systems to their limits. Barron, Hassiotis, & Paschos (2011) touched on some of the licensing and regulatory problems in the social services industry that in some areas includes hundreds of non-profit and 'for-profit' companies ranging from small to extremely large and most recently in the U.S. also involves large managed care organizations (MCOs). These organizations are hired by states to provide a care delivery system organized to manage cost, utilization, and quality of services. Unfortunately, in many countries regulatory authorities themselves are inefficiently managed, chronically understaffed and all too often focus almost exclusively on the physical aspects of community living settings, rather than on the more critical human side of service provision (Samuel, 2010). Barron et al. (2011) in their evaluation of social service systems in the U.K. found frequent instances of overuse of agency staff, inadequate staffing levels, particularly for people requiring 1-to-1 attention, as well as failure to implement a number of other regulatory requirements.

In spite of the challenges, however, many non-profit non-governmental organizations that provide community living supports are staffed by individuals who have a passion for working with people with disabilities, are highly committed to their work, and are making a big difference in people's lives. In many countries, people who are gravitating toward the social services employment sector have excellent credentials, including undergraduate and graduate

degrees in social work, psychology, occupational therapy, and other human service professions. They often supervise and/or work for small community living programs, in which they know each person who they support, provide these supports in a person-centered manner and view themselves not as caregivers, but as community advocates, whose job is to see that the people they are supporting have the opportunity to live inclusive lives within their community.

## Purpose of handbook

The purpose of this handbook is to highlight key topics in community living and employment opportunities and services/supports relevant to those within the human services systems, people with disabilities, and their families in the United States and the Russian Federation with the hope that users from both countries can learn from each other's initiatives. The handbook is based on the 21st-century premise that the experience of disability is largely due to societal barriers placed on individuals that prevent them from having positive experiences and life outcomes. If an individual with a disability is not able to find work because they have a physical disability, are unable to use a standard keyboard or find public transportation to a potential worksite, for example, it is our responsibility to find solutions to these accessibility limitations. Similarly, if a person is not able to understand complex instructions provided on a job, it is our obligation as a community to learn from the individual how we can provide such instructions in an understandable format.

The goal of this handbook is to raise the awareness of persons with disabilities, family members, employers, neighbors, healthcare providers, co-workers, and others in society about a wide variety of issues related to the employment and community-living of persons with disabilities. Each chapter provides readers

with basic facts about the topic of focus as well as strategies that can be used to enhance the quality of life of persons with disabilities and support them to lead valued, meaningful lives.

The handbook addresses the topics of transitioning from school to adulthood, working with families, health, wellness and relationships, community-based housing and supports, social networks, self-determination, guardianship, funding for services, opportunities for employment, supported and customized employment, and several other topical areas relevant to successful community living for persons with disabilities. Chapters of the handbook are authored by either U.S. or Russian professionals who are experts in their respective fields and are accompanied by case studies and concrete examples of innovative approaches to community living and competitive supported employment.

## References

- Barron, D. A., Hassiotis, A., & Paschos, D. (2011). Out-of-area provision for adults with intellectual disabilities and challenging behaviour in England: policy perspectives and clinical reality. *Journal of Intellectual Disability Research, 55*(9), 832-843.
- Bertoli M., Biasini G., Calignano M., Celani G., de Grossi, G., Digilio M. et al. (2011). Needs and challenges of daily life for people with Down syndrome residing in the city of Rome, Italy. *Journal of Intellectual Disability Research, 55*, 801-820.
- Blanck, P., Adya, M., Myhill, W.N., & Samant, D. (2007). Employment of People with Disabilities: Twenty-Five Years Back and Ahead. *Law & Inequality: A Journal of Theory and Practice, 25*(2), 323-353.
- Brown, I., Raphael, D., & Renwick, R. (1999). *Quality of life and life changes for adults with developmental disabilities in Ontario*. Toronto, ON: Centre for Health Promotion, University of Toronto.
- Emerson, E., & Hatton, C. (1996). Deinstitutionalization in the UK and Ireland: Outcomes for service users. *Journal of Intellectual & Developmental Disability, 21*, 17-37.
- Felce D, & Perry J. (1995). The extent of support for ordinary living provided in staffed housing: the relationship between staffing levels, resident dependency, staff± resident interactions and resident activity patterns. *Soc Sci Med, 40*, 799-810.
- Griffiths, D.M., Owen, F., & Condillac, R. (2015). Family feedback on the closure of institutions for persons with intellectual disabilities in Ontario. *Journal of Developmental Disabilities, 21*(2), 28-37.
- Hamelin, J., Frijters, J., Griffiths, D., Condillac, R., & Owen, F. (2011). Meta-analysis of deinstitutionalization adaptive behaviour outcomes: Research and clinical implications. *Journal of Intellectual & Developmental Disability, 36*, 61-72.
- Haney J. (1988). Toward successful community placements for individuals with mental retardation. In: Healt L., Haney J., & Novak A. (Eds.). *Integration of developmentally disabled individuals in the community*, pp. 125-168, Baltimore: Paul H. Brooks.
- Inge, K.J., Graham, C.W., Brooks-Lane, N., Wehman, P., & Griffin, C. (2018). Defining customized employment as an evidence-based practice: The results of a focus group study. *Journal of Vocational Rehabilitation, 48*, 155-166.
- Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: a systematic review. *American Journal on Intellectual and Developmental Disabilities, 114*(3), 193-222.
- Martínez-Leal, R., Salvador-Carulla, L., Linehan, C., Walsh, P., Weber, G., Van Hove, G., ... & Germanavicius, A. (2011). The impact of living arrangements and deinstitutionalisation in the health status of persons with intellectual disability in Europe. *Journal of Intellectual Disability Research, 55*(9), 858-872.
- McCormick, A. (2018). Quality of Life. In *Cerebral Palsy* (pp. 335-341). Springer, Cham. Samuel, M. (2010) CQC slammed by own staff as survey exposes low morale. Community Care. Available at: <http://www.communitycare.co.uk/Articles/2010/07/08/114865/CQC-slammed-by-own-staff-as-survey-exposes-low-morale.htm>
- Schalock, R.L., Keith, K.D., Verdugo, M.A. & Gómez, L.E. (2011). Quality of life model development and use in the field of intellectual disability. In R. Kober (Ed.), *Enhancing the Quality of Life of People with Intellectual Disabilities: From Theory to Practice*, 17-32.
- Schalock, R. L., & Verdugo, M. A. (2002). *The international handbook on quality of life for human service practitioners*. Washington, DC: American Association on Mental Retardation.

- Schalock, R. L., Verdugo, M. A., Gomez, L. E., & Reinders, H. S. (2016). Moving us toward a theory of individual quality of life. *American Journal on Intellectual and Developmental Disabilities, 121*(1), 1-12.
- Szoc, R. & Harvey, J. (2011). *Customized employment competency model*. Retrieved from <https://www.dol.gov/odep/pdf/2011cecm.pdf>
- Tichá, R., Lakin, K.C., Larson, S., & Stancliffe, R., Taub, S., Engler, J., Bershady, J., & Moseley, C. (2012). Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states. *Intellectual and Developmental Disabilities, 50*(6), 486-504.
- White, P., Edwards, N., & Townsend-White, C. (2006). Stress and burnout amongst professional carers of people with intellectual disability: Another health inequity. *Current Opinion in Psychiatry, 19*(5), 502-507.
- WHOQOL Group. *Measuring quality of life: The development of the WHOQOL instrument*. Geneva, Switzerland: World Health Organization; 1997.
- Young, L., Sigafos, J., Suttie, J., Ashman, A., Grevell, P. (1998). Deinstitutionalisation of persons with intellectual disabilities: A review of Australian studies. *Journal of Intellectual & Developmental Disability, 23*, 155-170.

# COMMUNITY LIVING

## CHAPTER 1

# Policy, Regulations, and Financing of the Community Living of Persons with Disabilities

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### Guiding questions

- What are the strengths and challenges of the manner in which community living options for people with disabilities are currently financed in the United States?
- What changes need to be made in regulations and policies related to community living options for people with disabilities in order for authorities to meet international, federal, and state/regional requirements?

## Introduction and background information

Over the past several decades, tremendous changes have occurred in countries around the world in the manner in which people with disabilities are supported. In most Western nations, the large majority of individuals with disabilities, who previously lived in institutions are now residing in small (2-3 person) community-based or other inclusive settings. Some countries have taken a more progressive approach to deinstitutionalization, and in these locations small community residences (formally referred to as group homes) are but one option available to individuals and their families. In the U.S., Scandinavian, and other Western countries including the U.K. and Australia many people with disabilities are making decisions to continue to live with their families with supports being provided in their family's home. Others are living within the community either independently or semi-independently with support, and in some cases now own their own homes.

The changes in community living described above have not come easily. What has been witnessed in most countries is an *evolution* (that has taken years to occur) rather than a *revolution* in community living. In all countries, including Sweden and Finland that have been leaders in the deinstitutionalization movement, institutions for people with more significant disabilities still exist. However, the number of people residing within them has decreased significantly and it is becoming clear that soon, we may soon see at least some countries supporting *all* of their citizens with disabilities within the community. This evolution and the movement of people with disabilities into the community would not have occurred in the absence of legislation, policies, and regulations that strengthened the rights of people with disabilities to have the services and supports provided

to them that would allow for a high quality of life within inclusive communities.

## The movement toward community living in the United States

Developing home and community-based service (HCBS) alternatives to institutional care has been a priority for the United States federal government and many states in the U.S. for the past thirty-years (Ng, Stone & Harrington, 2015). These efforts have been in response to consumer preferences (Ng, Harrington, & Kitchener, 2010), advocacy and self-advocacy on the part of people with disabilities, the Americans with Disabilities Act (ADA, 1991) and the Supreme Court *Olmsted* decision whereby programs that fail to provide community-based options for supports can be ruled discriminatory (U.S. Supreme Court, 1999). Recent federal laws and policies, such as the Patient Protection and Affordable Care Act of 2010 (ACA), New Freedom Initiative, and the Deficit Reduction Act of 2005 (Kaiser Family Foundation, 2010; Ng, Harrington, Musumeci, & Reaves, 2012) have provided opportunities for states to rebalance their long-term services and supports (LTSS) for people with disabilities away from institutional care and toward supports provided to people in their homes and the community.

In the U.S., services and supports needed by persons with disabilities of all types are funded through the Centers for Medicaid and Medicare Services (CMS). Medicaid is an entitlement program that finances the delivery of health care and long-term services and supports (LTSS) to people with disabilities and eligible low-income individuals. Under federal law, states are required to provide coverage to people who experience disability as well as those with age-related support needs who receive assistance through the Supplemental Security Income (SSI) program. These are referred to as mandatory eligibility groups. To qualify for Medicaid long-

term services and supports, individuals must meet both categorical and financial requirements as well as state-based disability eligibility criteria that determine the need for long-term care. Like many programs in the U.S., the Medicaid program is jointly funded by the federal government and states, but is essentially state-operated under federal guidelines. These are described by some as flexible and others as far too vague. As a result, on a national level, people with disabilities living in some states must meet different eligibility criteria than those in others and receive far more (or less) services and supports (Colello, 2017).

## Home- and community-based services for persons with disabilities (HCBS)

The vast majority of people in need of long-term services and supports desire to live in their own homes and communities. The Medicaid program, by far the largest funder of long-term services and supports (LTSS) for persons with disabilities in the U.S. (Eiken, Sredl, Saucier, Burwell, 2016), now supports a variety of programs to support persons with a variety of support needs living where they desire, whether that be with their families or in the community. Among the most widely used of these programs is home and community-based services (HCBS). For the past 38-years, states have used the authority under §1915(c) of the Social Security Act to waive certain federal Medicaid requirements to establish HCBS “waiver” programs (Ng et al., 2010; U.S. DHHS, 2010). These programs allow the provision of a wide range of HCBS to people with disabilities who would otherwise qualify for institutional care. The proportion of LTSS expenditures for HCBS has increased steadily in recent years though it varies across disability populations (Rizzolo, Friedman, Lulinski-Norris, and Braddock, 2013). In 2017, HCBS accounted for more than 75 percent of

the spending in programs targeting people with intellectual and developmental disabilities.

A variety of services are offered under HCBS waivers including: personal care services; home health care; various therapies; case management; transportation; community living; and home modifications (Harrington, Carrillo, Wellin, Norwood, & Miller, 2001; Kitchner et al., 2005). States are able to set an annual limit on the number of HCBS participants for each waiver and can establish waiting lists to control costs. They may also limit waiver programs to certain geographical areas and target specific groups for waiver programs (e.g., individuals with IDD) (Ng et al., 2010, 2011). States must apply to the Center for Medicaid and Medicare Services for HCBS waivers to be approved and demonstrate cost neutrality or that the average expenditures for each waiver do not exceed estimates of expenditures for institutional care. Waiver services must be restricted to individuals who meet the state criteria for institutional care though this varies by states. For people with intellectual and developmental disabilities this is typically established based on rating scales (e.g., The Supports Intensity Scale; Inventory of Client and Agency Planning) that focus on activities of daily living and adaptive behavior (Kitchener, Ng, Miller, & Harrington, 2005). As Ng, Stone & Harrington (2015) suggest, these criteria are intended to ensure that waivers are used as alternatives for institutional care for people with significant support needs. In spite of efforts to provide more LTSS within the community, significant differences exist in HCBS spending across states. In New Mexico, for example in 2010, 95% of LTSS spending was on home and community-based services, while in Mississippi it was merely 17% (Eiken, Sredl, Burwell, & Gold, 2010). Although it is clear that in the U.S. states are moving from serving people with even the most significant of disabilities from institutions to community-based programs, it must be understood that the physical



location where one receives services does not make it an institution or a setting/program that facilitates community inclusion.

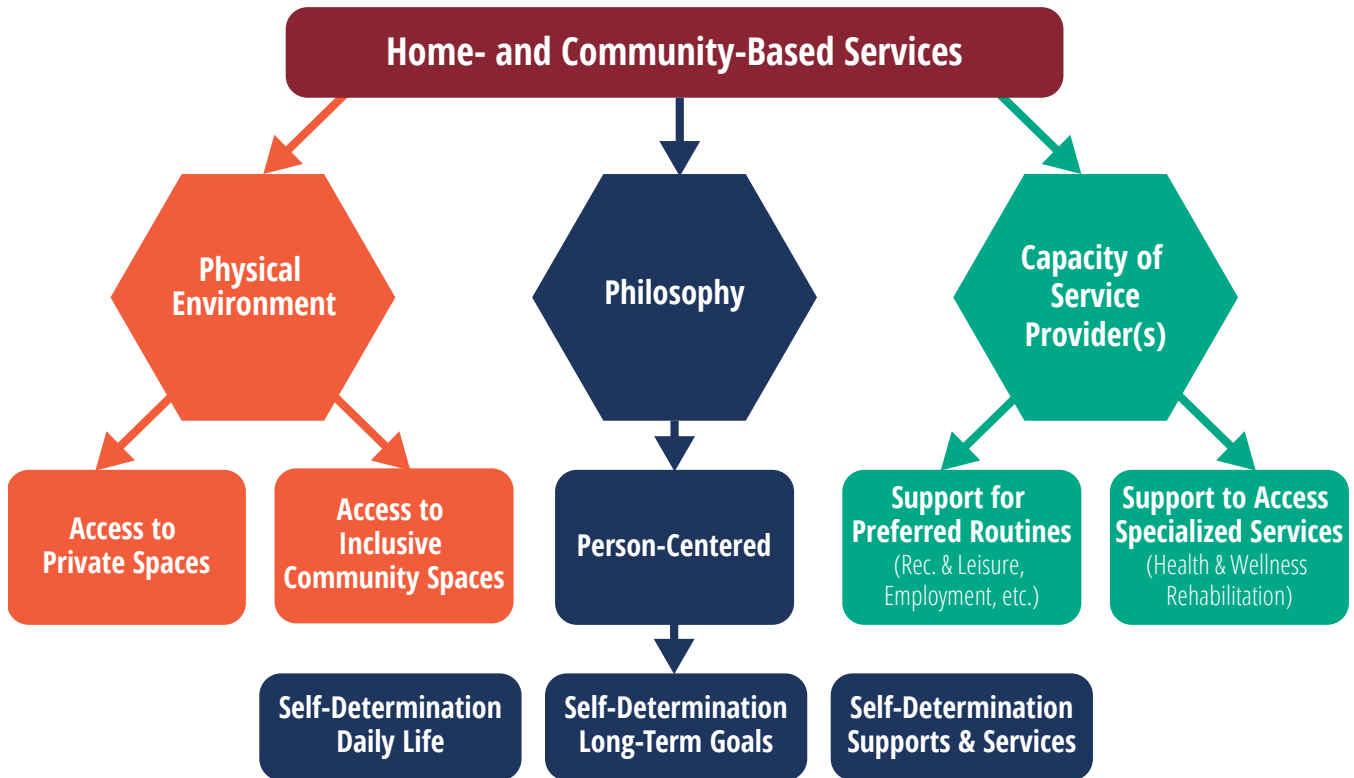
### **Characteristics of HCBS and institutional living**

Kane & Cutler (2009) suggest that five characteristics differentiate community from institutional living regardless of what terms people use to refer to the setting. The first of these characteristics, *environmental hallmarks*, refers to settings in which building materials, paints, carpets, and furnishings exist on an institutional scale (i.e., everywhere). The existence of *norms regarding the right of all persons to privacy* and private space is a second homelike quality absent in institutional settings. A third distinguishing feature of institutions is that everything is done in a *standardized* fashion and they are *highly rule governed*. Additionally, the persons with disabilities living within them are not involved in making any of the rules. Unlike one's home, institutional environments are typically quite *self-contained* and infrequently used as a base from which to explore the community for entertainment, employment and recreation and leisure activities. When persons with disabilities do venture out from institutional set-

tings, they almost always do so in groups rather than as individuals and on activities that are planned rather than spontaneous in nature. A final characteristic of settings that are institutional in nature is the absence of opportunity for and support of self-determination on the part of the residents. People with disabilities have little to no control over what they do on a daily basis, the food they eat, the time periods during which they are awake and sleep and when to move in or out. All of these decisions are under the control of program directors or staff. The challenge is whether, LTSS settings, including nursing facilities, can be re-shaped so they are no longer institutional.

As Kane & Cutler (2015) contend, community-based residential supports include small group housing options licensed by states or counties that can consist of small family homes (sometimes called adult foster homes), small residential care facilities, and assisted apartment living facilities. To truly facilitate inclusive community living, however such programs must possess a number of critical characteristics. These relate to the physical environment itself, the philosophy through which supports are provided and the capacity of supports (see Figure 1).

Figure 1. Framework for analyzing long-term services and supports (LTSS) programs



Adapted and expanded from Kane & Cutler, 2015 p. 287.

Programs that truly support community inclusion, unlike institutions, must be configured and provide a *physical environment* so that each person supported has access to both private and public space. This includes not only the right to privacy but also access to shared space (with others dwelling in the residence) that is able to be personalized in the same way that each of us personalize our homes, as well as access to the community and activities going on within it. The *philosophy* of such programs needs to be person-centered in the sense that staff do not perceive their roles as caregivers, but rather, as advocates whose jobs are to support the people with disabilities that they serve to achieve desired personal outcomes. This includes supporting their self-determination, informed choice and decision-making, and providing them with the necessary assistance (e.g., supported decision-making) to take

control over their lives even in areas where, without support, they would be unable to make informed decisions.

In response to the Affordable Care Act and New Freedom Initiative legislation as well as the demands of persons with disabilities, many states have incorporated some form of consumer direction within their HCBS programs. This can include initiatives such as consumer choice in the allocation of service budgets or persons with disabilities having the authority to hire and manage service providers. By 2010, 44 states allowed consumer direction within some or all three of the Medicaid HCBS programs (Ng, Stone & Harrington, 2015). The third critical area outlined by Kane and Cutler (2015) focuses on service capacity. This involves the capacity of the service provider to support the preferred routines of the recipient of services including recreation and leisure activities, volunteering

in the community, and employment. Because over fifty percent of persons with disabilities in the U.S. live at home with families after becoming adults, *states with the personal care waiver option may also allow the family members of participants to serve as support providers and be paid for assuming this role (CMS, 2009)*. By 2015, 32 states allowed family members to be paid personal care providers. Generally, the amount of funds a family caregiver is eligible to receive is dependent on an assessment of the service recipient's individual needs as well as the average wage for a home care aide in the state in which one lives, with the majority of caregivers receiving \$900-\$1,500 per month.

*Evidence for the effectiveness of HCBS.* Over the past two decades most states have evaluated their publicly funded HCBS programs. In a review of 30 studies that assessed the cost effectiveness of HCBS model rather than institutional care, Fox-Grage and Walls (2013) found that the research consistently provided evidence of cost containment and a slower rate of spending growth as states have expanded HCBS. Although few studies were found to document absolute cost savings, the studies consistently found much lower per-individual average costs for HCBS compared with institutional care. Additionally, the importance of personal care services in preventing institutionalization and encouraging deinstitutionalization has been shown in previous studies (LaPlante, Kaye, Kang, & Harrington, 2004; Muramatsu & Campbell, 2002; Ng, Stone, & Harrington, 2015).

## Alternative community-based funding and support options

Community living options for people with intellectual disabilities and developmental disabilities in the United States have led to federal government funding being provided to states. Each state, in turn, provides financial supports to social service agencies that operate at ei-

ther the county level or are private non-profit or for-profit entities. However, funding as well as services that meet the housing, community living, and employment needs of people with disabilities have been so insufficient that waiting lists for HCBS still exist in most states and advocates for persons with disabilities argue that the supports and support providers of the majority persons with disabilities are grossly under-funded. This has resulted in a service system in which the quality of services is at times less than optimal and support providers must deal with significant numbers of unfilled staff positions (Lemon & Lemon, 2003).

### Managed care and HCBS

Over the past 5 years, a number of states have initiated programs designed to provide home and community-based services to persons with disabilities through a managed care format. This financing model is similar to those used in many U.S. health insurance markets, in which an insurer organization receives bundled payments to serve designated groups of persons with disabilities within specified geographic areas across providers and settings. This approach is designed to improve quality of care based on the assumption that: (1) given the right incentives, providers will find the most efficient and effective ways to improve quality; and (2) given the right information, consumers will choose the most appropriate settings and types of care for their needs and preferences (Konetzka & Werner, 2010). The goal is to integrate care, reduce navigational challenges, and remove adverse incentives associated with fragmented financing and delivery, leading to both better outcomes and lower costs.

Managed care accounted for 14.8 percent of long-term services and support expenditures in 2014, compared to 5.0 percent in FY 2009. In spite of extremely limited research evidence that HCBS delivered through a managed care format saves money or improves outcomes,

continuing growth in this area is expected to take place (Eiken, Sredl, Burwell, & Saucier, 2016) as organizations that previously focused on the provision of health care enter the human services support market.

### **Family microboards and human service cooperatives**

In the U.S., over 50 percent of adults with intellectual and developmental disabilities (IDD) live with family members (Hewitt & Langerman, 2019). For years, families have provided extensive supports to their adult children with intellectual and developmental disabilities. In many cases, this has been without any support in terms of training, access to resources or respite care, as well as with little to no monetary compensation. Approximately ten-years ago, changes made by the Center for Medicaid and Medicare Services (CMS) the federal agency that funds community supports for people with disabilities, permit family members from states with the personal care waiver option to provide individualized funding directly to persons with disabilities and their families. Families apply for funding by documenting the needs of the individual and their cost (CMS, 2009). If the application is approved, they can then use the funds to purchase services from agencies, individuals or community organizations, to secure independent housing and employment for their adult children.

Over the past decade, families and advocates in many parts of the world have recognized that if they really desire to support persons with disabilities to build fully inclusive, person-centered lives, they will need to work outside of government funded programs. Finding avenues through which to use both available funding and the support of volunteers has led to the development of family microboards in Canada and support collaboratives in the U.S.

Small, 4-6 person organizations referred to as *family microboards* have been established and funded to support the community living of people with disabilities in British Columbia, Canada for some time now (Lemon & Lemon, 2003). A microboard typically consists of family members, friends, advocates, and professionals who work together to support one or a few persons with disabilities (Pedlar & Hutchison, 2000). Each member donates his or her ability to contribute to the success of the persons with disabilities who are being supported. Although originally developed to serve single persons, in recent years, microboards have extended their efforts to support small groups of individuals. Microboards are legally incorporated as non-profit societies and operate with assistance from a non-profit fiscal intermediary that receives funding from one or more sources that are pooled and used to contribute to the community living supports of the person in question. Microboards emphasize the importance of individuals with disabilities having a say in directing the services they need and when the concepts of self-determination, development of human capital, and person-centeredness are taken into consideration have been shown to produce outcomes that far exceed traditional agency-based supports (Stainton, Asgarova & Feduck, 2013).

In the U.S., families and advocates have attempted to better support the community living needs of persons with disabilities through the formation of human service cooperatives (HSCs). Similar to microboards, HSCs are non-profit organizations operated for the benefit of those using their services (U.S. Small Business Administration, n.d.). They bring together stakeholders including persons with disabilities, family members, advocates, and professionals to support the empowerment of people with disabilities and support their community living needs. HSCs have typically served people with disabilities who have similar support needs, but

unlike most microboards, support more than one individual with a disability (Shogren, Forber-Pratt, Nittrouer, & Aragon, 2013). This allows for the pooling of support funding to increase the options that are available to individuals. At this point there has been relatively little attention paid to human service cooperatives by researchers. Although individual cases would seem to indicate that this is a promising practice to support persons with disabilities leading more inclusive, self-determined lives, we still know relatively little about the relative costs and benefits of such an approach to service delivery.

## Funding and availability of social services for community living for people with disabilities in the Russian Federation

### Progress with Convention on the Rights of a Person with Disabilities (CRPD)

On May 2012, the Russian Federation signed the federal law on ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD). This act was a major step toward the Russian Federation becoming a State Party to the CRPD. Since that time, the CRPD and its basic principles have been ratified by the government. People with disabilities in Russia and their families as well as disability advocacy organizations are now calling on the Russian government to fully implement the convention and to take appropriate measures to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities.

### Federal Law # 442-FZ

In 2013, Federal Law # 442-FZ: On the Principles of Social Services for Citizens in the Russian Federation set rules for the provision

of the following types of social services in the Russian Federation:

- Social and domestic services, aimed at maintaining the livelihood of recipients of social services in everyday life;
- Social and medical services, aimed at maintaining and preserving the health of recipients of social services by organizing care, assisting in carrying out recreational activities, and systematically monitoring recipients of social services to identify deviations in their health;
- Socio-psychological services, aiding in correcting the psychological state of social service recipients for their adaptation in the social environment, including the anonymous provision of psychological assistance using a telephone helpline;
- Social and pedagogical services, aimed at preventing deviations in behavior and personal development of recipients of social services, the formation of their positive interests (including recreational activities), the organization of their leisure time, and helping families in raising children;
- Social and labor related services, aimed at assisting in finding employment and in solving other problems related to labor adaptation;
- Social and legal services, aimed at assisting in obtaining legal services, including those provided free of charge, in protecting the rights and legal interests of recipients of social services;
- Services aimed to increase the communication potential of social services recipients with disabilities, including special needs children; and urgent social services.

In most cases, the social services specified in Federal Law # 442-FZ are provided to citizens with disabilities by government run organizations (including psycho-neurological care homes). For adults with disabilities, however,

these services though available to all, are delivered in an extremely limited number of settings with people receiving supports while living at home with their families or in large institutions where they are under the guardianship of the institution's director. Both of these settings severely limit the extent to which people with disabilities are fully integrated into the community. One barrier to greater community living options being available to Russians with disabilities has been the fact that the government has, until a short time ago, been the sole provider of these supports.

Recently, non-governmental organizations, including the *Center for Curative Pedagogics* and the *Charitable Foundation Assisting People with Disabilities Life's Journey* in Moscow have begun to be included in the registry of social service providers. This has allowed these non-governmental organizations to receive government funding for the delivery of social services and supports activities. Prior to this expansion of approved service providers such non-governmental organizations were restricted with respect to both the types of supports they could provide and the number of people they served because their only source of funding were funds obtained from charitable foundations and grants.

### **Funding types and process for community-based supports**

In the Russian Federation today, funding for training and permanent assisted living programs for people with disabilities are provided in four different ways:

- By payments from the recipients of supports or their families;
- From charitable organizations;
- From grants and subsidies; and
- Through reimbursement of expenses incurred by social services providers listed in the registry

The process of receiving community-based supports is not an easy one for people with disabilities in the Russian Federation. Let us concentrate on funding option # 4 (reimbursement of expenses of social services providers listed in the registry). For an organization to receive reimbursement from the state, it is first necessary for it to be added to the registry of social service providers. The process of applying for inclusion in the registry is neither simple, nor quick for an interested organization and at the current time there are far more people with disabilities who desire alternative, community-based supports than the limited number of community-based organizations included in the registry can provide.

A person with a disability (or their family) who want to use the services of community-based organizations first needs to subscribe to the state's Individual Social Services Program. This can be done at a district Social Services Center by providing the necessary documents, including information with respect to the family income of the person with disability. The social services delivery format a recipient requires (home based, permanent or semi-permanent, etc.) is decided at this time. Determination of the specific services (social, domestic, psychological, legal, pedagogical, etc.) a recipient will receive is also made by the district Social Services Center and it is these supports that must be provided by the social services organization.

The fact that non-governmental organizations are now able to provide social services to citizens with disabilities and receive compensation for their work from the state budget is creating a healthier environment in the social services market. In addition to pushing the government to improve the supports it provides to people with disabilities, it also gives individuals with disabilities and their families significantly greater self-determination as they now have multiple service providers from which to choose. Furthermore, these new developments

are creating competition among social service providers. Innovations in the types and formats of services and supports will be a requirement if non-governmental organizations desire to develop and maintain a stable client base and funding. This should theoretically drive improvements in the quality of services available to people with disabilities.

Although recent developments have the potential to serve as a catalyst for improved services and supports, people with disabilities and their families will need to learn to choose their providers wisely. Recent funding alternatives have already led to new, community-based social service organizations being established and existing providers expanding their services. Although some of these entities may do an excellent job at supporting enhancing opportunities for community living, the funding provided by the state may not be sufficient for all of them to operate on a long-term basis. A fear of many people with disabilities is that the opportunities they experience today may be gone tomorrow.

It should also be noted that in spite of recent changes, community-based supports for people with more significant support needs, including those with intellectual disabilities are still changing at a very low pace. In Moscow, for example, there are only a handful of non-governmental social service providers who offer community-living apartment/flat options of any type. As of this date, the state does not offer any alternatives of this nature. In addition, many of the limited number of community-living slots available through progressive thinking NGOs are currently used for training purposes only for periods of two-weeks to three-months. Following this period of community living, people with intellectual and developmental disabilities must return to their less than community-based lives residing either with their families or living in institutional settings.



## Tips & Strategies

At this juncture, persons with disabilities in the U.S. have distinctly different options when it comes to community living. Legislation in the U.S., often a result of state and federal court rulings in favor of persons with disabilities, has both increased the amount of funding available for living within the community and encouraged states to spend increasingly larger percentages of the Medicaid Long Term Services and support funding on community based support options. However, there currently exist a number of inherent weaknesses in the current U.S. system. These often lead to people being placed on waiting lists, shortages of support staff, and other shortcomings. In spite of the problems, persons with disabilities in the U.S. have the opportunity to choose from a variety of community living options ranging from residing in small, staff-supported homes in the community or with their families to living independently.

Persons with disabilities, especially those with intellectual and developmental disabilities (IDD), living in the Russian Federation have limited opportunities for community living at this time. In spite of ratification of the CRPD and recent reforms that allow non-governmental organizations to provide some community-based supports, most adults with disabilities in Russia have two options - live with

their families or in institutions. In many of the country's largest cities, few, if any, community living options are available and those that are have typically been reserved for training purposes.

- **The need for advocacy.** At this point it is clear that there are many persons with disabilities in the Russian Federation who, if provided with the appropriate supports could live within the community. Progressive non-governmental organizations have shown that it is possible to support such individuals outside of the current government run system. Significantly greater advocacy with policy-makers on the part of persons with disabilities, their families, NGOs and other community champions, however, is needed to ensure that sufficient funding is made available to support such innovative practices and approaches.
- **Conduction and publication of research on deinstitutionalization in Russia.** At this time little data is available regarding the cost savings that would be incurred if people with disabilities in the Russian Federation were moved out of institutions (in which they were receiving quality care) and into community living situations. If policy-makers are to be expected to fund additional community living programs additional research must be undertaken to answer this question.
- **Research on the costs to society of having few community living options.** The absence of sufficient community living options for persons with disabilities has costs to society beyond those of

a fiscal nature. Many parents of children with disabilities spend their entire lives caring for their sons and daughters with disabilities. This reduces their capacity for employment and to be contributing to the society from an economic standpoint. Research in a number of countries has shown that long term caregiving to persons with significant support needs has a negative impact on caregiver health, social well-being, freedom and independence, family well-being and financial stability (Davis et al., 2010; Miodrag & Hodapp, 2010; Peer, & Hillman, 2014; Savage & Bailey, 2004; Weiss, Cappadocia, MacMullin, Vecili, & Lunsky, 2012). Studies of this nature need to be replicated in the Russian Federation and the results of these often neglected costs clearly communicated to policy makers.

- **Highlighting the positive contributions of persons with disabilities.** People with disabilities have the ability to make significant, positive contributions to their communities. In most societies, however, these contributions are all but ignored. As a result, the general public perceives persons with disabilities as the user of resources rather than citizen who are resources themselves. The creation and dissemination of public service announcements that highlight the contributions of citizens with disabilities as well as their capabilities has the potential to result in positive changes in attitudes towards people with disabilities on the part of policy makers and the general public.



## Resource

- [Application form to add an organization to the registry, as well as a list of organizations that are already in the registry](#)

## References

- Americans with Disabilities Act of 1990. Pub. L. 101-336.
- Centers for Medicare and Medicaid Services (CMS). (2009). §1915(j) Self-Directed Personal Assistance Services State Plan Option: Approved SPAs. Baltimore, MD. Retrieved from [http://web.bc.edu/libtools/downloadfile.php?filename=1270661696\\_CMS\\_Handout.pdf](http://web.bc.edu/libtools/downloadfile.php?filename=1270661696_CMS_Handout.pdf)
- Colello, K. J. (2017). Medicaid financial eligibility for long-term services and supports. *Congressional Research Service*, 43506.
- Davis, E., Shelly, A., Waters, E., Boyd, R., Cook, K., & Davern, M. (2010). The impact of caring for a child with cerebral palsy: quality of life for mothers and fathers. *Child: care, health and development*, 36(1), 63-73.
- Eiken, S., Sredl, K., Burwell, B., & Gold, L. (2010). *Medicaid long-term care expenditures in FY 2009*. Boston, MA: Thomson Reuters.
- Eiken, S., Sredl, K., Saucier, P., & Burwell, B. (2016). *Medicaid Expenditures for Long-Term Services and Supports (LTSS) in FY 2014*. Centers for Medicare and Medicaid Services & Truven Health Analytics: Contract No. HHSM-500-2010-000261.
- Fox-Grage, W., & Walls, J. (2013). *State studies find home and community-based services to be cost-effective*. Washington, DC: AARP Public Policy Institute.
- Harrington, C., Carrillo, H., Wellin, V., Norwood, F., & Miller, N. (2001). Access of target groups to 1915(c) Medicaid home and community based waiver services. *Home Health Care Services Quarterly*, 20, 61-80.
- Kaiser Family Foundation. (2010). Summary of new health reform law. *Patient Protection and Affordable Care Act (ACA) (Public Law 111-148)*. Washington, DC; Author. Retrieved from <http://www.kff.org/healthreform/8061.cfm>
- Kane, R. A., & Cutler, L. J. (2015). Re-imagining long-term services and supports: Towards livable environments, service capacity, and enhanced community integration, choice, and quality of life for seniors. *The Gerontologist*, 55(2), 286-295.
- Kitchener, M., Ng, T., Miller, N., & Harrington, C. (2005). Medicaid home and community-based services: National program trends. *Health Affairs*, 24(1), 206-212.
- Konetzka, R. T., & Werner, R. M. (2010). Applying market-based reforms to long-term care. *Health Affairs*, 29(1), 74-80.
- LaPlante, M. P., Kaye, H. S., Kang, T., & Harrington, C. (2004). Unmet need for personal assistance services: Estimating the shortfall in hours of help and adverse consequences. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 59(2), S98-S108.
- Larson, S.A. Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A.S....Faye, M.L. (2017). *In home and residential long-term supports and services for individuals with intellectual and developmental disabilities Status and trends through 2014. Report*. Minneapolis, MN: Institute on Community Integration RRTC on Community Living
- Lemon, C., & Lemon, J. (2003). Community-based cooperative ventures for adults with intellectual disabilities. *Canadian Geographer/Le Géographe Canadien*, 47(4), 414-428.
- Miodrag, N., & Hodapp, R. M. (2010). Chronic stress and health among parents of children with intellectual and developmental disabilities. *Current opinion in psychiatry*, 23(5), 407-411.
- Muramatsu, N., & Campbell, R. (2002). State expenditures on home and community-based services and use of formal and informal personal assistance: A multilevel analysis. *Journal of Health and Social Behavior*, 43, 107-124.
- Ng, T., Stone, J., & Harrington, C. (2015). Medicaid home and community-based services: How consumer access is restricted by state policies. *Journal of aging & social policy*, 27(1), 21-46. (Ng, Harrington, & Kitchener, 2010)
- Ng, T., Harrington, C., & Musumeci, M. (2011). *State options that expand access to Medicaid home- and community-based services*. Washington, DC. Kaiser Family Foundation. Retrieved from <http://www.kff.org/medicaid/8241.cfm>
- Ng, T., Harrington, C., Musumeci, M., & Reaves, E. (2012). *Medicaid home and community based service programs: 2009 data update. Report prepared for the Kaiser Commission on Medicaid and the Uninsured*. Washington, DC: Kaiser Commission on Medicaid and the Uninsured. Retrieved from <http://www.kff.org/medicaid/upload/7720-06.pdf>

- Ng, T., Harrington, C., & Musumeci, M. (2011). *State options that expand access to Medicaid home and community-based services*. Washington, DC: Kaiser Family Foundation. Retrieved from <http://www.kff.org/medicaid/8241.cfm>
- Olmstead v. L.C., 527 U.S. 581, 587 (1999).
- Peer, J. W., & Hillman, S. B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities, 11*(2), 92-98.
- Rizzolo, M. C., Friedman, C., Lulinski-Norris, A., & Braddock, D. (2013). Home- and community-based services (HCBS) waivers: A nationwide study of the states. *Intellectual and Developmental Disabilities, 51*(1), 1-21.
- Savage, S., & Bailey, S. (2004). The impact of caring on caregivers' mental health: A review of the literature. *Australian Health Review, 27*(1), 111-117.
- Shogren, K.A., Forber-Pratt, A.J., Nittrouer, C.L. & Aragon, S.A. (2013). The Emergence of a Human Services Cooperative to Support Families and Young Adults with Disabilities: Implications for Disability Services and Supports. *Research and Practice for Persons with Severe Disabilities, 38*(4), 259-273.
- Weiss, J. A., Cappadocia, M. C., MacMullin, J. A., Viecili, M., & Lunskey, Y. (2012). The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment. *Autism, 16*(3), 261-274.



## CHAPTER 2

# Challenges to Community Living in the Russian Federation and How to Overcome Them

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## Childrearing in Russia for typically developing children

A hundred years ago, following the Revolution in 1917, there emerged in Russia the concept that bringing up children collectively in dedicated facilities with specially trained professionals can be beneficial. Daycare nurseries and kindergartens (for older preschoolers) sprang up everywhere, enabling parents to devote as much time as possible to their jobs. At present, policies for bringing up typically developing children are flexible. Parents may choose to have their child attend a daycare center or not, hire a caregiver, or do the work of parenting themselves. The advantages of bringing up children in group settings are no longer supported.

## Childrearing in Russia for atypically developing children

Where children disabilities are concerned, the paradigm of entrusting them to professional corrective upbringing outside their family settings is still alive. Even 20 years ago, parents of children with disabilities were told that their children would develop better in special residential facilities. Some such facilities were boarding schools, while children with more significant disabilities were diagnosed as 'unable', i.e. no teaching was offered. Families that preferred not to part with their children often found themselves without much needed assistance. Children were spending their time in apartments not adapted for accessibility (for children with physical disabilities), without any socialization or education. Often, one of the parents (usually the mother) had to quit her job to take care of the child with a disability, while the family's standard of living declined significantly, since government disability assistance benefits were meagre. A traditional channel of was essentially impossible. Also, the Soviet system was very competitive and tended to deny that society included people with disabili-

ties or who were 'different'. That was considered a shameful admission. Thus, there is evidence that during Moscow Olympics of 1980, children from so-called subsidiary schools (for high-functioning children with mild intellectual disabilities) were sent away to psychiatric hospitals.

## Slow progress towards inclusion and acceptance of people with disabilities

Recently, Russia switched to officially supporting the notion of equality and value of all people, regardless of their disabilities. In 2012, Russia ratified the UN Convention on the Rights of People with Disabilities (CRPD). But daily realities lag significantly behind the legal framework or the government's official stance. Children and adults with disabilities as well as their parents are stigmatized, do not receive sufficient support and assistance, and are often harassed, starting even at playgrounds (parents of typically developing children often leave playgrounds with their kids once they spot a child with a disability there). Society is still steeped in superstition and fears surround people with disabilities, while awareness and information remain scarce. This situation leads to tensions and low levels of general tolerance as well as verbal aggression in public spaces and social media. Many parents share hostile attitude toward people around them and use hurtful words and comments. A person in a wheelchair can expect expressions of pity at best. One wheelchair-bound young woman who comes for social services to *Life Route Foundation* told us that she is frequently given alms money when using the subway, since people equate people in wheelchairs with beggars.

Moscow is a huge city with much daily stress and many issues with accessibility of public transportation. Recently, Moscow's government launched free assisted transportation service

for people with mobility issues (it is available to wheelchair users and mothers with children in wheelchairs). Thanks to the media and social network campaigns, society at large has become better informed about the disabled community. Many people (including known personalities) openly talk about children or siblings with disabilities, prominent figures support autism and Down syndrome awareness days, and public service advertisements appear in the streets. Yet, many are still scared of people who are different than the majority.



## Tips & Strategies

- What can help people with disabilities and their families feel safe and comfortable in their neighborhoods?
  - More information about children and adults with disabilities, positive stories in the media and social networks, movies and public service advertising
  - Additional training for healthcare and social workers on the ethics of communication with patients/clients (issues of communicating the diagnosis and maintaining a boundary between professional and personal advice)
  - Making people's environments and public spaces accessible to everyone
  - Educational system reforms are needed to enforce a universal right to education and respect for the rights and interests of all children in the educational system, whether they have special disabilities or not
  - Reforms in the system of residential facilities for children and adults with disabilities
  - Volunteerism (initiatives led by religious groups, college students, responsible corporate citizens, etc.)



## CASE STUDY

Family members of one young woman with a disability, who lives in training apartments of *Life Route Foundation*, told us the story of how people at an adjacent table in the restaurant asked to be reseated. She also told how neighbors refused to share an elevator ride with her, because of her 'strange' behavior – humming a song and swaying. The foundation's training apartments are part of a typical multi-unit apartment building. They were donated to the project by Moscow city government. Neighbors wrote and continue to write complaint letters, in which they say that they do not know what to expect of their 'odd neighbors', some of whom according to them appear to behave unpredictably and dangerously. In addition, they complain that they do not know, how to explain "these neighbors" to their children. One time, when the neighbors could not get all of the answers to the questions that they posed to the young people from the training apartments who stepped out for a smoke, they summoned the police. The neighbors assumed that because they could not have their questions fully answered meant that the youngsters were high on drugs.

## CHAPTER 3

# Transition from School-Age to Adulthood

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### Guiding questions

- How does the United States help youth with disabilities transition to adult life?
- What is the best way to address employment needs of youth with disabilities?



## Transition for youth with disabilities in the U.S.

In the United States, education for people with disabilities is guided by the Individuals with Disabilities Education Act (IDEA, 2004). Under this legislation, a child is assessed and, if appropriate, referred for special education services. When services to receive a free and appropriate education are deemed necessary for the child, an Individual Education Plan is written by a team that includes the parents, the individual, school professionals and any outside agency deemed necessary by the school or parent. IDEA also stipulates that services for students with disabilities must occur in the Least Restrictive Environment (LRE). Section 300.114, LRE 2 of IDEA states:

To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are nondisabled; and

(ii) Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

Educators must always look through this lens in planning for a student's education and transition. From an early age, most students with disabilities are educated together with their non-disabled peers. IDEA also mandates that transition from school age to adulthood must be addressed in an Individualized Education Plan (IEP). According to IDEA, schools in the U.S. are required to begin discussing the transition needs of students no later than age 14. At or before the age 16, the IEP team must take into consideration the individual's needs in the areas of functional living, employment, community living and post-secondary training and develop a transition plan. The individual must be

included in developing the plan, including the goals and objectives for the transition process. Other members of the team are the general and special teacher, educational and transition specialists, family member(s), and staff from vocational rehabilitation and community-based services. If the transition goals are not met by the end of the traditional 12th year of school, the individual can continue receiving services until they reach their 21st year of age. A crucial part of this plan is the inclusion of the individual's hopes and dreams for their future. It is also important to coordinate between the different team members in supporting the person's goals. Through formal and informal assessment, the individual's strengths, interests, and areas of need emerge and a transition plan is written. Informal assessments may include: parent questionnaires, interviews with the individual being assessed, observations, and various informal surveys. Formal assessments may include: aptitude tests, interest inventories, adaptive behavior and daily living skills assessments, and self-determination assessments.

It is important to connect individuals with disabilities to the various community and employment agencies that provide services to young adults and adults with disabilities, so the person with a disability receives the necessary supports to be and remain successful in their adult lives. These agencies may provide individuals support in the areas of housing, employment, financial literacy, and community participation. Some are government agencies such as Rehabilitative Services, while others are non-governmental agencies designed for the purpose of helping individuals with disabilities.

Services for youth between the ages of 18 to 21 are typically provided through specialized transition programs. Schools must provide these services to individuals who continue to have unmet special education needs after graduating from high school. These programs are designed to assist individuals in meeting their

goals of gaining independence as an adult. A transition program usually includes instruction in independent living skills, (i.e. cooking, cleaning, peer relationships, etc...) recreation and leisure activities, (i.e. learning how to be involved in the community doing things the individual enjoys doing in their free time) employment and post-secondary training (i.e. specialized training programs, college, trades training etc.).

An integral component of any transition program is employment, whether paid or unpaid. Paid employment means working for an employer that pays you a wage or having your own business. It may be a retail store, a restaurant, office building, childcare center or a wide variety of things people do to earn money. Unpaid work experiences maybe in the same settings but the individual volunteers their time. Unpaid settings would be utilized for exploring the world of work and learning job readiness skills to ensure success for future paid employment. Students may also volunteer or do an internship to discover their strengths and interests or to advocate for themselves and others with disabilities to have better opportunities in society. Employment drives our sense of achievement. It provides us with purpose and when paid, it gives us financial independence.

## Work-Based Learning (WBL)

A Work-Based Learning (WBL) program is fundamental to the transition process. WBL is a formalized learning program that consists of instruction by a licensed work coordinator specializing in working with individuals with special needs. WBL activities occur concurrently at school and worksite. WBL involves sequential building of knowledge and skills in career awareness and exploration as well as critical thinking skills (MDE, 2019). WBL includes classroom instruction, job development, and exploration in the community. The classroom component includes instruction in: workplace safety, rights and responsibilities, rules, con-

duct and expectations, employability, career planning, financial literacy, technology and communication. These combined experiences help a person learn the necessary “soft skills” of employment. Building community partnerships with local businesses is a critical element to a successful WBL program. The students get experience in “real work” environments and employers have an opportunity to see the value of the individuals’ work.

Lindsey et al. (2018) conducted a review of literature focused on the benefits of hiring people with disabilities. In their review they found that employers see many benefits to hiring individuals with disabilities. Among the benefits are improvements in profitability (e.g., profits and cost-effectiveness, turnover and retention, reliability and punctuality, employee loyalty, company image), competitive advantage (e.g. diverse customers, customer loyalty and satisfaction, innovation, productivity, work ethic, safety), inclusive work culture, and ability awareness. Secondary benefits for people with disabilities included improved quality of life and income, enhanced self-confidence, expanded social network, and a sense of community.

Including and supporting students through a well-planned transition process in schools and transition programs is critical to assure that we are providing them with the best opportunities to succeed in their future personal and professional lives.



## Tips & Strategies

- Assess student's abilities and interests in the areas of employment, post-secondary education and independent/supported living.
- Develop a good transition plan that takes into consideration the individual's interests, abilities and needs in the areas of employment, post-secondary education and independent/supported living.
- Develop community partnerships with local businesses who can provide jobs and job training for young adults with disabilities.
- Involve students in a variety of community activities to expose them to new environments and people.
- Provide assessment and make recommendations for assistive technology and communication devices, where needed, to ensure the individual's voice is heard.
- Connect individuals and families to adult service providers that can assist them once they leave the school system.
- Teach and practice self-determination and self-advocacy.

## CASE STUDY

Mika is a young woman with a moderate cognitive delay. She has struggled with academic tasks throughout her education. She lives at home with her parents. She is expected to keep her room clean and take out the trash but has limited knowledge of how to cook or do laundry. Mika is given an allowance and must pay for her own entertainment. She belongs to a friendship group at her high school where special education and general education students plan and do activities in the community together. She also participates in several of the adapted sports leagues her school district offers. Mika volunteered at a daycare center and at a library with a supervising adult (job coach). She hears a lot about going to college from her friends. She wants to go to college too. She talks about becoming a doctor. Mika is graduating from high school this year, so her IEP team is meeting to create a graduation plan.

### What will this plan look like?

Mika's IEP team is examining her latest 3-year evaluation to help in writing her IEP goals and objectives and to develop a transition plan for after her graduation. Before the meeting, Mika and her parents are invited to visit the transition program in her district to see if this program is something Mika is interested in attending.

Transition testing reveals Mika's overall academic performance is significantly discrepant from her same aged peers. She has developed some life skills but not enough to live independently. She is involved recreation and leisure activities. Her parents would like her to continue to be involved in her community, live with friends or in her own apartment and develop healthy adult relationships.

Mika is shy and quiet among adults, but outgoing and social among peers. She often gets distracted by peer relationships. She is re-

luctant to ask for help and when she does not understand something, she refuses to try the task. To be successful as an adult, she needs to learn appropriate adult social interactions, e.g. to ask for help appropriately and to complete tasks that are asked of her.

Her team thought that Mika needed to become more aware of the skills she needed to be successfully employed.

She did not understand what becoming a doctor entailed. She liked to watch doctor shows on television and thought it would be fun because they were always friendly and having fun. She did not like reading or math, or the thought of blood.

In high school she was involved in a Work Based Learning program. She spent part of her school day doing an internship along with three other classmates and a job coach at a local grocery store in her community one semester and at a gym daycare another semester. Through these experiences she began to develop awareness of different jobs, her interests and her job skills. She decided she enjoyed working at the gym and wanted to become an exercise instructor.

Mika's team decided she should attend the transition program her school district offers for students with special needs. They developed a plan for her transition from high school. This plan would be reviewed and revised at least annually.

The first year Mika will continue to develop her job skills by doing an internship for two days a week at the local gym. She will initially have a job coach with the intent to use more natural supports in the work environment with time. She will explore opportunities to become an exercise instructor. Her independent travel skills will be evaluated by a travel instructor and if feasible, a plan will be implemented to teach her how to travel independently in her community.

She will be involved in life skills and career seminar classes two days a week. In the life skills-class she will learn about cooking, housekeeping, and healthy relationships. Her career seminar will teach her about getting and keeping a job, understanding her paycheck, managing her money, communication skills and continuing her career exploration and job training. Her Rehabilitative counselor will help her find a program to become a certified exercise instructor.

One day a week she will be involved in community partnership activities she and her peers choose. It may be going to a museum, a mall, a bowling alley, a doctor's office a bank and or a nature park.

At home she will become more responsible for taking care of herself and tasks around the house. She will learn to do her own laundry and prepare meals for herself and her family. With her parents and the guidance of an agency developed to assist families of individuals with disabilities, she will begin to explore future living arrangements.

## Transitions to adulthood for individuals with disabilities in the Russian Federation

Based on [Navigating Laws project](#) developed by staff lawyers of [Special Childhood Centre for Curative Pedagogics](#).

### Typical transition to adulthood for someone with a disability in Russia

As per Russian law, adulthood starts at 18 years of age. The law assumes that from that point on, a person fully understands the importance of his/her actions and is capable of controlling them. Yet, for most young adults with intellectual disabilities such "full understanding of their actions and ability to control them" are not possible. Some would need continued support for many more years, in some cases forever.

In Russia, 18-year-old individuals with intellectual and development disabilities generally stay in parental homes, and the parents support them and make all of life's important decisions for them. The government pays the person with a disability a pension, but the parents get no additional benefits, even if they need to be full-time caregivers of a grown-up child, which makes continued employment impossible. The biggest fear of aging parents is to have their adult child placed in an institution. One can be placed in such a facility either voluntarily (based on the request of a legally capable person with a disability or his guardian) or end up there by default involuntarily after parents' deaths (if no other relative expressed the desire to house the relative with a disability). An average residential facility in Russia is a large building with 200 to 1,000 residents. Understandably, the quality of living in such settings leaves much to be desired, while in some facilities the conditions are simply unbearable.

### **2012 starts a new outlook for the future**

In 2012, Russia ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) that provides a clear legal basis for supporting adults with disabilities to live the lives they desire. A flurry of lawmaking activities in the social field followed as the country set upon a challenging, but an essential path of implementation of the Convention's guidelines. The central tenet of UN Convention on the Rights of Persons with Disabilities (a cornerstone document for all Russian lawmaking in the field) is independent living in the local community as chosen by the person with a disability. Such independent living is to be arranged with the support of the state (representing society), which must ensure accessibility of services required for active living. The central principle is that the life of a person with a disability must be organized in accordance with his will and preferences. The same principle is to be

applied to the exercise of the person's legal capacity. Exercising legal capacity in the cases of people with disabilities having who are unable of doing so themselves also presumes that their representative will respect their rights, wills, and preferences. All arrangements should be free from conflict of interest and undue influence and also commensurate with and adjusted to the circumstances of specific persons. While these theoretical underpinnings sound great, the realities of being an adult with a disability in Russia change very slowly, as progress runs into the public's resistance and fears, as well as legislative and financial constraints.

### **Current problems with transitioning to CRPD**

People with intellectual disabilities are the least protected social group, whose rights get abused most often due to their communication issues (difficulty with comprehension of situations, with speech, and expression of their desires). Parents and non-profit organizations are the primary movers of changes favorable to people with intellectual disabilities.

While children with disabilities in Russia still receive insufficient support, the supports today are far greater than 10-20 years ago. Unfortunately, adults with intellectual disabilities and their families face the dearth of services needed to support an active, healthy, and dignified lifestyle. Very few get an education beyond public school, and an even a smaller percentage manage to get jobs or any employment at all.

### **Progress now and in the future**

*Life Route Foundation* offers assistance to people with developmental disabilities and is one of the few groups in Russia developing services required to integrate young adults into active living (family counseling on questions of post-public-school education, daytime activities programs, workshops, and transitional hous-

ing). In the future, the Foundation hopes to disseminate templates for successful programs to government agencies and other non-governmental organizations that would provide social services to people with intellectual and related disabilities.

## Resources

- [US Department of Labor; Youth](#)
- [MN Department of Education; CTE Work-Based Learning](#)
- [Articles on Employment and Youth with Disabilities](#)
- [Office of Disability Employment Policy](#)
- [Work Based Learning Toolkit](#)
- [Job Accommodation Network](#)
- [Transition Toolkit Autism Speaks. MN](#)
- [Talking Safety](#)
- [Department of Labor, Skills that Pay the Bills](#)
- [Transition Curriculum](#)

## References

- Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004)
- Lindsay, S., Cagliostro, E., Albarico, M., Mortaji, N., & Karon, L. (2018). A systematic review of the benefits of hiring people with disabilities. *Journal of Occupational Rehabilitation, 28*(4), 634-655. doi: 10.1007/s10926-018-9756-z.
- Minnesota Department of Education (MDE). *Career technical education: Work-based learning*. Retrieved from <https://education.mn.gov/MDE/dse/cte/prog/wbl/>



## CHAPTER 4

# Housing Options: Institutional vs. Home and Community-Based Permanent Living Arrangements

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### Guiding questions

- How does selection and development of permanent housing support the key values of high quality of life, valued social roles, protection of human and civil rights, self-determination, and community inclusion?
- How do you develop housing options that recognize the preferences and goals of the person with disabilities?



## Overview

Where one lives and with whom are very important decisions relating to many aspects of life satisfaction. Most people in the U.S. choose where and with whom they live. These decisions are made based on many factors, including: closeness to friends, family and work; and the size and look of the home. Unfortunately, many persons with disabilities do not have the opportunity to decide where and with whom to reside and the chance to make these choices decreases as level of disability increases (Stancliffe et al., 2011).

The types of community-based settings/program states currently offer individuals with disabilities (e.g., intellectual and developmental disabilities – IDD) include:

- **Congregate settings or small community residences (group homes):** These are settings of 4 or more people in which the provider owns the housing and provides LTSS to the individuals living in the homes. Individuals generally receive 24-hour supports in these types of living arrangements. However, they are most often unable to choose roommates or staff, develop personal schedules and if they are not satisfied with the supports provided, have no option other than finding alternative living arrangements.
- **Shared living:** One common form of shared living are host/foster families in which individuals with disabilities live with a family other than their biological family. The family supports daily living skills and other individual needs in their home. Host family arrangements are available in every state, except Delaware and Mississippi (Larson et al., 2018). Other shared living arrangements that are becoming more frequent include a person with and without IDD sharing an apartment. The roommate without IDD may receive room and board or other compensation for providing supports to the roommate with IDD. Shared living models vary from state to state, but provide living and support arrangements much closer to what a typical person would experience during adulthood.
- **Clustered apartments:** Clustered apartments is an arrangement in which a number of adults with disabilities rent an apartment in an apartment complex. A single service provider organization provides supports to such group of individuals with disabilities.
- **Supportive housing:** Supportive housing is affordable housing, where tenants usually pay one-third of their income in rent, paired with onsite support services. Supportive housing has been more widely used with other populations (e.g., people experiencing homelessness), however, it is increasingly being used to support adults with IDD.
- **Cooperative housing:** Cooperative housing is an option for individuals who want to own their own home, but who also want the benefits a community can offer. Cooperative housing is frequently used in senior housing arrangements.
- **Individual home ownership or rentals:** Using this option, individuals live in an apartment they or their family own or rent. Some states offer subsidies through state funds and there are also limited federal rental subsidies available. Supports may be provided through smart-home technology, waiver-funded supports, and/or unpaid supports from family and friends.
- **Secondary suites or “in-law” apartments:** In-law apartments are accessory living spaces with their own entrance, kitchen, bathroom and living space. These living arrangements allow adults with IDD greater independence, while having family nearby for support, if needed (Larson et al., 2018; Housing Opportunity Development Corporation, and Center for Independent Futures).

Despite a range of options, many individuals with disabilities are not satisfied with their current living arrangements. Rourke, Grey, Fuller, & McClean (2004), for example, found that over 60% of persons with IDD expressed a desire to move from their current residence. Over 50% identified difficulties related to staff, including lack of support for independence and staff shortages as factors. Individuals who lived independently were significantly more likely to express satisfaction with their place of residence, and significantly less likely to express a desire to change residence, than those who lived in residential care. Results of the 2016-17 National Core Indicators-Adult Consumer Survey indicated that 47% of persons with IDD reported having no say in choosing where to live and 59% have no say in choosing with whom they live.

## The Final Rule and housing options

Over the past 20 years, there has been a push by the federal government via Medicaid funding requirements towards more community-based housing for individuals with disabilities. Home and community-based waivers were introduced in 1995 to encourage this trend across states and service providers. Home and Community Based Services (HCBS) Medicaid waivers reimburse fees for services to individuals living in community settings (Atack et al., 2019). Due to both the Olmstead court ruling and the Americans with Disabilities Act (ADA), waivers for institutional-based services (e.g., intermediate care facilities — ICFs) for individuals with IDD within Long-Term Services and Supports (LTSS) have been reduced, while HCBS waivers have increased (Eiken, 2015). These policies have decreased the number of institutional care facilities to 0 in some states and decreased them significantly in others.

The Centers for Medicare & Medicaid Services (CMS) issued the *Final Rule* in 2014 to prioritize reimbursing service provided to

individuals in the most integrated setting that is appropriate (Department of Health and Human Service, Final Rule, 2014). The final rule requires that all home and community-based settings are selected by the individual from among setting options, ensure individual rights of privacy, dignity and respect, and freedom from coercion and restraint; optimize autonomy and independence and facilitate choice regarding services and who provides them.

## What are the advantages of home and community-based living arrangements?

Ideally, the goal is to secure housing that is the least restrictive or intrusive, while ensuring the safety and well-being of individuals with disabilities. The living environment should not stifle intrinsic motivation or erode one's abilities and should not restrict opportunities to live and interact with the surrounding community more than is necessary. Ultimately, community-based living arrangements allow for increased independence and provide learning opportunities and self-awareness, especially in relation to others and the surrounding environment.

Home and community-based living arrangements foster an improved quality of life that enhance self-determination and community inclusion. The right kind of housing can cater to the preferences and goals of the person, rather than to the needs of the system. The hope is that persons with disabilities can live in homes that provide personally meaningful lives where the person chooses how to decorate his or her environment, what and when he or she drinks or eats, what clothes the person wears, who he or she associate with, and what activities he or she does, etc. Likewise, in those settings individuals may refrain from doing things that they do not want to do. This autonomy not only recognizes their individual preferences, but also promotes the development of basic

life skills and self-sufficiency. In addition, home and community-based living arrangements can serve to facilitate interactions with the community, which, in turn, aids in their development of desirable social skills as well as in changes in attitudes of the community.

From 1988 to 2011, the number of persons with IDD who live in community-based settings has increased significantly, which theoretically means that persons with IDD have more opportunities for inclusion in society (Woodman, Mailick, Anderson, & Esbensen, 2014). Research has demonstrated a positive relationship between quality of life and the move of individuals with IDD out of institutions into community settings, with the strongest benefits associated with settings that support self-determination (Wehmeyer & Bolding 2001; Larson, Lakin, & Hill, 2012; Woodman et al., 2014), and independent living (Houseworth, Stancliffe, & Tichá, 2018). Compared to other settings, independent living arrangements have been associated with more choice overall (Lakin, et. al., 2008; Tichá, et. al., 2012; Houseworth, Stancliffe, & Tichá, 2018) and improved preventative health care (Bershinsky et al., 2012). Family settings have been associated with a stronger sense of safety and less loneliness (Stancliffe, Lakin, Taub, Chiri, & Byun, 2009), but less physical activity (Stancliffe et. al., 2012; Hsieh, Heller, Bershinsky, & Taub, 2015). Congregate settings (small to medium sized group homes) have been associated with improved preventative health care (Bershinsky et al., 2012), but more issues with mental health (Scott & Haverkamp, 2014). Outcomes associated with residing within supported living environments (e.g., group, independent, and family homes) however, differ significantly from person-to-person (Houseworth, Tichá, Smith, & Ajaj, 2018).

## What are the potential challenges to providing home and community-based living arrangements?

Housing options may be limited by a lack of resources. For instance, many persons with disabilities do not have financial resources to own or rent their own homes. Other external resources, such as government support, may be limited. In addition, some cognitive or physical disabilities may make living on one's own very difficult or cost prohibitive. In such cases, a group home setting may be necessary.

Other challenges may limit the desired effectiveness of home-and community-based living arrangements. Even when resources are available to pay individuals to provide in-home services or to work in a group home setting, the personnel must be trained and monitored to ensure they maintain a person-centered approach that does not restrict the clients' autonomy and self-determination.

In addition, some members of the community may have difficulty when encountering persons with disabilities in public. They may act negatively or interfere in the provision of services in a way that could be detrimental. However, this may stem from a lack of familiarity and is just another argument for community inclusion that can promote understanding and tolerance in society.

It is important to recognize that housing choice is complex, requiring consideration of multiple factors including: quality of neighborhood, access to transportation, distance from family and preferred activities, level of independence supported, and access to supported decision-making. An individual's desire to reside in an independent or supported living situation might be person-centered, but not match for his/her current skill levels and support needs. Furthermore, conflict between the desires of persons with IDD for independence/self-determination and a family focus on safety and supports can make it difficult to maintain consensus as to the best living situation.



## Tips & Strategies

Identification, selection, and development of permanent housing that fits the needs and abilities of persons with disabilities can be a challenging process. Some things to consider when embarking on this process include the following:

- Begin the conversation early. It may be best to begin considering options during adolescence to begin finding good matches and building consensus.
- Assess the individual strengths, needs, and preferences of the individual. Begin with what a person wants to do, can do, and then consider what they can do with supports.
- Identify what resources such as funding and family support systems are currently available to the individual. What already exists to support the individual in terms various housing options.
- Determine what further support is required to ensure the safety and well-being of the individual beyond what currently exists and explore how that support could be obtained.
- Begin the process and end the process with a “less-restrictive environment” approach.
- Building off the previous recommendations, work to match the individual’s preferences, strengths, and support needs with what is available in a person-centered and pragmatic manner: Develop person-centered support planning that increase independence and community integration

## CASE STUDY 1

Rajwood is an Intermediate Care Facility for adults with severe cognitive disabilities; however, it is not to be confused for anything other than a home. This seven-bedroom house is located in your typical American neighborhood, located near a local shopping mall and a park in the heart of Maplewood, Minnesota. This split-level home has a main floor, which consists of an entryway, kitchen, dining room and a quarter bath in the hallway leading to the garage. The upper level includes a living room, a full bathroom and three bedrooms, while the lower level has three bedrooms and a small family room. The basement has one bedroom and is where the laundry room and utilities are located. The service provider receives funding to operate the home from the Minnesota Department of Health and Human Services, which receives partial funding from the federal government.

On the outside, the house is on a wooded corner lot centered between one house on the right and the backyard backing up to another house. In the backyard, there is a large patio covered by a gazebo and picnic table. A swing sits on the patio next to the gazebo. A large yard and quiet cross streets surround the front and side of the house, which run through the neighborhood. The neighbors across the street, as well as, the neighbors to the right are friendly and supportive of the provider running the home. Refer to the photo below for the visage of the house.



Four men with disabilities live in the house and each has their own private bedroom. Each bedroom has a bed, dresser, closet, personal belongings and other furnishings as chosen by the individual. Additionally, each of the men, or their families, decorated the rooms in a manner that reflects their preferences and highlights their unique personalities. Additionally, the rest of the house is decorated and arranged in a manner that blends preferences of all the residents. Aside from decorating, the home has been retrofitted and adapted to accommodate the specific needs of the four men living there. For example, handrail support bars were installed in the upstairs bathroom so that it is easier for the residents to get in and out of the tub without relying on staff for assistance. All four gentlemen are ambulatory and able to move independently. However, as they age, physical needs may increase, and further adaptations may be necessary.

The home is open 24 hours a day, 365 days a year and is staffed at all times while the men are home. The home operates with support staffing patterns in three shifts. Daytime shifts are generally from 8:00 am to 2:00 pm, evening shifts are from 2:00 pm to 10:00 pm, and overnight shifts are from 10:00 pm to 8:00 am the next morning. There are typically three support staff during daytime and evening shifts. Overnight shifts include one awake overnight staff and one asleep overnight staff for a ratio of one staff person per two residents.

Each support staff is assigned specific job duties to complete during their scheduled shift and assignments are rotated to reduce employee burnout. The primary function of support staff is to provide active support, which seeks to increase skills and participation in activities of daily living for the individuals with disabilities. For example, each resident works toward independence in daily hygiene, preparing meals, taking medications, going shopping, cleaning, and participating in social activities at home and in the community. Support staff

work with each individual to breakdown steps of everyday tasks and make adaptations to each step so that the men can participate in and do as much of the tasks on their own as possible.

The four residents range from the ages of 43 to 52 and have been diagnosed with autism and intellectual disability. Two out of the four individuals use augmented communication devices consistently. One out of the four individuals does not communicate using words. The men have various other medical conditions, including scoliosis, etc. Two of the four men receive psychotropic medications to assist with behavioral control, while another takes medications to assist with a sleep disorder. All individuals have individualized behavior management programs that address maladaptive behaviors, identifying more adaptive ways to meet their wants and needs as well as identifying different ways to calm and to cope with difficult situations.

Support staff receive training in all areas mandated by Minnesota Department of Health and Human Services regulations. Additionally, staff receive training in areas of autism, behavioral and Activities of Daily Living (ADL) training, communication skills, individual program plans, use of positive reinforcement, gentle and/or proactive teaching strategies, and positive behavioral supports.

A typical week for the men includes going to work, participating in community activities, socializing with friends and family and working on daily living skills. For example, each resident at Rajwood has a job at a community day program, where they work Monday through Friday with weekends and holidays off. The men are at work for a minimum of six hours per day during the workweek.



## CASE STUDY 2

Timothy is a 54-year old man with an intellectual and developmental disability (IDD), who receives services under the Medical Assistance Community Access for Disability Inclusion (CADI) home and community-based services waiver. He became a homeowner in 2011 with the help of the Housing Access Services (HAS) program initiated by the Minnesota Department of Human Services in partnership with The Arc of Minnesota, a non-profit organization that assists people with IDD to live more independently. Before 2011, Timothy had been living in public group housing in Minneapolis for 10 years. Eventually, he decided he wanted more privacy and a quieter neighborhood.

His first step was to meet with HAS staff and together they formed a plan to search for a place that would match his needs and budget. They found several potential homes and helped Timothy view them until they found the one that best matched his needs. It was a condominium that was purchased with a monthly payment Timothy could afford. While HAS typically helps people rent apartments, all agreed that buying the place with a mortgage made the most sense for Timothy.

Initially, HAS helped Timothy and his brother weigh the pros and cons when buying his new place. Next, HAS staff assisted Timothy in connecting with a mortgage company and made sure he fully understood the purchase and agreements. After the purchase was approved, HAS helped with moving and finding the new furniture Timothy would need. Finally, Hennepin County made sure Timothy had access to his providers for the services he would require in his new residence.

Timothy likes his neighbors and has come to share a key with his neighbor across the hall in case of an emergency. He feels like his new place is quiet and more independent than living in public housing. He has been a leader in

self-advocacy for individuals with IDD, promoting more independence in their lives, including in housing.

## Housing options for people with disabilities in the Russian Federation

### Cultural background in Russia: Living situation in family homes

In Russia, most of adult children with disabilities live with their parents. In the Russian culture, especially in small cities, many families that have no relatives with disabilities also continue to live together for several generations — grandparents, parents, children, and sometimes grandchildren. Most often this happens due to income reasons — a young family is not capable to buy or rent housing. Senior relatives often help to take care of children. When grandparents become weaker, family members often take care of them as well, primarily their working children. If there is a relative with a disability in a family, it usually seriously reduces family's material well-being, since one of the employable parents will take care of the person with a disability (child or adult) and will not be able to earn money. Government assistance to a family that has a relative with a disability is a pension (at subsistence level), and a small care allowance for a relative, who is providing care.

### Situation in institutional settings

The state also provides families the opportunity to house their child or an adult with a disability in an institution. Living conditions in Russian institutions are usually rather harsh. Even though the resource base of institutions in most regions of Russia have recently improved (at least, there are enough diapers and other care supplies), the other aspects of life in these facilities leave much to be desired.

Most people with disabilities — children and adults living in institutions, spend all day

in beds (if they are not mobile on their own). They do not go for walks and they eat food in the same room where they live. Rooms can accommodate from 3 to 20 people. There are no doors or partitions in the shower rooms and bathrooms. We often learn about cases of compulsory psychiatric treatment for bad behavior. A person's desire to walk along the hallways or smoking at the wrong time, a harsh statement addressed to personnel, who is often rude to residents, can be construed as bad behavior. Rarely in any institution the administration cares about the daily engagement of residents, let alone about their education or work. Visiting relatives and friends residing in these facilities is possible only on a posted schedule or by making a prior arrangement with the administration. The visitation may not be allowed for various reasons — due to bad behavior or a medical quarantine in an institutional unit. It is very difficult to protect one's rights in these facilities. The residents become hostages of a bad or good attitude of the staff and are hesitant to complain, fearing the consequences.

### **Situation in assisted living settings**

Currently in Russia, there are only a few cases when people with disabilities, who need daily support, do not reside with their parents or in custodial institutions. In St. Petersburg, there is an assisted living home for 19 people (founded by parents' association initiative). In Pskov, Vladimir, Nizhny Novgorod and several other cities and towns, young people with disabilities share assisted living apartments with social workers, who help them with daily routines. Such precedents inspire parents from other cities to establish similar apartments and homes. Laws as well as legal and financial mechanisms of such projects are not yet fully defined. Charitable organizations or groups of parents create projects suitable for the needs of specific people in each of these individual cases. In different regions of Russia, financing

of such projects is carried out in different ways. It is becoming gradually possible to arrange partial or full financing of such housing formats at the state expense.

In Moscow, the largest and the wealthiest city in Russia, there is not a single home or assisted living apartment for people with disabilities. There are known precedents of establishing training apartments, where young people with disabilities could get the experience of independent living without parents. Several years ago, the Center for Curative Pedagogy, in cooperation with the College of Technology No. 21, implemented the Training Apartment project, where college students with disabilities could live. The project got closed due to lack of funding to pay the aids. In 2018, the Life Route Foundation opened training apartments for 10 people in an apartment building. The foundation is facing enormous resistance from the local community that does not want to live next to people with disabilities. Neighbors at the apartment building call the police, asking to check residents with disabilities for drugs. They also ask that the residents use separate entrances and elevators. They write complaints to the Moscow mayor. Here is a quote from one of their complaints:

*"We ask you to stop this reckless social experiment that violates the rights of more than 700 residents, including children, which is being carried out on a large scale in a single-entry business-class apartment building where this residential building is simply used to create a psycho-neurological institution!"*

The fears and protests of "ordinary" people are understandable. Many of them have never encountered people with disabilities before. They do not know what to expect as they all heard horror stories and myths broadcasted by segregation culture and the non-progressive media.

We understand that the integration of people with disabilities into the community and the realization of their right to be included in the community is a process that will take many years. This process requires training, outreach and support of all members of the community - people with disabilities and their relatives, people without disabilities, professional care workers as well as government officials adhering to the new humanitarian standards.

## Resources

- [Housing Opportunity Development Corporation](#)
- [Center for Independent Futures](#)
- [The Arc: Housing Issue for People with Disabilities](#)
- [Consortium for Citizens with Disabilities Housing Task Force](#)
- [The Autism Society of America: Residential/Housing](#)
- [Outcomes, Inc.](#)

## References

- Atack, L., Versegny, J., Maher, J., Herie, M., Poirier, M., MacNeil, F., & Grimley, M. (2019). An Emerging model for semi-independent living for persons with intellectual and developmental disabilities. *Inclusion, 7*(1), 57-70.
- Bershadsky, J., Taub, S., Engler, J., Moseley, C. R., Lakin, K. C., Stancliffe, R. J., ... & Bradley, V. (2012). Place of residence and preventive health care for intellectual and developmental disabilities services recipients in 20 states. *Public Health Reports, 127*(5), 475-485.
- Department of Health and Human Services (2014). *Final Rule, Medicaid HCBS*. Center for Medicaid and CHIP Services.
- Eiken, S., et al. *Medicaid Expenditures for Long-Term Services And Supports (LTSS) In FY 2013*. Truven Health Analytics, 2015. Print.
- Hsieh, K., Heller, T., Bershadsky, J., & Taub, S. (2015). Impact of adulthood stage and social-environmental context on body mass index and physical activity of individuals with intellectual disability. *Intellectual and Developmental Disabilities, 53*(2), 100-113.
- Houseworth, J., Stancliffe, R. J., & Tichá, R. (2018). Association of state-level and individual-level factors with choice making of individuals with intellectual and developmental disabilities. *Research in Developmental Disabilities, 83*, 77-90.
- Houseworth, J., Tichá, R., Smith, J., & Ajaj, R. (2018). Developments in living arrangements and choice for persons with intellectual and developmental disabilities. *Policy research brief, 27*(1). Minneapolis: University of Minnesota, Institute on Community Integration.
- Lakin, K. C., Doljanac, R., Byun, S. Y., Stancliffe, R., Taub, S., & Chiri, G. (2008). Choice-making among Medicaid HCBS and ICF/MR recipients in six states. *American Journal on Mental Retardation, 113*(5), 325-342.
- Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). *In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2016*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
- Larson, S., Lakin, C., & Hill, S. (2012). Behavioral outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: US studies from 1977 to 2010. *Research and practice for persons with severe disabilities, 37*(4), 235-246.
- Rourke, A. O., Grey, I. M., Fuller, R., & McClean, B. (2004). Satisfaction with living arrangements of older adults with intellectual disability: Service users' and carers' views. *Journal of Learning Disabilities, 8*(1), 12-29.
- Scott, H. M., & Havercamp, S. M. (2014). Mental health for people with intellectual disability: The impact of stress and social support. *American Journal on Intellectual and Developmental Disabilities, 119*(6), 552-564.
- Stancliffe, R. J., Lakin, K. C., Taub, S., Chiri, G., & Byun, S. Y. (2009). Satisfaction and sense of well being among Medicaid ICF/MR and HCBS recipients in six states. *Intellectual and Developmental Disabilities, 47*(2), 63-83.
- Stancliffe, R., Lakin, K., Larson, S., Engler, J., Taub, S., & Fortune, J. (2011). Choice of living arrangements. *Journal of Intellectual Disability Research, 55*(8), 746-762.
- Stancliffe, R. J., Lakin, K. C., Larson, S. A., Engler, J., Taub, S., Fortune, J., & Bershadsky, J. (2012). Demographic characteristics, health conditions, and residential service use in adults with Down syndrome in 25 US states. *Intellectual and Developmental Disabilities, 50*(2), 92-108.



- Tichá, R., Lakin, K. C., Larson, S. A., Stancliffe, R. J., Taub, S., Engler, J., ... & Moseley, C. (2012). Correlates of everyday choice and support-related choice for 8,892 randomly sampled adults with intellectual and developmental disabilities in 19 states. *Intellectual and Developmental Disabilities, 50*(6), 486-504.
- Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research, 45*(5), 371-383.
- Woodman, A. C., Mailick, M. R., Anderson, K. A., & Esbensen, A. J. (2014). Residential transitions among adults with intellectual disability across 20 years. *American Journal on Intellectual and Developmental Disabilities, 119*(6), 496-515.

## CHAPTER 5

# Supporting Inclusive Community Living: A Person-Centered Approach

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### Guiding questions

- What are the primary components of person-centered inclusive community living?
- What are the skills, knowledge, and attitudes/beliefs of direct support professionals that facilitate inclusive community living?

## Introduction

If one is to provide high quality supports to persons with intellectual disabilities and developmental disabilities (IDD), an understanding of the competencies needed by direct support staff to provide such services is essential. Those competencies, in turn, need to be driven by an understanding of the multidimensional nature of community living. Similar to the approach championed by Nye-Langerman and Hewitt (2019), we view living within inclusive communities as dependent upon the preferences of the individual with a disability, their self-determination, social connectedness, and the culture and context within which they live. Inclusive community living will therefore look somewhat different across cultures and for each person with an intellectual and developmental disability.

**Figure 3. Critical features of community living**



Given this complexity, community living needs to possess a number of critical features if it is to lead to true inclusion in society and a high quality of life. These competencies include: (1) engagement with individuals and groups of

one's choosing; (2) a sense of social connectedness to others; (3) reciprocity in relationships such that persons with disabilities both initiate social interactions with others and have others initiate interactions with a sharing of responsibility for providing each other with support; (4) valued social roles with persons with disabilities, though experiencing challenges, viewed by others as competent and capable and with their own unique gifts and capacities to contribute; and (5) self-determination, a process through which persons exercise the degree of control they prefer over those areas of life that they consider to be important (see Figure 1).

We start with the assumption that all people with intellectual and developmental disabilities (IDD) have the capacity to participate in, enjoy, and profit from community living. This is clearly demonstrated by several decades of research in the U.S. and other countries that indicates that persons living within the community experience greater self-determination, social inclusion and a higher quality of life than those residing in institutional settings (Kozma, Mansell, & Beadle-Brown, 2009; Larson, Lakin, & Hill, 2012; Young, Sigafoos, Suttie, Ashman, & Grevell, 1998). In addition, people with intellectual and developmental disabilities clearly indicate that they prefer living in community setting over residing in institutions (Nota, Ferrari, Soresi, & Wehmeyer, 2007; Wehmeyer, & Bolding, 2001).

People with IDD depend on a wide variety of services and supports to successfully live within the community. The individuals who provide such supports, referred to as direct support professionals or DSPs, play a critical role in providing home and community-based services to people with IDD and other disabilities. Most often, these staff persons work within an individual's own home or flat, the home of the family of the person with the disability, or in small (2-3 person) supported living program in the community. In addition to supporting

people with a disability in tasks of daily living, an equally important aspect of their job is to assist the individual to engage, connect with, work, and recreate within inclusive settings (i.e., environments frequented by persons without disabilities). Since the deinstitutionalization of persons with disabilities in the U.S. and other western countries in the 1980s, there have been continuing difficulties in retaining persons to serve as DSPs due to non-competitive wages and a current shortage of such professionals that is likely to become worse in the near future. There is no denying, however, that when properly trained and supported, DSPs play a critical role in people with disabilities not only being physically present in the community, but more importantly being socially and psychologically included in a wide variety of settings.

## Critical competencies

Over the past several decades the role of a DSP has evolved from a basic caregiver to human service professional who assists people with disabilities to lead self-determined lives and contribute to their communities. At the heart of this evolution of the role of the DSP has been the concept of *person-centered thinking and practices* (Amado & McBride, 2003; O'Brien, 2002; Taylor, J. E., & Taylor, 2013). Within the person-centered thinking framework, DSPs not only focus on the traditional roles of caregivers (e.g., ensuring health; supporting activities of daily living), but also on delivering personalized services that assist people to achieve their personal desired life outcomes. This involves first understanding and then supporting what is most important to the person, their dreams and goals for the future, and those areas of life in which they desire to devote their energies. DSPs must strike a balance between helping the people they serve gain access to what is important to the person they serve (e.g., going to the movies) as well as what is important for

them (having sufficient and nutritious food to eat).

To facilitate this change from caregiver to navigator/advocate, a set of competencies for DSPs was developed in the by Taylor, Bradley, and Warren (1996). Referred to as the *Community Support Skill Standards (CSSS)* for DSPs, these competencies have become the standard in the field, adopted by the *National Alliance for Direct Support Professionals (NADSP)*, and validated as critical for the success of community living (Bayes, 2010; Bogenschutz, Nord, & Hewitt, 2015; Hewitt & Larson, 2007).

- **Participant empowerment.** Competent DSPs enhance the ability of the people they serve to lead self-determined lives by providing the support and information needed to build self-esteem and assertiveness, and to make decisions.
- **Communication.** DSPs should have the capacity to use a range of communication strategies and skills to establish collaborative relationships with the people they serve.
- **Assessment.** A DSP should be knowledgeable about formal and informal assessment practices in order to respond to the needs, desires, and interests of the people they serve.
- **Community and service networking.** DSPs should understand the formal and informal supports available in the local community and be skilled in assisting the people they support to both identify the supports they need and gain access to them.
- **Facilitation of services.** Competent DSPs are knowledgeable about a range of person-centered planning techniques and understand both their potential role in assisting persons with their service planning and implementing plans in a collaborative manner. Competency Area
- **Community living skills and supports.** The well-trained DSP has the ability to match

specific supports and interventions to the unique needs of the people they serve recognizing the importance of friends, family, and community relationships.

- **Education, training and self-development.** DSPs should be able to identify areas for self-improvement, pursue necessary education, and share this knowledge with others.
- **Advocacy.** DSPs should understand those challenges in the community experienced by the persons they support and be able to use effective advocacy strategies to overcome them.
- **Vocational, educational and career support.** DSPs should be knowledgeable about the career and educational goals of the people they support and assist them to reach their goals.
- **Crisis intervention.** A well-trained DSP should possess the necessary skills and knowledge for crisis prevention, intervention, and resolution techniques and should match the strategies used to the unique needs of individuals.
- **Organization participation.** A DSP should be familiar with the mission and practices of the support organization and take an active role in the life of the organization.
- **Documentation.** The effective DSP is aware of the requirements for documentation in their organization and able to manage these efficiently
- **Building and maintaining friendships and relationships.** Competent DSPs effectively support the persons they serve in the development of friendships and other relationships.
- **Providing person centered supports.** DSPs should provide all supports in a person-centered manner and in those areas defined by the people they serve as most important. When requested by the persons they serve to assist in developing and implementing

person-centered plans the DSP has the ability and motivation to do so.

- **Supporting health and wellness.** Well trained DSPs promote the health and wellness of the people they support on an ongoing basis (NADSP, 2007; Taylor, Bradley, & Warren, 1996).

## The education and training of direct support professionals (DSPs)

Recent exposés highlighting the poor decisions and failures of DSPs have increased the scrutiny of this role and resulted in increased attention being paid to their training and support. Members of this group are expected to have a plethora of skills and knowledge as well as a set of positive attitudes and beliefs revolving around community inclusion, person-centered thinking, and the gifts and capacities of people who have for years been viewed by society through a medical, deficit-based lens (Mansell, 2016). Nearly all states in the U.S. have now established rules and regulations regarding the minimum training a DSP must receive prior to beginning the job. Federal legislation in the U.S., including the Developmental Disabilities Assistance and Bill of Rights Act (DD Act PL 106-402, 2000), the HCBS Settings Final Rule (2014) as well as court decisions, have made it critical for states to establish regulatory oversight over providers of services to ensure that their staff the skills necessary to effectively support the people they serve. Unfortunately, much of the training that has been developed in reaction to current regulations tends to focus more on the caregiving aspects of the job and state regulations than on the person-centered aspects of services.

Advances in the education and support of DSPs have focused on Competency-Based Training (CBT). CBT programs in the U.S. tend to be based on *National Alliance for Direct Support Professionals* standards and break down

education into what a DSP needs to know, the skills they must possess, and the attitudes and beliefs that support a person-centered, high quality approach to the delivery of services (Nye Langerman & Hewitt, 2019). Such programs include online courses and assessments, in-person training, coaching, and mentoring, and in some contexts certification after an individual passes a written exam. As of this date, a number of training programs have been accredited by the National Association of Direct Support Professionals, including Direct Course: College of Direct Support developed by the University of Minnesota's Institute on Community Integration; The National Alliance for Direct Support Professionals (E-Badge Academy that offers DSPs the ability to earn electronic badges as a way to demonstrate their knowledge, skills, and values on the job; and The PATHS Program - a certificate training program to prepare students for a career of DSPs. The provision of opportunities to complete credentialing programs similar to those noted above, especially when such achievements are accompanied by incentives (e.g., higher rates of pay), is one way to increase the capacity of the direct support workforce.



## Tips & Strategies

- The adoption of person-centered approaches to thinking, support planning and the delivery of services to people with disabilities based on a social rather than a medical approach to disability is a critical starting point for all community living programs. Advocates of this approach are supported by research evidence that all persons with disabilities, given appropriate supports, can successfully reside in the community.
- In developing community living programs for persons with disabilities in geographic areas where they have not previously existed, it is critical to recruit and train persons whose attitudes and values support this approach. Individuals who have previously served in a primary caregiving role or view their role as “controlling” or “doing things for” as opposed to “with” the persons they support are typically not the best selections. Although it may seem convenient to hire DSPs from among persons who have previously worked in institutions, this approach rarely works. Rather, a new, often younger cohort of people to serve as direct support professionals will need to be hired.
- Providing supports to persons with disabilities can be a challenging process. The challenges experienced can be significantly reduced if the approaches one

uses to interact and provide services are based on recent research evidence or have been designated by appropriate authorities as promising practices. Relying on programs that are solely supported by theories from decades past and with little research evidence to back up their use only serves to make life more difficult for both persons with disabilities and those who support them.

- A critical aspect of supporting the community living of people with disabilities is to ensure that they are able to develop positive relationships with the staff who support them. The matching of DSPs to the people with disabilities they support while not an exact science can be done on the basis of a number of factors including: behavioral style; common interests; skills that are congruent with what the person with disability would like to learn; gender, age, etc.
- Using high schools and technical colleges in the U.S. and in the Russian Federation colleges to create a pipeline for young persons with an interest in disability to receive free training in the area. If provided as part of elective courses and taught based on the principles of universal design for learning, this training has the potential to benefit the entire community.



## CASE STUDY

When Mark was a student at a local university, he needed additional funds for his education as a computer/information technology engineer. He therefore answered an advertisement in the campus newspaper for direct support professionals placed by an organization that provided home and community-based supports to persons IDD. After reading the advertisement, Mark contacted the organization and within 6 days found himself sitting in training sessions focused on how to administer medication, chart client progress, deal with challenging behavior, and provide support for activities of daily living. Following his training, Mark felt confident that he could successfully handle any issue that might come his way. This sense of confidence was abruptly shattered, when he found himself placed in a home that provided supports to three young men with autism who when separated from their routine had a history of engaging in inappropriate behavior. Mark's first thoughts were that while his training was valuable, it only provided him with the bare minimum of skills he needed, and these were mostly focused on what to do in emergencies and the procedures for documenting interventions and supports. How to most effectively communicate with the people he would now be supporting was left out of his educational experiences.

As Mark began taking the young men he supported out in to the community, he realized that his job was going to be a challenge. Tim liked outdoor activities, especially hiking. Michael was an indoor person who could spend hours playing video games. Jim was unlike the others and communicated freely albeit incessantly about how he was good with computers and his need to find a job in that area. Mark also learned that people in the community could either be quite understanding and supportive of the men or show an almost complete lack of respect for their rights and feelings. As

his time on the job grew, Mark found himself learning or needing to learn a new skill or piece of knowledge every day. He tried everything to see if there were any possibilities for him to advocate for the young men when they attended sporting events and other community functions frequented by large groups of people.

Luckily for Mark, the provider organization for whom he worked was involved in a project to train those persons who served as front-line supervisors how to use evidenced-based on-boarding procedures for people who had recently been hired. Through this program, Mark's supervisor learned about how he liked to be supervised, those things he preferred to do independently, the best approach to take when he needed to change his strategies for working with a client, and his training needs. They met individually for 30 minutes on a weekly basis for the first 9-months that Mark was on the job. These sessions not only provided Mark with the opportunity to learn new things about the young men he supported with respect to the competencies he needed to be an effective DSP. Combined with lots of reinforcement from his supervisor when he took the initiative and responded to his clients in a person-centered manner, these sessions were not only experiences Mark looked forward to, but kept him excited about his job to the point that when he finished his university program, he applied and was accepted into a Master's Degree Program in Social Work. Through the provider for whom he worked, Mark had access to an on-line training program for direct support professionals. This allowed him to specifically select educational coursework that was specific to the support needs of the men with whom he was working and receive a training certificate following his successful completion of the program. This learning opportunity both kept him interested in his job and allowed Mark to continue to develop his skills and knowledge.

## Staffing competencies, stability, challenges & recruitment at a Russian non-governmental organization

### Staffing at Life Route Foundation

The staff of 37 salaried personnel and more than 20 volunteers are engaged in six programs of the Life Route Foundation in Moscow that serves approximately 100 clients. Many employees have pertinent work/volunteering experience gained at the Center for Curative Pedagogics (CCP), the founding organization of the Life Route Foundation. The Center for Curative Pedagogics provides psychological and pedagogical assistance to children with developmental disabilities and their families. The Life Route Foundation was established in 2009 by the initiative of the CCP to implement programs for adults with developmental disabilities.

Some employees (about half) have either psychological or pedagogical education. The rest gained their competencies while volunteering or during a special training focused on assisted living required to be taken by employees supporting persons with disabilities living in an apartment.

The basic work principles of the Life Route Foundation are:

1. **Social model of disability** (a person becomes disabled not only and not so much because of a primary physical or cognitive impairment, but because there are no conditions for inclusion of such an individual in everyday life), and:
2. **Basic principles of curative pedagogics**
  - » Integration – basic principle of education and community living.
  - » Education – the fundamental need of every child and adult. There are no children or adults, who cannot be educated.



- Education and life in the family and community provide maximum opportunities for the development of abilities for children and adults.
- Children and adults with developmental disabilities need concerted actions of parents (guardians) and specialists.
- Teamwork is much more effective than the work of a specialist working alone.
- The key to providing successful assistance to children and adults is the understanding of their challenges and respect of their human dignity.

Despite the difficult working conditions and the tasks set for our employees, we do not experience staff turnover. Possible reasons why people want to continue working in the Life Route Foundation are:

- Organization's values align with personal values
- The opportunity to obtaining professional skills within the organization
- Regular meetings to discuss tasks, track results, and discuss issues with colleagues (not only with a manager)
- Flexible work schedule

## Staff challenges

Let's consider the difficulties that the staff (aides, social workers) face while assisting adults with special needs based on the example of a training apartment team:

### Staff ask themselves:

- What role to play? Where is the line between "serve" - "make" - "help" - "make something pleasant"? How to spend free time? Should you suggest activities: board games, walks, workshops, conversations?
- Should a person with autism be given time for auto-stimulation and stereotypy, or is it

better to distract the person? Is this behavior a form of recreation and is it necessary? Perhaps it is an undesired behavior? A person can interrupt auto-stimulation only with active intervention.

- How to maintain a therapeutic approach, that is, to see prospects, set goals and reach them, while developing yourself instead of just providing care and friendly talk?
- How to help a person to follow a diet and take medication if he/she does not want to do so?

### Additional difficulties faced by staff:

- Using public transportation: The assistants encounter a lot of unusual behavior by persons with disabilities, such as micro-aggressive outbursts. During the rides in public transportation, the aids assisting individuals with disabilities become stressed themselves and feel the tension of others.
- Problems with neighbors in an apartment building: There is a sense of insecurity and isolation and the feeling of infringement of rights. For example, they are asked to use a separate elevator.
- Difficulties with parents of adults with disabilities: With regard to many care requirements (what to wear, what meals to prepare, how to entertain), the wishes of parents do not always coincide with the therapeutic tasks and even the opinions adults with disabilities.

## Staff recruitment

What are the criteria for recruiting a team for work in training apartments?

- Experience working with adults with developmental disabilities, such as volunteering or caring for a family member with a disability or who is elderly. Relevant education is welcome, but is not a prerequisite.

- An expressed interest in this type of work. What is the person's interest and motivation.
- The desire to learn, attend seminars, readiness to write reports and read articles/books on the subject.
- The ability to seek help and the ability to follow instructions.
- No difficulties with needing stay awake during work shift (for night aids).
- Mental poise, the ability to deal with someone else's attention while in public, not always well-meaning (The ability to be in public places with adults with disabilities when they may be displaying unusual, attention-drawing behavior).

## Resources

- [American Association on Intellectual and Developmental Disabilities \(2016\). Position Statement on Direct Support Professionals \(DSP\) Workforce.](#) Washington D.C.: AAIDD
- [National Association of Direct Support Professionals \(2019\). Competency Areas for Direct Support Professionals](#)
- [New York State Office for People with Developmental Disabilities DSP core Competency Evaluation tools](#)
- [The Arc \(2018\). DSP and Frontline Supervisor Competency Sets](#)
- [University of Pennsylvania \(2019\). Direct Support Professionals Competencies and Training Content](#)
- [National Association for the Dually Diagnosed \(n.d.\) The National Association for the Dually Diagnosed \(NADD\) Competency-Based Direct-Support Professional Certification Program Developed in association with The National Association of State Directors of Developmental Disabilities Services \(NASDDDS\)](#)

## References

- Amado, A. N., & McBride, M. (2003). *Increasing person-centered thinking - Improving the quality of person-centered planning: A manual for person-centered planning facilitators*. Minneapolis, MN: Institute on Community Integration.
- Bayes, C. A. (2010). *Comparative perspectives of direct support professionals working with adults with intellectual disabilities regarding standard competencies*. Louisville, KY: University of Louisville.
- Bogenschutz, M., Nord, D., & Hewitt, A. (2015). Competency-based training and worker turnover in community supports for people with IDD: Results from a group randomized controlled study. *Intellectual and Developmental Disabilities, 53*(3), 182-195.
- Chowdhury, M., & Benson, B. A. (2011). Deinstitutionalization and quality of life of individuals with intellectual disability: A review of the international literature. *Journal of Policy and Practice in Intellectual Disabilities, 8*(4), 256-265.
- Developmental Disabilities Assistance and Bill of Rights Act of 2000 Pub. Law No. 106-402 (2000)
- Centers for Medicare and Medicaid Services (CMS) (2014). HCBS Setting Requirements final rule CMS-2249-F; CMS-2296-F.
- Hewitt, A., & Larson, S. (2007). The direct support workforce in community supports to individuals with developmental disabilities: Issues, implications, and promising practices. *Mental retardation and developmental disabilities research reviews, 13*(2), 178-187.
- Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential settings for people with intellectual disability: a systematic review. *American journal on intellectual and developmental disabilities, 114*(3), 193-222.
- Larson, S., Lakin, C., & Hill, S. (2012). Behavioral outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: US studies from 1977 to 2010. *Research and practice for persons with severe disabilities, 37*(4), 235-246.
- Mansell, J. (2006). Deinstitutionalization and community living: progress, problems and priorities. *Journal of Intellectual and Developmental Disability, 31*(2), 65-76.
- Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disability. *Journal of Intellectual Disability Research, 51*(11), 850-865.

- Nye Langerman, K., & Hewitt, A. (2019). Hiring, training and supporting the direct support workforce. In K. Nye Langerman & A. Hewitt eds.) *Community Living and Participation for People with Intellectual and Developmental Disabilities*. Washington D.C: American Association on Intellectual and Developmental Disabilities.
- O'Brien, J. (2002). Person-centered planning as a contributing factor in organizational and social change. *Research and Practice for Persons with Severe Disabilities*, 27(4), 261-264.
- Taylor, J. E., & Taylor, J. A. (2013). Person-centered planning: Evidence-based practice, challenges, and potential for the 21st century. *Journal of Social Work in Disability & Rehabilitation*, 12(3), 213-235.
- Taylor, M., Bradley, V., & Warren, R., Jr. (1996). *The Community Support Skill Standards: Tools for managing change and achieving outcomes*. Cambridge, MA: Human Services Research Institute.
- Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of intellectual disability research*, 45(5), 371-383.
- Young, L., Sigafoos, J., Suttie, J., Ashman, A., & Grevell, P. (1998). Deinstitutionalisation of persons with intellectual disabilities: A review of Australian studies. *Journal of Intellectual and Developmental Disability*, 23(2), 155-170.

## CHAPTER 6

# Self-Determination: A Critical Aspect of Community Living

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### Guiding questions

- What unique contribution does self-determination make to community living outcomes of persons with intellectual and developmental disabilities?
- In what ways can community living programs support the self-determination of persons with intellectual and developmental disabilities?

## Introduction

Whether residing in a large industrial city or a small village in a rural area, the exercise of self-determination is linked to a high quality of life for people with intellectual and developmental disabilities (IDD). But what is self-determination? Viewed from a social-ecological perspective, self-determination refers to an individual's capacity to exercise the degree of control they desire within the context of their relationships with other persons, groups, systems, and/or cultures over those areas of life that are important to them (Abery, Olson, Poetz, & Smith, 2019; Abery, Ticha, Smith & Grad, 2017). The construct includes, but is not limited to an individual's causal agency (Shogren, Wehmeyer, Palmer, Rifenshark, & Little, 2015). It also focuses on the goodness-of-fit people experience between desired and actual levels of personal control. Self-determination, accordingly, is the product of both the person and the environment—of the person using the skills, knowledge, and beliefs at his/her disposal to act on the environment with the goal of obtaining valued and desired outcomes (see Figure 1). Self-determination is viewed as driven by the intrinsic motivation of all people to be the primary determiner of their thoughts, feelings, and behavior and involves, but is not synonymous with independence and autonomy. Rather, it entails the person determining in what contexts and to what degree they desire to exercise control over various aspects of their lives, share this control with trusted others, or voluntarily relinquish it.

The degree to which people are able to exercise self-determination is facilitated by the skills, knowledge and attitudes/belief they possess. *Skills* supportive of self-determination include: informed choice and decision-making; the setting of personal goals; problem-solving; advocating for oneself; and communicating effectively with others. *Knowledge* of the one's rights; strengths and challenges, preferences

(i.e., likes and dislikes); and the service system also contribute to self-determination. The third set of characteristics associated with self-determination are a person's *attitudes and beliefs*. Those supportive of self-determination include: an internal locus of control and a high sense of self-efficacy; self-confidence in one's personal capacities; resilience; the willingness to take reasonable risks and confront life's challenges; and a sense of determination.

As Walker and colleagues (Walker et al., 2011) have noted, the advantage of a social-ecological approach to understanding self-determination is that it is not a deficit, but rather, a strength-based framework. It also does not include the assumption that a person with a disability needs to change or develop additional personal capacities to exercise self-determination. Instead, those skills, attitudes/beliefs and knowledge bases originally conceptualized as "necessary" for self-determination are viewed as facilitators that support, but are not needed for its exercise if one has a supportive environment. This approach allows for variation in the manner in which self-determination is conceptualized in various cultures. These differences may result in quite a dramatic variation in the levels of control being exercised by individuals. In some cultures, for example, personal control is highly valued, while in others a more collectivist approach is taken. Some cultures have a long-standing history of supporting self-determination of their people and reinforcing its exercise, while others tend to be more selective, upholding the rights of only select groups to exercise self-determination, while denying this right to a host of marginalized groups, including persons with intellectual and developmental disabilities (IDD).

## Outcomes associated with self-determination

Although some individuals view self-determination as an outcome in and of itself, we prefer to think of it as a process that serves as a mean to an end. The question one should therefore ask is, to what extent do individuals with disabilities who are self-determined experience positive life outcomes?

Over the past 30-years, a substantial number of studies have been undertaken that document the impact of self-determination. Research findings indicate that self-determination predicts employment as well as community access and participation. Persons who exercise higher levels of self-determination are more likely to be employed and receive a higher wage and better benefits than those who have lower levels of self-determination (Shogren & Shaw, 2016; Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015; Wehmeyer & Palmer, 2003). People who are self-determined are also more likely to live independently and both develop and maintain positive social relationships (Martorell, Gutierrez-Rechacha, Pereda, & Ayuso-Mateos, 2008; Shogren & Shaw, 2016). The exercise of self-determination is associated with greater access to *inclusive residential opportunities* (Shogren & Shaw, 2016), increased community participation (McGuire & McDonnell, 2008), success in postsecondary education (Anctil, Ishikawa, & Scott, 2008), and more positive recreation and leisure outcomes (McGuire & McDonnell, 2008). As one might expect given these findings, people with disabilities who exercise higher levels of self-determination experience an increased quality of life (Lachapelle et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Shogren, Lopez, Wehmeyer, Little, & Pressgrove, 2006).

## Challenges to self-determination faced by persons with disabilities

Based on the outcomes persons with IDD experience when they are self-determined, it should be apparent that it is one of the keys to successfully living within the community. One might therefore assume that practically all persons with disabilities are supported to be self-determined. Research, however, indicates that this not the case. A substantial number of barriers exist to individuals with intellectual and developmental disabilities living in both the U.S., the Russian Federation and other countries in acquiring and refining the capacities that support self-determination, having opportunities to exercise these capacities on an ongoing basis, and experiencing the degree of personal control they desire over those aspects of life most important to them.

The simple ability to effectively communicate “yes” and “no” verbally or in a non-verbal manner make it possible for persons with even the most significant disabilities to exercise self-determination if they are provided with adequate supports. All too often, however, such assistance is not available to the people who need it, or the individual is never provided with opportunities to make their own choices and decisions.

Personal capacities, although not *necessary* for the exercise of self-determination, serve to facilitate this process when supports are not available or barriers encountered. If people with IDD are not provided with the opportunity to practice choice- and decision-making, problem solving, goal setting, communication, self-advocacy, and self-regulation skills, one cannot expect them to use these capacities to foster their self-determination. If family and service providers fail to take the time needed to explain the service system and how it works as well as one’s rights as a citizen and person with a disability, it has the potential to limit the ability of individuals to speak out for themselves

and exercise desired levels of personal control. Attitudinal and belief systems can also serve to limit outcomes in this area. An external locus of control, low sense of self-efficacy and inaccurate attributions for success and failure, and medical, educational and social service systems that view persons with disabilities with pity or possessing “defects” that need to be cured, all serve to place such individuals at a disadvantage when attempting to assume personal control over their lives (Abery & Stancliffe, 2003).

There are numerous environmental factors that have the potential to limit self-determination at each level of the individual’s ecosystem. A family’s belief that it needs to protect its offspring all too often lead to people with IDD being severely limited with respect to the risks/challenges that they are able to take in life. Self-determination does include the willingness to take some risks. Parents and providers who focus on protection and removing rather than managing risk, make it difficult for persons with IDD to have opportunities to exercise personal control, learn from their mistakes, and grow in the process. Low expectations of people with IDD can also serve as potential barriers to the outcome of interest (Wehmeyer & Abery, 2013). Parents, employers, direct support professionals and teachers all too often assume that if a person with IDD is not currently able to demonstrate a skill (e.g., making a choice or decision) than they will not have the ability to engage in that activity at a later time, or within a different context. Opportunities for the exercise of self-determination are thereby limited to what those serving in a support role think a person is able to do rather than what they might actually have the capacity to do in the future.

For adults with IDD, the community-based social service system itself presents multiple barriers to self-determination. Direct support professionals (DSPs) all too often are unaware of the preferences of the people with disabilities they serve and lack the training and expe-

rience to support them in achieving important personal goals. Inexperienced, undertrained staff who possess minimal competencies, have little understanding of state and country regulations, persons with intellectual and developmental disabilities, and/or self-determination. Opportunities for decision- and choice-making, the direct teaching and modeling of self-determined behavior, and the development of a wide variety of other skills supportive of self-determination are often quite limited (Abery, Ticha, & Grad, 2018). In addition, the need of provider organizations to minimize liability often leads to the belief that one must eliminate, rather than manage risk and challenges in a person’s life. As a result, persons with IDD are often not allowed to make mistakes, or within reason, experience the consequences of less than optimal decisions and choices, making it difficult for them to use their mistakes as learning experiences.

### CASE STUDY 1

Jason is a 24-year old young man with Down syndrome who two years ago had a conversation with his parents about his desire to move out of his family home and into his own apartment. Although his parents supported the idea, they believed that their son would need significant supports to make this happen. After contacting Jason’s case manager, a social worker in the county in which he lived, the family and Jason looked over three small community residential programs in his area. Following these visits, Jason and his parents met with case manager and a program selected for him. It did not take long for Jason to find that the home that was selected *for* as opposed to *with* him was not going to meet his needs. Though he was quite independent, Jason’s support staff would not allow him to go into the community alone. When openings occurred for both new staff and residents, neither Jason nor his fellow

residents were involved in making these selections. In addition, both meals and community activities were undertaken in a group format even when Jason and/or his roommates did not want to take part.

After six months of frustration, Jason and his parents contacted his case manager and set up a meeting, but nothing really happened. Fortunately for Jason, one of his roommates had just joined a local self-advocacy group and invited him to attend some of their meetings. Once Jason joined the group, he learned a lot about how to communicate what he wanted his life to be like and assert himself in planning meetings. He also learned about his rights as a citizen and person with a disability including his right to say “no” to those who were involved in his service planning. One of the approaches that helped Jason the most was that in the self-advocacy group he attended he was paired with another member who had extensive advocacy experience. This person served as Jason’s mentor, helping him practice speaking up for himself and encouraging him every time he took a step forward.

The next time his planning team met, Jason clearly articulated what he liked and disliked about his current living situation. He clearly informed his parents and case manager: of his goals and objectives; what he wanted to have control over in his life; areas in which he wanted to share control with trusted others; and even a few aspects of life in which he did not desire to exercise control because he did not have the necessary understanding to make informed decisions. He also let his caseworker and parents know that he was now “overqualified” for the job at which he currently worked and wanted to look for alternative employment where he might have the chance to develop new skills. One of the key contributions Jason’s parents made at this time to support him was find a local human service professional with experience in supportive decision-making who

could both assist Jason with developing a person-center plan for his future and support him to make as many decisions as he desired on his own with necessary supports.

Over the past year, Jason’s life has changed in many ways. He now lives in an apartment he shares with another person with a disability and a young man of approximately his age who serves as a support for him and his roommate with cerebral palsy. This young man is not paid directly for his services, but lives in the apartment rent free as compensation for the supports he provides. The funding Jason receives for community living supports was not sufficient for him to find an apartment he could afford on his own. However, his parents learned that by combining the supports their son received with those to which his roommate with a disability is entitled, they could afford a nice three bedroom flat that the three could share. Jason also changed his job and now works as a chef’s assistant at a local restaurant that he believes will provide him with a chance for career advancement.

## Freedom of choice and why it is a problem in the Russian Federation

Providing a choice (even if in seemingly insignificant everyday situations) to young adults with disabilities is one of the main priorities in the work of the Life Route Foundation. Why is it important to provide opportunities for making choices? Often, people with disabilities have not been afforded a choice in everyday life decisions since childhood. When an adult person lives with parents, it is not uncommon that a parent makes most of the everyday choices, which can later lead to difficulties with decision-making for the person with a disability. In fact, a person with a disability in his or her 20s-30s might not have ever independently chosen his clothes/hairstyle, etc.



In cases of people living in institutions, the situation is even worse. In these institutions, people have to follow a strict daily schedule, monotonous planned weekly food menus, supervised walks and trips outside of the institution, and tight control by the personnel, and monitoring the behavior of residents. Adults living in the institutions face a “deprivation” in making choices and life decisions. When meeting people living in these facilities, we see that in many situations they are not able to make a decision on their own or make a choice from two simple options. They are also terrified of making mistakes.



### CASE STUDY 2

Misha is 36 years old, lives in an institution, and attends Life Route Foundation classes (cooking, ceramics). He began to attend Life Route Foundation classes 2.5 years ago. During the first class on social adaptation (in this case, it was “cooking”), it became clear that he needed a rather substantial support from a volunteer. Despite the fact that until adolescence, Misha lived with his mother (therefore, unlike many others living in institutions, he knows how society functions outside of an institution, and knows for instance, how raw, unprepared food looks), during his life inside an institution, he lost many skills, including cooking skills. During the first few months with Life Route, Misha refused to choose what he would like to cook - this choice very often had to be made for him. At first, he also had difficulties with food preparation - Misha argued that he was unable to do anything “right” and therefore he refused to try anything, fearing that he would make a mistake. He believed that he would be punished for making a mistake. When Misha managed to slice a tomato, for about half a year he refused to do anything else, but to slice tomatoes.

In order to help Misha learn how to make these seemingly trivial choices, the Foundation

volunteers began to reduce the choices to two products, use images of cooking processes for recipes during cooking classes, and began to give Misha more time to think about the decision.

After 2.5 years of attending the class, Misha has learned to follow almost any recipe. Now he needs minimal help from a volunteer. Unfortunately, however, the difficulties with choice making still remain. He still finds it difficult to choose when he faces unknown activities and is afraid to do “something wrong”.



### CASE STUDY 3

Klara is 26 years old, lives in an institution, attends Life Route Foundation classes (cooking, ceramics). Klara began to attend Life Route Foundation classes 2.5 years ago. Klara in contrast to most of those living in institutions, does not only have issued clothes (state purchased and distributed among the residents of institutions), but also her own personal clothes given to her sometimes by the institution personnel. These items were not chosen by Klara herself, who is a young, cheerful girl, for whom it is important how she looks and what she wears.

About a year and a half ago in a class, a group of young people living in one of Moscow's institutions, together with the staff and volunteers of the Life Route Foundation, started to make ceramic products. Money from the sales of these products became the first salary for Klara. However, at a store, she had great difficulty in making a choice. First, it was difficult for her to comprehend if the money she had was enough for a desired item. Second, it was difficult for her to determine a subjective value of this or that item - she understands what she wants, but, if there is not enough money for

everything, she is unable to choose from several options. It is difficult for her to understand what she wants more.

In order to ease choice making for Klara, the Foundation volunteers came up with a shopping system. First, Klara and a facilitator discuss what it is that she would like to buy for herself. This happens outside of a store. When Klara and the volunteer are together in the store, the volunteer takes pictures of all items Klara likes, along with the price tags. Then, when the initial selection process of favored items is finished, a volunteer discusses with her what she remembered most of all that she saw. Finally, Klara looks at all the photos and makes her final choice.



## Tips & Strategies

- **The exercise of self-determination is a life-long process. It begins shortly after birth and continues throughout life.** At the programmatic level, a number of strategies and interventions have been designed to support the self-determination of people with IDD. Program and system level supports have aimed at both increasing opportunities for self-determination and ensuring that individuals with disabilities develop the capacities supportive of this outcome.
- **Individuals and families.** At the family level, parents can foster the development of choice- and decision-making; problem solving; goal setting and self-regulation skills at an early age and should pay special attention to it during the transition years. Parent can start with simple either/or types of choices (e.g. "You can either wear this shirt today or this one"). They can then progress to more complex decision-making, where a person must create his or her own alternatives from which to choose. Young adults can thereby learn a structured process that enables them to make informed decisions after considering a variety of factors (Wehmeyer, 1998; Wehmeyer & Abery, 2013).
- **Community living programs.** During their adult years, individuals with IDD need to have access to experiences and opportunities that facilitate the contin-

ued development and refinement of those individual capacities (skills, knowledge, and attitudes/beliefs) supportive of self-determination. In most cases, this means that the systems within which the individual functions need to possess the knowledge and resources to support ongoing opportunities for self-determination both with respect to the exercise of desired levels of personal control on a day-to-day as well as a long-term basis (Wehmeyer & Abery, 2013).

- **Program/support planning.** Utilizing person-centered approaches to support planning (O'Brien & O'Brien, 1999; O'Brien & Mount, 2005; Smull, et al., 2005) and training direct care staff to deliver services in a person-centered manner are a critical aspect of facilitating self-determination. Having the opportunity to determine who attends one's support planning meeting, voice one's preferences and desired life outcomes while having others respect and honor them is a critical aspect of community living. Ensuring that supports are directed not only at what is important for the person but also focus on what is important to them provide the opportunity for the direct exercise of self-determination as well as the refinement of skills supportive of this process.
- **Self-directed support programs.** In recent years, greater opportunities have become available in many states in the U.S. for people with IDD to direct their own community supports. Such self-directed support programs make it possible for recipient of services, or their

representatives if applicable, to have decision-making authority over services and take responsibility for managing these supports. Within self-directed support programs, persons with intellectual and developmental disabilities determine the services they desire to purchase, who provides them, and how services are provided (Medicaid.gov, 2015).

- **Use of supported decision-making.** Many people with intellectual disabilities in the U.S. are currently subject to guardianship and conservatorship. Such "substitute decision-making" arrangements deprive adults with IDD with the opportunity to exercise self-determination and have their decisions legally recognized. Supported decision-making is a process in which individuals with disabilities are assisted in making decisions for themselves and effectively communicate these choices to others (Boundy & Fleischner, 2013). It is an approach through which the individual with a disability retains their decision-making authority and at the same time is provided with support from trusted others (e.g., friends, family members, professionals). When needed, these individuals are available to explain issues in a manner that the person can understand and use to make informed decisions (Dinerstein, 2012; Blanck & Martinis, 2015; Quality Trust, 2013). Supported decision-making is consistent with Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) and supports persons with disabilities to be "causal agents" in

their own lives (Wehmeyer, et al., 2000). The process of supported decision-making approach represents two critical aspects of self-determination that must be kept in mind when a society attempts to move from the institutional care of people with intellectual and developmental disabilities to an inclusive community-based system. The first centers on the belief, supported by research, that all persons with intellectual and developmental disabilities are capable of exercising self-determination if they are provided with appropriate supports. The second was exemplified perfectly and succinctly by Valerie Billingham over 20-years ago when she stated – “Nothing about me...without me.” (Billingham, 1998). Billingham’s comment, though originally directed at persons with disabilities who find themselves in the role of patients and the health care professionals who serve them, applies perfectly to the community living context.

## Resources

- [Center for Self-Determination](#)
- [National Gateway to Self-Determination. Serves as a clearinghouse for resources, training, and information on promoting self-determination](#)
- [PACER’s National Parent Center on Transition and Employment](#)

## References

- Wehmeyer, M.L., Abery, B.H., Mithaug, D. & Stancliffe R.J. (2003). *Theory in Self-Determination*. Springfield IL; Charles C. Thomas.
- Stancliffe, R.J., Shogren, K.A., Wehmeyer, M.L., & Abery B.H. (Eds.) (2019). *Choice, Preference, and Disability: Promoting Self-Determination across the Lifespan*. New York, NY: Springer Publishing Company.
- Abery, B.H. Olson, M., Poetz, C., & Smith, J.G. (2019). Self-determination and self-advocacy: It’s my life. In A.H. Hewitt & K Nye Langerman (eds.) *Community Living and Participation for People with Intellectual and developmental disabilities*, 117-140. Washington D.C.: American Association on Intellectual and Developmental Disabilities.
- Abery, B.H., & Stancliffe, R. (2003). A tripartite ecological theory of self-determination. In M. Wehmeyer, B.H. Abery, D. Mithaug, & R.J. Stancliffe (Eds.) *Theory in Self-Determination*. Springfield IL; Charles C. Thomas.
- Abery, B.H., Ticha, R., Smith, J.G., & Grad, L. (2017). Assessment of the Self-Determination of Adults with Disabilities via behavioral observation: SD-CORES. Manuscript submitted for publication.
- Anttil, T. M., Ishikawa, M. E., & Tao Scott, A. (2008). Academic identity development through self-determination: Successful college students with learning disabilities. *Career Development for Exceptional Individuals*, 31(3), 164-174.
- Billingham, V. (1998). *Through the Patient’s Eyes*, Salzburg Seminar Session 356
- Blanck, P., & Martinis, J. G. (2015). The right to make choices: The National Resource Center for Supported Decision-Making. *Inclusion*, 3(1), 24-33.
- Boundy, M., & Fleischner, B. (2013). *FACT SHEET: Supported decision making instead of guardianship: An international overview*. Training and Advocacy Support Center (TASC).
- Dinerstein, R. D. (2012). Implementing legal capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The difficult road from guardianship to supported decision-making. *Human Rights Brief*, 19(2), 1-5.
- Lachapelle, Y., Wehmeyer, M. L., Haelewyck, M. C., Courbois, Y., Keith, K. D., Schalock, R. & Walsh, P. N. (2005). The relationship between quality of life and self-determination: an international study. *Journal of Intellectual Disability Research*, 49(10), 740-744.
- McGuire, J., & McDonnell, J. (2008). Relationships between recreation and levels of self-determination for adolescents and young adults with disabilities. *Career Development for Exceptional Individuals*, 31(3), 154-163.

- Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disability. *Journal of Intellectual Disability Research*, 51(11), 850-865.
- O'Brien J., & Mount, B. (2005) Make a difference: A guide-book for person-centered direct support. Inclusion Press.
- O'Brien, C.L., & O'Brien, J. (1995). *The origins of person-centered planning: A community of practice perspective*. Responsive Systems Associates, Lithonia, GA.
- Quality Trust for Individuals with Disabilities. (2013). *Supported decision-making: An agenda for action*. Retrieved from <http://jenny.hatchjusticeproject.org/node/264>
- Shogren, K. A., Lopez, S. J., Wehmeyer, M. L., Little, T. D., & Pressgrove, C. L. (2006). The role of positive psychology constructs in predicting life satisfaction in adolescents with and without cognitive disabilities: An exploratory study. *The Journal of Positive Psychology*, 1(1), 37-52.
- Shogren, K. A., & Shaw, L. A. (2016). The role of autonomy, self-realization, and psychological empowerment in predicting outcomes for youth with disabilities. *Remedial and Special Education*, 37(1), 55-62.
- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenshark, G. G., & Little, T. D. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *The Journal of Special Education*, 48(4), 256-267.
- Smull, M.W., Sanderson, H., Sweeney, C., & Skelhorn, L. (2005). Essential lifestyle planning for everyone. Researchgate.net.
- Walker, H. M., Calkins, C., Wehmeyer, M. L., Walker, L., Bacon, A., Palmer, S. B., & Abery, B. (2011) A social ecological approach to promote self-determination. *Exceptionality*, 19(1), 6-18.
- Wehmeyer, M.L. (1992). Self-determination and the education of students with mental retardation. *Education and Training in Mental Retardation*, 12(1), 302-314.
- Wehmeyer, M.L. & Abery, B.H. (2013). Self-determination and choice. *Intellectual and Developmental Disabilities*, 51(5), 399-411.
- Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive disabilities three-years after high school: The impact of self-determination. *Education and training in developmental disabilities*, 131-144.
- Wehmeyer, M.L., Palmer, S., Agran, M., Mithaug, D., & Martin, J. (2000). Promoting causal agency: The self-determined learning model of instruction. *Exceptional Children*, 66(4), 439-453.

## CHAPTER 7

# Importance of Engagement in Activities of Daily Living

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### Guiding questions

- Why is it important that people with disabilities are engaged in different types activities of daily living?
- What is the difference between being actively engaged in daily life and receiving services under a “hotel” model?

## Introduction

All of us, regardless of whether we have a disability or not, deserve to live fulfilling lives in our communities. This means having friends, interacting with family and colleagues, working, learning, enjoying culture and sports, engaging in religious and spiritual activities, having access to healthcare and needed supports, and participate in other aspect of life we find meaningful.

Historically, many people with disabilities lived in restrictive settings (institutions and other congregate living arrangements) that prevented them from exercising their legal and human rights and living fulfilling lives. Many state and regional entities assumed that people with disabilities were not able to express their preferences and make their own choices and decisions. Many people with disabilities therefore lost their legal powers to the state, regional authority or the facility where they were residing. As a result of this assumption and having lost their decision-making power, people with disabilities were stripped of opportunities to engage in activities of daily living that we all typically participate in to some degree, e.g. cooking, cleaning, getting mail, shopping, etc. As we all know, not all of these activities are always enjoyable. They provide us, however, with a sense of duty, accomplishment, and sometimes satisfaction. Another important aspect of being engaged in one's own activities of daily living is that we are able to constantly make choices and decisions about what to buy, what to eat, what to wear, etc. Choice-making and decision-making provides as with a sense of agency and self-determination (Abery & Stancliffe, 2003; Wehmeyer & Abery, 2013). Being engaged in one's own activities is an important aspect of living a fulfilling life.

People with different types of disabilities require different types and intensity of supports to be engaged in daily activities. Formally, basic activities of daily living (ADLs; hygiene, dressing,

etc.) and instrumental activities of daily living (IADLs; shopping, cooking, etc.) have been used to assess the skills people possessed, given their disability. Based on the levels of functioning, needed supports and services are provided for the person to be able to participate in their daily activities as they need and desire to (Graf, 2007).

All too often, the concept of ADLs and IADLs have restricted supports and services for people with disabilities mostly to addressing their basic and sometimes instrumental needs, with the overarching motive to keep the person safe. While safety is a necessary aspect of experiencing a quality life, there are other important aspects of life quality for which a person with a disability may need supports. These other life components include recreation and leisure, material well-being, emotional well-being, sense of belonging, social relationships, etc. (Schalock, 2004). Some of the activities motivated by these aspects of quality of life may naturally contain a certain risk factor, including feeling rejected or disappointed in a relationship or in a job, overspending, starting a new hobby, etc., but without a certain level of risk, life loses its purpose and dignity.

## Supporting basic and instrumental activities of daily living (ADLs and IADLs)

One promising approach to increasing the opportunities for people with disabilities to have self-determination over their activities of daily living is known as Active Support (Mansell, Elliott, Beadle-Brown, Ashman, & MacDonald, 2002; Qian, Larson, Tichá, Stancliffe, & Pettingell, 2019). Active Support (AS) is an approach to preparing staff to better support higher levels of engagement in meaningful activities of people with intellectual and developmental (IDD) and related disabilities. Active Support was originally developed in the UK

and Australia as a training and organizational approach to increase the capacity of direct-support staff to plan for and/or engage people with disabilities in skill development, meaningful daily activities, and new opportunities (Ashman, Ockendon, Beadle-Brown, & Mansell, 2010). The intervention is based on the premise that people with disabilities need to be provided with opportunities to engage in activities of their daily lives with appropriate supports, rather than being dependent on staff doing all or most of the tasks for them. The latter approach has been referred to as the “hotel model”. In settings that implement the “hotel model”, people with disabilities tend to be less active and spend a lot of time waiting for the staff to make or do something for them, e.g. prepare lunch, clean their room, turn on television on the channel the staff likes to rather than the person with disability, etc. In settings that have implemented AS in contrast, staff support people with disabilities in making meals, cleaning their space and in watching what is of interest to them. Some of the key components of AS include: task analysis, graded assistance, positive reinforcement, staff working as a team, and supporting consumers’ choices. The intervention has demonstrated a promise in increasing social and nonsocial engagement of people with IDD in community-based residential settings (Wilson, Reid, & Green, 2006; Qian, Tichá, Larson, Stancliffe & Wuorio, 2015).

Staff who have undergone AS training have learned to support individuals with disabilities to engage in their daily activities. With this approach, staff typically need to change their mindset from doing things for the person with a disability to arranging their environment in such a way that the person can do the activity by themselves or with supports. Active Support can initially be more challenging for staff, especially for those who are used to doing the activities for the person with a disability, rather than with them. This “hotel model”, however,

is limiting the person with a disability not only from being engaged in their own life, but also in learning new skills. When support staff embrace and utilize the AS approach, the people who they support tend to be more engaged, happy and satisfied with their own lives.

## Supporting meaningful activities of daily living (MADLs)

### Person-centered approach

In order to support a person with a disability in activities he or she finds not only necessary and useful, but also meaningful, fun, and exciting, a person-centered approach, rather than a systems-centered approach, is helpful to find out what the person’s goals and dreams are and how best to support the person in working toward them. In a system-centered approach in contrast, it is typically the diagnosis, rules and regulations that dictate what supports and services the person will receive. Person-centered service systems are based on: (a) a process of continual listening and learning, focusing not on what is “important for” the individual as determined by professionals, but rather, what is important to the person now and in the future; (b) having the person and their family involved in service planning and the outcomes derived from it with the goal of facilitating the person to develop a better life on his or her own terms (Sanderson, 2000).

Smull, Bourne and Sanderson (2009) articulated how professionals can integrate person-centered ways of working in their practice, emphasizing that it is not only the presence of a person-centered plan that makes a difference, but the quality of learning that goes into the plan, the commitment of the people around the person, and the knowledge of the individual being supported. According to Smull and colleagues, staff who apply a person-centered approach in their work will: (1) listen, learn and understand what is important to and



important for each person; (2) develop person centered-descriptions that describe the balance between what is important to and important for; (3) engage all critical people in this work including the person, family members, and other the person wants, and (4) view person-centered planning as an ongoing process, rather than an isolated event (Smull, Bourne, and Sanderson, 2009). This person-centered values system can be used to make comprehensive changes to services and support systems through facilitating the creation of infrastructures that support the independence, self-determination, and dignity of persons with IDD, as well as involve an individual as an equal partner in service planning.

## Self-determination

Another critical component of supporting people with disabilities in engaging in meaningful activities is self-determination. Self-determination has been defined by well-known theorists and researchers in special education and disability in the US and Australia from the perspective of an individual who is the one in control and empowered, having free will or agency (Wehmeyer, 2004) over those things in life that matter to them (Abery & Stancliffe, 2003; Wehmeyer & Abery, 2013). The environment in which a person with a disability lives and the social networks of which he or she is a part impacts their self-determination (Abery & Stancliffe, 2003; Wehmeyer & Abery, 2013). When staff understand and respect the self-determination of the people they support, they in turn are more likely to be engaged in activities that are meaningful to them. See Chapter 6 by Abery & Muratova for more detail on this topic.

## Conclusion

Persons with disabilities who live independently or semi-independently in the community and are supported by staff who understand

and apply the concepts of Active Support, person-centeredness and self-determination are much more likely to engage in basic, instrumental and meaningful activities in their daily lives. Most of us take activities of daily living for granted, be it the “chores” we need to do, or activities we do voluntarily for enjoyment. Not everyone, however, is able to participate in such activities without encouragement and support, even though taking care of one’s of daily needs and responsibilities is a critical part of feeling accomplished and part of the community.

## Activities of daily living in the Russian Federation

### Potential difficulties with independence

In Russia, activities related to daily life, including cleaning, grocery shopping, and cooking in families with children and young adults with disabilities are almost always carried out by parents, usually mothers. Presumably, this situation is due to the following:

- Teaching skills of daily living to children and young adults with disabilities tends to be time-consuming and can run into challenges. For instance, the learning process needs to be broken into several steps and should include many repetitive iterations in order for the person to master the task.
- Not every daily activity can be taught due to hypersensitivity of some children to noises, water, odors, etc. Some individuals with disabilities never get rid of their fear of vacuum cleaners, or blankly refuse to wash dishes.
- From the parents’ perspective, if their child with a disability is not able to perform the activity in a perfect way for a long time, they often abandon further efforts of teaching the child.
- When parents focus their efforts for many years on medical rehabilitation and psycho-

logical counselling, they tend to put teaching skills of daily living on the back burner.

- Parents experience physical and mental fatigue and crave some personal time. Cooking or cleaning may come to be the only time when a parent 'attends to herself', i.e. is not in contact with the child. Daily chores become a legitimate opportunity 'to take a respite from the child'.
- Skills of daily living are sometimes rated as being of lesser importance than academic knowledge. Parents of children with developmental issues tend to assign top priority not only to their ability to walk, talk, as well as read, write, and count. Thus, we frequently run into cases where young adults with disabilities can read, recite lengthy poetry by heart, perform as actors in inclusive theatres, or engage in sports, yet need their mothers' help to wash themselves, shave, or use the restroom.

### **The typical client living at an apartment as part of the Training Apartment project**

Clients of 18 and older whom we see in the *Training Apartment project* run by *LifeRoute Foundation* usually have no assigned housekeeping duties. Safety concerns explain why most parents do not teach their children to turn on the stove or use an ironing board. Parents would give caregivers written instructions and lists of clothes for a young man or woman to wear. Few buy their clothes themselves or are involved in making choices. One mother of a 20-year-old young woman with a disability told us that prior to her enrollment in the project, she drew no distinction between her own clothes or house slippers and her daughter's. After the young woman started living in the training apartment, all such things began to be perceived as personal items.

When young adults with disabilities have an ingrained habit of having their needs satisfied without an effort, but also without the opportunity to make decisions and choices, difficulties in relationships with parents often follow. Relations fall into an established pattern, where the person with a disability issues demands, and parents satisfy them and generally serve them. It is very hard to depart from those set roles. Parents complain that while at home, their children do not want to do any work and start an argument if pressed to assume some housekeeping duties. Parents note that in other settings, such as daily occupation programs, workshops, or a training apartment, all adults with disabilities get themselves somehow involved with daily chores, and many perform them with pleasure.

The majority of learning time in training apartments of the *LifeRoute Foundation* is devoted to teaching social skills associated with daily living. To the maximum extent possible, adults with disabilities residing in the apartments do their own shopping, cooking, laundry, and housecleaning. For their parents, that is always the stated desired outcome. Yet, transferring the skills acquired through project participation to family home settings proves very difficult. The likelihood of living skills generalizing from the training stage to becoming ingrained would have been much higher, if the training could be followed by supported living in a place separate from parental home.

### **The typical at client living in an institution as part of the Life Route Foundation project**

In institutions for people with disabilities in the Russia, personnel provide comprehensive services. Meals are served on plates in exact portions, dirty dishes are collected and washed by cafeteria workers or nurses, dirty clothes are collected for laundry and returned clean. There are cases when residents get different clothes out of laundry. It is common for residential fa-

cilities to provide clothes in bulk, and in case of common sizes the clothes get randomly sorted after washing. The same shirt can be worn by two different people on two consecutive days. All personal hygiene items (toothbrushes, soap, etc.) are also purchased wholesale. If a person needs something in addition, he or she must fill out a request form. If approved, the item in question will be bought by a social worker with the cost deducted from that resident's allowance.

Therefore, people in residential facilities get excluded from activities important for independent living. They frequently do not know how to cook (some never saw an unsliced onion or uncooked pasta in all their lives), or they do not understand why dishes need to be washed (since tableware at such facilities magically reappears clean by the next meal). They also do not understand at what point clothes become dirty and why they need to be laundered. Without the experience of independent shopping, people with disabilities cannot navigate a grocery store or have difficulty planning their expenditure on food items. This situation dramatically affects the capability of people with disabilities to adjust to independent living.

This type of adjustment to the tasks of daily living is emphasized within the framework of *LifeRoute Foundation* project aimed at people with disabilities living in institutions. Volunteers help with teaching cooking and related skills (using electrical stove and oven, dishwashing, proper food storage, etc.), shopping for food and other essentials, and teaching financial literacy. As part of camping trip programs, volunteers also teach people to do their own laundry.

This approach could be taken further by adding the next step of the person with a disability living in a training apartment as they are transitioning from an institution to living in the community. This step would provide the person with the opportunity to adjust to independent

living and practice daily living skills, which in turn could pave the way to community-based supported living.



## CASE STUDY

Peter and Lily are young adults with a mild disability who grew up in an institution. As in any other institution, when they were growing up, they were confined to their rooms most of the time with the exception of going to a common dining hall for meals and playing in the institution's yard at certain times of the week. This confined lifestyle resulted in the lack of engagement of Peter and Lily in their daily activities, which not only led to their limited cognitive, social and linguistic stimulation and development, but also the lack of opportunities to acquire skills for daily living, e.g. cooking, gardening, budgeting, etc. Luckily, Peter and Lily became friends early on despite the lack of socialization and language developed promoted at the institution. They developed their own mode communication they both understand, not based on conventional language formation. Their communication style is almost like a secret language no one else can decode.

Today, in their early 20s, Peter and Lily are in the process of transitioning from living in the institution to living independently. In order for the transition to be successful, they need to catch up on their daily living social and skills development they missed while living in the institution. They are working with an NGO that organizes weekly opportunities for people with and without disabilities and support staff to cook, eat, clean, play music, discuss, and celebrate events together in a location in the community. Lily started attending first and really enjoyed this opportunity. Soon, Peter wondered where she was going and started joining as well. Now, when they go out to join the group, they work as a team. They not only enjoy participating the activities, learning new

skills as well as just spending time together. In fact, they realized that they would like to live together in an independent apartment. The NGO has developed a plan for them to engage in various activities of daily living that include basic (e.g., hygiene), instrumental (e.g., cooking, shopping) as well as meaningful activities to both Peter and Lily, including going to a park, going to the movies, and getting a puppy. The NGO used many components of Active Support, person-centered planning and self-determination in this process. For example, the NGO staff discussed with Peter and Lily what kind of interests they have, what work they en-

joy doing and how they like to spend their free time. They also talked about their goals and dreams for the future. The staff assessed what kind of supports Peter and Lily would need to be successful in living independently and in getting a job. They further discussed Peter and Lily's communication and advocacy needs for a successful entry into living and working in the community.

By engaging in inclusive activities in their community and gaining the necessary skills for daily living with the support of a local NGO, Peter and Lily are ready to begin working, move in to their new apartment, and get a puppy – in short, live a life that they desire.





## Tips & Strategies

- Every human being, regardless of their ability or disability, is able to participate in their daily lives with the appropriate supports
- Being engaged in the activities of one's life brings everyone a sense of agency and self-determination, leading to their greater life satisfaction and quality
- Taking responsibility for one's daily activities not only improves the person's quality of life, but also lead to the acquisition of new skills necessary for living independently
- Apply the concepts of Active Support, person-centeredness and self-determination when you support a person with a disability to increase their opportunities for life satisfaction and learning new skills
- The "Hotel model" of services is outdated and does not support people with disabilities in achieving their optimal life outcomes and inclusion in their communities

## Resources

- [Active Support video](#)
- [Frontline Initiative on Person-Centered Planning](#)
- [Self-Determination video](#)

## References

- Abery, B. H., & Stancliffe, R. J. (2003). A tripartite-ecological theory of self-determination. In M. L. Wehmeyer, B. H. Abery, D. E. Mithaug, & R. J. Stancliffe, *Theory in self-determination: Foundations for educational practice* (pp. 43-78). Springfield, IL: Charles C. Thomas.
- Ashman, B., Ockendon, J., Beadle-Brown, J., Mansell, J. (2010). *Person-Centred Active Support: a Handbook*. Brighton: Pavilion.
- Graf, C. (2007). The Lawton Instrumental Activities of Daily Living (IADL) Scale. *Annals of Long-Term Care*, 15(7). Retrieved from <https://www.managedhealthcareconnect.com/article/7453>
- Mansell, J., Elliott, T., Beadle-Brown, J., Ashman, B., & Macdonald, S., (2002). Engagement in meaningful activity and "active support" of people with intellectual disabilities in residential care. *Research in Developmental Disabilities*, 23, 342-352.
- Qian, X., Larson, S., Tichá, R., Stancliffe, R., Pettingell, S. (2019). Active Support Training, Staff Assistance, and Engagement of Individuals With Intellectual and Developmental Disabilities in the United States: Randomized Controlled Trial. *American Journal on Intellectual and Developmental Disabilities*, 124(2), 157-173.
- Qian, X., Tichá, R., Larson, S. A., Stancliffe, R. J., & Wuorio, A. (2015). The impact of individual and organizational factors on engagement of individuals with intellectual disability living in community group homes: A multilevel model. *Journal of Intellectual Disability Research*, 59(6), 493-505.
- Sanderson, H. (2000). *Person-centred Planning: Key Features and Approaches*. York: Joseph Rowntree Foundation.
- Schalock, R.L. (2004). The concept of quality of life: what we know and do not know. *Journal of Intellectual Disability Research*, 48(3), 203-216.
- Smull, M. W., Bourne, M. L., & Sanderson, H. (2009). *Becoming a person-centered system*. National Association of State Directors of Developmental Disability Services, Alexandria, VA.
- Wehmeyer, M.L., & Abery, B.H. (2013). Self-Determination and Choice. *Intellectual and Developmental Disabilities*, 51(5), 399-411.
- Wilson, P. G., Reid, D. H., & Green, C. W. (2006). Evaluating and increasing in-home leisure activity among adults with severe disabilities in supported independent living. *Research in Developmental Disabilities*, 27, 93-107.

## CHAPTER 8

# The Importance of Social Networks in Community Living and Employment

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### Guiding questions

- How do social relationships aid people with disabilities to feel included in the community?
- What strategies assist in building social networks for people with disabilities?

## Introduction

Social inclusion, based on the social networks one establishes and maintains with friends, family, neighbors and coworkers is a critical aspect of personal wellbeing. Research has demonstrated, however, that people with disabilities experience higher rates of social isolation and often possess a restricted set of relationships primarily with their families and support staff (Simplican, Leader, Kosciulek, & Leahy, 2015).

Possessing a rich, interconnected social network is one of the most important factors that contributes to a person's quality of life regardless of whether the individual has a disability or not (Arslantas, Adana, Ergin, Kayar, & Acar, 2015). In addition, studies have shown that in the absence of a supportive network, people are more likely to experience loneliness and depression (Peerenboom, Collard, Naarding, & Comijis, 2015).

According to Cobigo et al. (2012), when people are socially included, they possess "a sense of belonging in a social network within which they receive and contribute support, experience valued social roles and are trusted to perform those social roles in the community." The essential characteristics of social inclusion therefore include being "recognized as competent, trusted to perform a social role in the community, and having membership in a social network within which one receives and contributes support" (Simplican et al., 2015, p.20). In a similar manner, Forrester-Jones et al. (2006) views the essential characteristics of being socially included as possessing socially integrated relationships within the community that further one's economic and social participation.

Established social relationships and membership in a social network are essential in order for the individual to develop social capital, a potentially powerful resource that can be used to improve the lives of all people with and without disabilities. Social capital refers to the

extent to which an individual is connected to others (e.g. friends, colleagues, etc.) and the degree to which such relationships are reciprocal (Allik & Realo, 2004). According to Condeluci et al. (2008), there are three types of social capital: (1) instrumental (e.g., people taking care of each other's pets when each individual is away from home), (2) emotional (i.e., individuals providing social-emotional support to each other that results in each feeling a sense of belonging, cared-for, and loved), and (3) informational (e.g., friends sharing information about job openings with each other). Access to social capital has been linked to many benefits, including improved health, and positive behavioral, educational, and vocational outcomes. Thus, it is critical that if we are to effectively support the community living of people with disabilities they have the opportunity to become a part of diverse social networks through developing friendships and other social relationships either independently or with supports.

Reciprocity in social relationships is a critical component of successful social connectedness (Simplican et al., 2015). Reciprocity refers to that aspect of social interaction between individuals in which the person is both the provider and recipient of various types of social support. This may entail something as simple as initiating social interactions with others who have previously initiated interactions with you, doing favors for others who have helped you in the past, looking after others in your community who also look after you, and back and forth greetings with neighbors when you see them in the community (Bates & Davies, 2004). Milner & Kelly (2009) found that reciprocity with others is a key factor in the sense of membership and belonging people with disabilities experience in their communities. For at least one group of people with disability, persons with intellectual and developmental disabilities, research has found that while reciprocity in functional areas (information and instrumental support) typi-

cally exists, there is significantly less reciprocity in areas related to social-emotional connectedness (Van Asselt-Goverts, Embregts, & Hendriks, 2013) and that the main providers of all types of support are staff as opposed to family and friends.

A lack of social capital on the part of people with disabilities serves as a major barrier to full inclusion (Walker et al., 2011) and often results such individuals living *in* the community but not really being *of* the community. People with access to social capital have the resources, capacity, and supports to achieve greater inclusion and a higher quality of life experiencing a more emotionally satisfying lifestyle, exercising choices with a far greater range of alternatives, and having greater autonomy in decision-making, (i.e. greater self-determination).

Supporting social connectedness starts with the conviction that all persons have the right to develop and maintain friendships and other valued social relationships with peers of their own choosing, experience a sense of belonging, and fully participate and develop a presence in the community. True social connectedness is achieved when persons with disabilities develop and maintain supportive circles of friends; are able to develop and maintain the levels of emotional closeness they desire within their social relationships; and are no longer viewed as “special,” or pitied, but rather, treated in a manner similar to their peers without disabilities. Walker et al. (2011) extend this definition by including societal factors including the acceptance of people with disabilities within work and community settings.

Over the past several decades, considerable effort has been extended to develop educational program that focus on supporting persons with disabilities (especially those with intellectual disability and autism spectrum disorders) to develop *social skills*. We disagree with this approach for a number of reasons the first and foremost of which is that all too often the

capacities in question are learned in situations that are not “real-life” and therefore fail to generalize. Providing individuals with disabilities with the opportunity to develop relationship building skills that provide them with a variety of ways to establish reciprocity on the other hand, though more complex, is of greater use. Although we have typically thought of such skills as having their greatest usefulness as part of social encounters in which all of the persons involved were physically present this is no longer the case. Obst and Stafurik (2010), for example, found that people with disabilities who participated in online communities reported receiving social-emotional and informational support and developing a sense of community belonging which were positively associated with their well-being in the areas of personal relations and personal growth.

## Factors influencing the development of social networks

There are several factors that influence the development of social networks and the social capital of people with disabilities. One of the first to consider is the accessibility of places and activities where a person with a disability can interact with others beyond their family members and support staff (e.g., a sports venue, art event, farmers market, etc.). It is obvious, that if a person is unable to physically access an environment they are unable to use it to develop social relationships. However, environments that are physically accessible can be inaccessible in a variety of other ways. In many business establishments (e.g. pubs and restaurants) for example, people with disabilities are made to feel unwelcomed by staff and/or other customers. This can be subtle, as in when menus in Braille are not available to persons who experience vision loss, or not so subtle such as in situations where people with disabilities are seated by wait staff in the



least public areas of a restaurant that are least accessible.

When people are in the community, they are much more likely to experience social encounters with others when in small group or alone. Unfortunately, all too often when individuals with disabilities go out into the community it is in the context of scheduled group outings that often include 4-6 or more people with disabilities plus their staff. This approach fails to provide the opportunity for one-to-one interactions that are much more likely to lead to the development of relationships with others.

A factor closely related to participation in community-based activities is the type of residential setting in which a person lives. The larger the setting, the more likely activities will be planned by support staff for a *group* of people with disabilities who live together rather than activities being individualized based on the unique, needs, interests, and desires of each person. It is typical for staff in such large residential settings (e.g., group homes) to plan activities for the entire group of residents based on the availability of transportation and staff. This often results in people with disabilities going together to places that are convenient for staff, based on their interests, and convenient (i.e., short distances from the places where people live). As with any group of people, when individuals with disabilities access the community in large groups, they have few opportunities to interact with others on a one-to-one basis. In many instances they also end up taking part in activities in which they are not particularly interested creating a situation in which they have a reduced likelihood of meeting another person with similar interests and preferences two factors that significantly

increase the likelihood that an ongoing social relationship will be developed.

As indicated by Condoluci et al. (2008), the presence of various types of social capital/ relationships affect different aspects the person's life. In the presence of *instrumental relationships* that exist within the context of social networks with friends or neighbors the people with disabilities are more likely to be able maintain live independently, work, spend time in the community engaging in activities of one's choosing without having to rely solely on a provider agency and its staff for support.

Having friends or a partner provides also provide individuals with the opportunity to develop social capital that is *social-emotional* in nature. People with disabilities have the same (if not in some cases a better) capacity of empathize with others, listen to a person's problems, and assure them that things will turn out well, as their counterparts without disabilities. Providing his type of support to others not only fulfills the reciprocity responsibility that is part of social capital but increases the likelihood that when the person with a disability needs social-emotional support, it will be there.

Having colleagues or friends who provide *informational* social capital and being able to provide such information to others has a number of potentially positive outcomes. From the standpoint of the recipient of support it is likely to result in an improved financial situation, greater access to the community and therefore better access to other opportunities in society. Providing such information to others enhances the extent to which an individual is valued in his or her community thereby leading to a more positive social role.

Arguably, the most important aspect of developing social networks is the reciprocity that exists within the context of the relationships people with disabilities develop. Historically, the attitude toward people with disabilities has been to view them as persons in need of help,

support, and sometimes also pity. This attitude has often prevented people with disabilities from developing reciprocal or mutual relationships with others. In order for people with disabilities to develop rich, densely interconnected social networks, they need to feel they have valued social roles in society, regardless of their disability. The best way to facilitate reciprocal relationships is to assure that people with disabilities have the necessary access and supports to live, learn and work in the community alongside with those without disabilities.



## Tips & Strategies

- It is much more likely that people with disabilities will develop rich, interconnected social networks that provide social capital and meet their needs when they live in settings similar to those experienced by the general population (i.e. by themselves or with one of two friends). Residing in institutions that serve large numbers of people limits the development of the natural social networks and tends to decrease the potential for reciprocity in relationships developing.
- Similar to the majority of the population, people with disabilities have many different characteristics. Unfortunately, members of this group are often defined by a single feature...their disability. Providing opportunities for members of the community to really get to know the people with disabilities who are their neighbors, including their preferences, likes and dislikes, special interests etc. makes it much more likely that they will be viewed as persons who are just as unique as their peers and have as many positive characteristics.
- All too often people with disabilities are viewed by the general population solely as users of resources. Members of this group, however, do not just receive support, but also have the capacity to serve as supports to others by being a friend, a colleague, a neighbor, and to the soci-

ety as a whole. Finding ways to highlight the positive contributions people with disabilities currently make to society is likely in the long run to have a positive impact on the way they are perceived by the general public and the extent to which their social roles are valued.

- Given that social networks lead to better opportunities for employment, independent living, and involvement in the community it is critical that people with disabilities be provided with opportunities to develop such social capital. This will require a person-centered approach in which individuals with disabilities have the chance to access the community with needed supports: by themselves or in small groups, to engage in activities that are of personal interest; and with opportunities to challenge themselves and try new things.



## CASE STUDY

Jan is a very determined young man with vision loss and a mild intellectual disability, who now runs his own health and wellness spa. Becoming a successful business owner was not an easy journey for Jan. When he completed high school, he desired to earn sufficient salary, so that he could live independently in the community with minimal supports. One of his high school mentors suggested he tried to apply for a job in the hospitality industry. Jan thought he might like this kind of work and went to a local hotel that was advertising a number of employment opportunities, including the positions of a receptionist and a lower-level manager.

As soon as Jan entered the hotel, he was questioned by the staff about his disability and what kind of help he needed. He responded by indicating that he was there to apply for one of the advertised positions. Hotel staff ignored his response and kept asking whether he needed any help. During this encounter, Jan felt very uncomfortable and disappointed. From that moment, he decided that he did not need anyone's pity, but would rather strike out on his own so that he could be his own boss. Luckily, Jan had several friends with whom he shared his unpleasant experience and consulted about other job possibilities. His friends advised him to start a spa specializing in massage and other wellness therapies. They also discussed the need for other people with vision loss living in the city to obtain employment and the possibility of Jan eventually hiring other therapists with disabilities to work at his spa.

Jan liked the idea of running his own business, but he had a lot of work to do. He needed to learn about how to start such a venture, local regulations, budgeting resources, and managing its operations. These were all areas in which Jan had very limited knowledge and which were not part of his program at school. After some time, Jan learned from one of his friends that there is a foundation in his city that provided seed funding for small business ventures and basic management training. He took this opportunity and with the help of one of his friends applied for seed funding, which he subsequently received. With start-up funding and mentoring from staff at the foundation, Jan was able to launch the spa business and after a period of time to also hire several other therapists with disabilities. Jan's business is now flourishing, which makes him as well as his friends very proud. Jan has also become a role model in his community for other people with disabilities with respect to what is possible to achieve with the help of friends and other supporters. Jan's friends and others in the community who as-

sisted him were critical to his success. His social network was able to support Jan in creating and maintaining a job and business he loves and where he feels successful. If it were not for his friends and community members who believed in him, he may not have been able to find the job he wanted, create a success business, and serve as a community employer.

### Jan and one his therapists at his wellness spa



## Resources

- [Frontline Initiative on Social capital: The real route to inclusion](#)
- [Friends: Connecting people with disabilities and community members](#)

## References

- Allik, J., & Realo, A. (2004). Individualism-collectivism and social capital. *Journal of Cross-Cultural Psychology, 35*, 29-49.
- Arslantaş, A., Adana, F., Ergin, F. A., Kayar, D., & Acar, G. (2015). Loneliness in elderly people, associated factors and its correlation with quality of life: A field study from Western Turkey. *Iranian Journal of Public Health, 44*, 43-50.
- Bates, P., & Davis, F. A. (2004). Social capital, social inclusion and services for people with learning disabilities. *Disability & Society, 19*(3), 195-207.
- Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., & Martin, L. (2012). Shifting our conceptualization of social inclusion. *Stigma Research and Action, 2*(2).
- Condeluci, A., Ledbetter, M.G., Ortman, D., Fromknecht, J., DeFries, M. (2008). Social capital: A view from the field. *Journal of Vocational Rehabilitation, 29*(3), 133-139.
- Milner, P., & Kelly, B. (2009). Community participation and inclusion: People with disabilities defining their place. *Disability and Society, 24* (1)1, 47-62.
- Obst, P., & Stafurik, J. (2010). Online we are all able bodied: Online psychological sense of community and social support found through membership of disability-specific websites promotes well-being for people living with a physical disability. *Journal of Community and Applied Social Psychology, 20*, 525-531.
- Peerenboom L., Collard R. M., Naarding P., & Comijis H. C. (2015). The association between depression and emotional and social loneliness in older persons and the influence of social support, cognitive functioning and personality: A cross-sectional study. *Journal of Affective Disorders, 182*, 26-31.
- Simplican, S., Leader, G., Kosciulek, J., & Leahy, M. (2015). Defining social inclusion of people with intellectual and developmental disabilities: An ecological model of social networks and community participation. *Research in Developmental Disabilities, 38*, 18-29.
- van Asselt-Goverts, A. E., Embregts, P. J., & Hendriks, A. H. (2013). Structural and functional characteristics of the social networks of people with mild intellectual disabilities. *Research in Developmental Disabilities, 34*(4), 1280-1288.
- Walker, H.M., Calkins, C., Wehmeyer, M.L., Walker, L., Bacon, A., Palmer, S.B., ... Johnson, D.R. (2011). A social-ecological approach to promote self-determination. *Exceptionality, 19*(1), 6-18.



## CHAPTER 9

# The Role of the Family in the Life of a Person with Disabilities

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### Guiding questions

- How can a family best support a young person's transition from adolescence to adulthood?
- What are the most important steps to take to help a young person with disabilities lead the best life possible?

## Introduction

When a young person with a disability in the U.S. reaches the age of 16, laws require that his or her individualized education plan (IEP) include goals, plans and services to help transition to adulthood. Families are a required partner in this planning and play a very important role in helping youth attain the future they want.

Parents often know the most about what a child likes to do, how they do or do not participate fully in their community, and what skills and abilities they need to be more independent. Planning for a child's transition from adolescence to adulthood is one of the most important things families can do to help pave the way for a fulfilling, successful life.

Up until this age, the parents or guardians of the young person clearly are making most of the decisions for their child. But transition recognizes that youth with disabilities are growing up, and just like their peers, they, too, deserve to make more decisions for themselves and increase control over their own lives. Regardless of physical or cognitive ability, youth can and should play an active role in the transition journey with the encouragement and guidance of their families.

During transition, parents and youth learn new skills side-by-side, and as youth begin to take on more responsibility, parents must find new ways to provide support. As a result, the term “transition” applies to all members of the family; all are going through a time of transition. The roles within the family begin to change, and it can be an uncomfortable time for parents as they learn to let go of controlling all aspects of their child's life.

### The role of the family during transition is to:

- **Advocate:** The family can take a proactive approach, making sure teachers, social workers, and counselors start to build tran-

sition plans early. Success depends upon allowing sufficient time to understand a young person's skills, needs and desires—no matter what type of disability he or she has—and then helping the young person set and achieve key goals. During transition, a family can ask many questions and share information to ensure the most holistic plan possible.

- **Gather information:** During transition, families can help by learning about options for employment, post-secondary education and training, and independent living. Parents can visit a college campus to help a young person visualize a future and explore what services are available to support students with disabilities. In terms of housing, parents can help by looking at different types of housing and related services to determine what would work best for their young adult. While social workers can help families explore options, networking with other families often provides valuable suggestions and contacts.
- **Help youth speak for themselves:** Young people, no matter the disability, need a strong sense of their strengths, abilities, interests and values. They also need to understand how their disability might affect them at work, school or in the community. During transition, parents can help their child both name what they want to do and speak about their disability.
- **Expand networks:** As children with disabilities become adults, they often need support from social and community networks. Parents can help youth expand their network by inviting new people into their lives to provide social, recreational, work, peer mentoring or volunteer experiences. When a young person with disabilities interacts with an increasingly wider circle of people, he or she is much more likely to find work opportunities, form friendships, and take advantage of recreation and social resources throughout

the community. As parents age, it is important for people with disabilities to have this expanded network, so support and care is not dependent on families only.

- **Learn new skills:** Parents can help their child build a resume by finding job and volunteer experiences through a network of friends, family, religious and community organizations. Parents can also help their young person learn to accept direction, manage time, engage in appropriate personal communication, dress properly, and manage money.
- **Plan for health care needs:** During transition, families can help adults with disabilities begin to make their own doctor appointments and manage their prescription drug use. Families can make sure that health needs are included in transition planning as lack of management can jeopardize learning and employment.

The role of the family in transition is vital. Helping young people successfully transition from childhood to adulthood builds a wider network—beyond parents—to support and care for the person with disabilities. It also helps ensure that young people with disabilities get to choose a life that is personally meaningful.



## Tips & Strategies

- Start a transition plan when your child reaches adolescence (12 to 13 years of age). Do not wait until he or she approaches the actual transition age (16).
- Talk with other parents whose children are older than yours. They are often the best source of information.
- With your child's educators, therapists, and counselors, make a list of skills your child wants and needs to learn and take it step-by-step to build lasting success.
- Ask your child to name what he or she most wants to do, learn, achieve. Their voice must be the strongest in the transition planning process.

## CASE STUDY 1



Sam is a young man with cerebral palsy who uses a power wheelchair. He has normal cognitive abilities and was an excellent student in high school. However, he needs a great deal of physical support to write and type. He also has eye fatigue when reading.



Sam wanted to go to college after high school. His family visited several college campuses to determine which would work best. A school social worker strongly recommended a program at a community college, which had a relationship with the school district Sam attended. The family agreed that this program might provide a helpful transition from a fully supported high school setting to a more independent college setting.

However, Sam and his family quickly learned that the college did not have adequate resources to support students with disabilities. The school district program was relatively new and was not well integrated into the college. He often seemed on his own, without any staff who understood him or his needs. As a result, after the first year, Sam's family reviewed choices and Sam chose a new university that had a skilled staff of disability experts to help him be successful.



In advance, Sam's family arranged for a visit to the technology lab at PACER Center, a center for children with disabilities and their families. There he was introduced to some helpful tools for notetaking and transcription, which greatly improved his ability to attend and be independent in college. Sam also was able to take advantage of software that read a book for him. By following along both visually and audibly, he

was able to learn more efficiently and with less fatigue.

During his time in college, Sam took over managing his schedule and completing all of his assignments using technology and university staff support. His family provided guidance if he requested, but he became fully in charge of his learning and daily life. Sam lived at home during college, which allowed the family to adjust to his independence in daily living without having to deal with housing.

Sam graduated in three years with honors and has a job writing and managing social media for a technology company. With his family, he is now exploring options to live independently. The challenge for Sam is his need for personal care attendants (PCA) to help him with dressing, meal preparation, bathing, etc. Given his physical disabilities, he needs full assist with most daily tasks. He now manages his PCA schedule, but low unemployment and low wages for PCAs has created a workforce shortage. It is difficult to find capable and reliable PCAs, which is inhibiting Sam's ability to live independently. His family continues to provide a great deal of his care. They recently formed a family group focused on figuring out ways to deal with the workforce shortage and housing issues.

## CASE STUDY 2

Maria is a 26-year-old woman who has intellectual and developmental delays. As a member of a large family, she learned important social and life skills that serve her well in daily life. After high school, she attended a transition program for youth with disabilities ages 18-21. She learned important job skills and had an excellent internship experience working in a business that printed slogans on T-shirts. Towards the end of her transition program, Maria and her family got connected to an employment specialist who helped her research job possi-

bilities. Because she has limited reading and math abilities, it took her several months to find a good match. Her employment specialist learned about her love for sports and connected her with a major sports facility, which provided on-the-job training.

Maria liked living at home with her many brothers and sisters. But as they grew up and left for college, she was increasingly isolated because she lived in a neighborhood outside of the metropolitan area where most people were the age of her parents. Her parents researched options and Maria moved into a supportive housing complex with four apartments. While she is living independently, Maria and her family learned quickly that the supportive services were not adequate for her needs. While a supervisor was on-site during the evenings, there were no organized social activities, support for going out into the community, or further skill building opportunities. The supervisor was really only there to make sure there were no safety issues.

Maria's family learned through this process that she needed more help to develop an integrated community life. She is on the waiting list for another housing option with more staff who can provide support for her to make new friendships, participate in community life, and continue to learn skills for independent living.

## Resources

- [PACER Center](#)
- [PACER Center National Parent Center on Transition and Employment](#)
- [The ARC Minnesota, Planning Your Future](#)



## CHAPTER 10

# Health, Wellness, and Sexuality

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### Guiding questions

- What is the health status of people with disabilities in the United States?
- What are people in the United States doing to improve the health of people with disabilities?

## Health status of people with disabilities in the U.S.

People with disabilities often experience poorer health, not related to their disability, than people without disabilities. This difference in health status stems from a number of reasons. Although life expectancy has increased for people with disabilities as people have moved to the community from institutions, people with disabilities are more likely to have health conditions, such as high blood pressure, diabetes, and cardiovascular disease than people without disabilities (Reichard, Stolze & Fox, 2011). These conditions are often related to lifestyle choices, such as being sedentary or having poor diets. Organizations that provide supports to people with disabilities often do not pay enough attention to the need for physical activity and teaching skills that can promote better health.

In the United States, people with limited incomes receive a health insurance program called Medicaid. Medicaid pays for medical care. Dental care may not be covered depending on where people live. Payments to providers are low, so many health care providers and dentists will not take people with disabilities as patients (Anderson et al., 2013). Public health and prevention efforts often leave out people with disabilities. Another barrier to appropriate healthcare to people with disabilities is that healthcare providers do not always receive sufficient training to provide appropriate care to people with disabilities (Anderson et al., 2013).

Addressing the barriers to better health for people with disabilities is becoming more important. Researchers, providers, and health-care providers are all developing better ways to improve the health of people with disabilities, including: developing health education programs, better training for health care providers, and emphasizing the need for service providers to support people to make healthier lifestyle choices.

## Improving the healthcare system for people with disabilities

One of the ways the health care system is working to improve the health of people with disabilities is through the development of “medical homes.” Medical homes are clinics designed to improve the health of people with complex health needs by offering person-centered, comprehensive health care by providers with the skills and knowledge to better care for people with disabilities. Medical homes also provide care coordination across multiple health care providers and specialists.

## Teaching people with disabilities about health and wellness

It is important to teach people healthcare self-advocacy and health literacy skills. Health literacy is a person’s ability to understand basic health information and to make appropriate health decisions. Parents and providers can support health literacy by people to share health information with healthcare providers and to ask questions about their health of healthcare providers. Other health literacy skills include learning about taking medications and other health-related activities, and learning about healthy lifestyle choices such as being physically active or eating nutritious meals. Knowledge is an important part of health self-advocacy. This knowledge includes learning about one’s body and how it works.

Tools have been developed to help people increase their health literacy, including health passports. Health passports are a portable way for people with disabilities to share important information about themselves with their health care providers. Other tools include using plain language to explain health concepts to people. Plain language means that things are written or explained in ways that are easy to understand. Pictures, models (such as models of the human body), and videos can be used to demonstrate

skills (for example, exercises) and to teach complex topics. When people are given opportunities to understand concepts related to their health, they are better able to make informed decisions.

The teach-back method is another way to increase the ability of people with disabilities to learn about their health. In this method, people are taught some important aspect of their health using plain language and other teaching tools. The person with disabilities is then asked to teach what they have learned to the person providing the instruction. This process is repeated until the person with disabilities understands the concept being taught (to the extent that the persons cognitive abilities allow).

### Is sexuality seen as an important part of health for people with disabilities in the United States?

Sexuality is an uncomfortable topic to talk about in the United States, particularly for people have disabilities. Unfortunately, research tells us that people with disabilities experience high rates of sexual abuse. Therefore, it is important that people with disabilities learn about healthy relationships, about how their bodies work, and about sexuality. Abuse prevention is not the only, and may not even be the most important, reason to teach people with disabilities about sexuality and human relationships. People with disabilities often report being lonely and long to have intimate relationships (Amado et al., 2019). Sexuality is an important part of the human experience, and everyone deserves the right to have intimate relationships, should they desire one.

Parents and providers of support services are starting to recognize that relationships and sexuality education is important to people with disabilities as they grow into adulthood. Education programs are being developed to meet this important need. For example, disability

advocacy organizations are partnering with agencies that work with sexual violence centers to address the needs of people with disabilities who have experience abuse. These efforts are also teaching people with disabilities about abuse. Self-advocates and advocacy organizations are leading the efforts to push for training and education about healthy relationships and sexuality.

### CASE STUDY 1

My Home, Inc. is a small residential service provider in the United States. They have been operating small group home for people with disabilities for about 30 years. In recent years, the people that they have been supporting have started to reach middle age. Several years ago, three of the people the agency supported died from diseases that can be often be addressed with lifestyle changes. The agency's CEO looked at the number of people they supported with diseases, such as Type II diabetes or cardiovascular disease. She recognized that the residential program was in large part responsible for this situation because they had been providing supports for people for decades. She decided that the organization needed to change its practices.

The organization decided to focus on increasing physical activity and improving people's nutrition. All staff was required to take nutrition courses. Cooking classes were offered for staff who did not know how to cook. These classes were also open to people with disabilities being supported. People were encouraged to be more physically active. Some houses chose to have gardens to grow fresh vegetables. Other simple changes were encouraged, such as drinking water rather than sugary drinks. The results of these changes were that many of the people with disabilities who were supported to learn about their health and how lifestyle choices might affect their health. A

number of people lost significant amounts of weight, became more physically active, and some were able to reduce medications related to diabetes and high blood pressure. The organization regularly holds “wellness nights”, where people can learn more about their health or participate in some fun activities. People served by the organization thought that the activities were a lot of fun and were proud of the changes they made to improve their health.

Nancy was one success story. She lost nearly 50 pounds and was able to reduce the medications she needed for her diabetes. Her favorite part of the experience was shopping for new clothes. Sally learned that she loved to be physically active. She decided to become a certified indoor cycling instructor and teaches classes at her local community center.

As the agency changes its practices, they are recognizing the other aspects of health that are important, such as mental and emotional health, healthy relationships and the need for social connections, and the need for meaningful activities. The organization has created a culture of health and wellness that has benefited both the people receiving support services and the staff providing the *supports*.

## Sexuality, health, and wellness for people with disabilities in the Russian Federation

### Lack of sexual health professionals and education for people with disabilities

Russia experiences an acute shortage of professionals in the field of sexual health (doctors, psychologists) capable of working with people with disabilities. As far as people with disabilities are concerned, this area of life has been historically ignored. By contrast, today it is obvious that the topic is very much in demand among the community of parents, who want to know how to discuss with their children ques-

tions about their bodies, sex, and sexual relations.

Overall, human sexuality still remains a taboo in Russia. Thus, public schools still do not have classes on sexual education for children. In institutions, adults with disabilities are frequently perceived as children by staff, and therefore it is believed that they should not engage in sex, and that pregnancy is highly undesirable (there are known cases of forcible abortions inflicted on women in such facilities). Men and women meet infrequently and never in private since they are housed on different floors. Young adults get some scattered and vague knowledge about sex from movies and TV series or have learned something from their parents in case of those who previously lived with their families. As a result, their perceptions of one’s own body, boundaries (for self and others), and sexuality are often badly distorted.

### CASE STUDY 2

Cyril is 28 years old, lives in a residential facility, and attends programs of Life Route Foundation. When Cyril started attending classes at Life Route Foundation, many female volunteers found him touching their shoulders, buttocks, and breasts. Staff realized that his behavior was driven not only by sexual attraction, but also by complete lack of the sense of physical boundaries expected by other people. How can physical boundaries and what is or is not proper be comprehended by a person whose own body has been handled by others without asking for his permission over many years (a person like Cyril could be dragged by hand from one place to another; at residential facilities an injection may be administered without prior permission and warning that it may hurt or be unpleasant, etc.)? Every time Cyril tried to touch the female who escorted him, we told him about it being inappropriate and showed a picture card depicting the concept. A year and

a half after Cyril started attending the Foundation's workshop, he stopped making passes at the female escorting him.

### Medical decisions

The primary custodians of childhood physical health (nutrition, medical screenings, treatment of acute and chronic illnesses) are typically parents. In the case of adults with intellectual and developmental disabilities, they generally remain in the care of their mothers or fathers, and consequently, do not take care of their own health. When adults with disabilities live in special residential facilities (i.e., institutions), all medical decisions are made by the staff. Unfortunately, we find that most residents of such facilities do not have access to quality healthcare, where physical health is concerned (dental care, gynecology, cardiology), yet when it comes to psychiatric treatment, it is available freely and indiscriminately, resulting in excessive dosages of administered drugs. What residential facility staff are after is to make their charges easier to control and more docile.

In principle, medical personnel of residential facilities are duty bound to inform residents about what medication has been prescribed to them and for what reason, while residents have the right to refuse to take some or all of their medications. But in reality, almost all residents take the medications without a clue about what they are and why they are needed. Refusal to take one's medication may be seen as disobedience or bad behavior.

### CASE STUDY 3

Nicki is 25 years old, lives in a residential facility, and attends programs of Life Route Foundation. For residential facility staff, Nicki is one of the "teacher's pets". She helps with cleaning chores, works on packaging overshoes, participates in many sports activities, and performs in the facility's amateur theatre. She believes that

thanks to such model behavior, she gets off lightly when it comes to excessive medication: she gets only one pill "so that her heart would not burst out". Nicki knows what her medication is called. In truth, it is not a cardiac medicine, but a tranquilizer. Volunteers advise that Nicki should write a letter of request asking to spell out the reasons for prescription of her tranquilizers.

### Lack of attention medical diagnosis

Against the background of extensive psychiatric treatment, the monitoring of residents' physical health is quite desultory. Health issues are taken seriously only in acute life-threatening cases. Staff would say about many individual residents things, such as "she has an ob-gyn problem", or "he has some kidney issues", but establishing an actual diagnosis and deciding what must be done about it or what should be avoided remains at the discretion of the staff.

### CASE STUDY 4

Oleg is 21 years old, lives in a residential facility, and attends programs of Life Route Foundation. Ever since he was admitted to the institution, it has been known that he has cardiac issues. Yet, he had never had a thorough medical examination. Therefore, the staff (driven partly by fear for his life) would prevent Oleg from participating in almost any activity, such as outings or even long walks on facility grounds. A year after he got involved in the program of Life Route Foundation, volunteers arranged an examination for him in a private cardiological practice. The exam revealed that he has only half the heart, and it is located on the wrong side. Nonetheless, the cardiologist ruled out only vigorous physical activity and found no medical ground for excluding Oleg from anything else. This year, he will attend Life Route Foundation's summer camp for the second time.



### Lack of attention to emotional health

Residents of institutions live isolated lives, which in itself works against their overall physical and emotional wellbeing. Any emotion, desire, or feeling that appears (to staff members) to be unduly intense is ascribed to a resident's mental health issue and viewed as something demanding psychiatric treatment. Residential facilities overemphasize and overdo psychiatric treatment, while offering insufficient care of physical health and emotional health, or even ignoring physical and emotional health issues entirely.

### CASE STUDY 5

Vasia is 36 years old, lives in a residential facility, and attends programs of Life Route Foundation. When he learned that classes at the Foundation will be canceled for a week, he became very upset and flipped over an armchair in the lobby. Following that, he skipped classes for two months, and was prescribed sedatives. At that point in Vasia's life, classes at Life Route Foundation were his only regular outlet beyond the confines of the residential facility. Having those classes canceled lead to him being genuinely and sorely upset. Yet, the staff did not bother to think through the situation. Vasia did not need sedatives, but rather emotional support and reassurance that classes will resume after a week's lapse.

### Therapeutic intervention

In Life Route Foundation classes for people with intellectual and developmental disabilities living in residential facilities, the main emphasis is always on talking through and working through one's emotions. Much class time is spent on participants' accounts of what their past week was like, what was joyful and what was upsetting or made them angry. Volunteers

actively participate in such discussions, in part to make attendees see that they can legitimately express any kind of emotion.

### CASE STUDY 6

Alex is 36 years old, lives in a residential facility, and attends programs of Life Route Foundation. Alex lived with his mother until his early teens. With time, his mother started losing her eyesight. When she was no longer able to take care of him, he was placed in a boarding facility for children, and moved to an institution, when he got older. In all that time, Alex never once saw his mother, and none of the staff ever tried to reach her by phone. One day, Alex was told that his mother passed away.

During classes, Alex's counselor tries to talk about his life outside institutional settings – about his mother, grandmother, and grandfather and what they used to do together – all in order to let him feel that other people are not callously indifferent to his life and emotions.



## Tips & Strategies

- Offer opportunities to include preferred physical activity and affordable, healthy foods into daily life.
- Teach people with disabilities about how their bodies work.
- Educate direct support professionals on how to support physical activity and healthy eating.
- Include lifestyle and other health goals into service plans.
- Encourage community organizations (such as community centers or public health agencies) to include people with disabilities in their programming.
- Teach people with disabilities to communicate with health care providers about their health.

## Resources

- [England National Health Service Health Passport](#)
- [Florida Center for Inclusive Communities Health Passport](#)
- [Partnerships in Wellness curriculum](#)
- [Plain Language Resources](#)
- [Center for Parent Information & Resources: Sexuality Education for Students with Disabilities](#)
- [Massachusetts's Healthy Relationships, Sexuality and Disability](#)

## References

- Amado, A., Van Ness, J., Hall Lande, J., & Dosch Brown, R. (2019). Friendship, love and fun: Social inclusion and relationships. In (Nye-Lengerman, K. & Hewitt, A., Eds.) *Community Living and Participation for People with Intellectual Disabilities*, AAIDD.
- Anderson, L. L., Humphries, K., McDermott, S., Marks, B., Sisirak, J., & Larson, S. (2013). The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellectual and developmental disabilities*, 51(5), 385-398.
- Reichard, A., Stolze, H., & Fox, M. H. (2011). Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *Disability and Health Journal*, 4, 59-67.



## CHAPTER 11

# Guardianship

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### Guiding questions

- What is the role of guardianship in community living and employment?
- What are different ways a guardian can support a person with IDD to exercising their rights, making choices and having control and direction in their life?

## Introduction

For people with intellectual and developmental disabilities (IDD) in the United States and across the world, the idea of living in a community, doing things they want to do with people they choose and exercising their self-determination in making decisions about their life, is just that, an idea. Progress has been made in providing services and supports to make this idea a reality for people with IDD; however, community living remains out of reach for most people with IDD, who continue to live in isolation from the community in protective environments under the presumption of incompetence.

One example is in guardianship proceedings, where it is often only the identification of a person's diagnosis of IDD that is used as sufficient evidence to make a determination of incompetence or incapacity to justify the appointment of a guardian (Shogren, Wehmeyer, Matinis, & Blanck, 2019). Scholars assert that subjecting a person with IDD to guardianship when they turn 18 robs them of their right to exercise self-determination and to learn to make decisions in the same way their peers without disabilities do (Abery & Stancliffe, 2003; Bach, 2007; Dhanda, 2007; Wehmeyer & Abery, 2013). More recently, self-advocates and allies in the United States and internationally have begun advocating for increased use of alternatives to guardianship, such as supported decision making (United Nations, n.d.).

## What is guardianship?

The history of guardianship goes back 2,000 years and is founded on the principle of "paterfamilias" or parent of the state. What this means is that parents were required to give up legal rights to their children with disabilities in order to receive institutional care. This is no longer the practice in the United States. While each country has their own laws and regulations on guardianship, there are some com-

mon elements to be found in most laws (Kleist, Hewitt, & O'Neil, 2019).

In the United States, guardianship is a legal process where a court appoints a person to make decisions for someone else. The general criterion that is used when establishing guardianship involves: (a) determination that the person lacks capacity to make or communicate decisions; (b) the person needs the supervision and protection of a guardian and no less restrictive alternative exists; and (c) the person chosen to act as guardian does so in the best interests of the person (UGPPA, 2007). While laws in the United States governing guardianship have a requirement to demonstrate that no less restrictive alternatives to guardianship exist, this is rarely enforced for individuals with IDD because the legal system continues to operate in a paradigm that individuals with IDD are vulnerable adults and must be protected (Shogren, Wehmeyer, Matinis, & Blanck, 2019).

Who can be a guardian varies for people with IDD. Guardians are often parents, siblings, other relatives or in some situations, friends or former caregivers. They may also be paid private professional guardians or public guardians from state or local government agencies. This may vary from state to state as well as across countries. Generally, the standard for choosing a guardian is for the person to be someone who is the most suitable and best qualified among those available and willing to act as a guardian for the specific person. This decision is generally made based on evidence that is presented to the court. Occasionally input from the person with a disability is considered by the court (Kleist, Hewitt & O'Neil, 2019).

How much decision-making power a guardian has depends on what powers the guardian has been granted by the court, which varies both in the United States and across countries. Guardians may be granted the power to make decisions about where a person lives; what services and supports a person should receive;

taking care of a person's belongings; medical care and treatment; entering into legal agreements or contracts with others. Sometimes guardians may also be granted the power to restrict a person's right to vote, get married or have children. Restricting an individual's right to vote varies by state. For example, in Minnesota, U.S., restricting the right to vote must be written into the order appointing a guardian and should require evidence that a person is not capable of exercising their right to vote. In practice, some judges will allow the guardian the power to restrict a person's right to vote based solely on the diagnosis of IDD. With respect to the right to have children, courts may grant the guardian the power to consent to sterilization of the individual with IDD to prevent pregnancy. The Arc U.S. and other advocacy organizations have positions against this practice of involuntary sterilization of individuals with IDD (Joint Position Statement of AAIDD and The Arc, 2016).

Plenary guardianship is the most restrictive. Under plenary guardianship the court grants all the powers to the guardian to make decisions for a person with IDD. The court might also grant a less restrictive guardianship that limits the powers of the guardian to only those areas where there is a demonstrated need for a substitute decision maker. These types of less restrictive guardianships vary by state and country and may be called limited guardianship, conservatorship, surrogate, legal representative or similar terms.

## Current advances

Since the late 1990s, efforts to reform guardianship have included increased emphasis on the use of alternatives to guardianship for people with IDD. These alternatives include using healthcare directives (also known as living wills) for medical decisions and powers of attorney for contractual or financial decision-making support.

Internationally, the Convention on the Rights of Persons with Disabilities (CRPD) has created an impetus for change in disability laws demanding a shift from a substitute decision-making model to a supported decision-making model (Dinerstein, 2012; Lawson, 2007; McSherry, 2012; Minkowitz, 2012). The CRPD has been important in advancing supported decision-making in international law as the preferred response when a person's decision-making ability is brought into question due to impairment or disability. The CRPD recognizes that there are times when people with disabilities may require support in making decisions and that depending on the course of the disability or illness, varying levels of support may be needed (Dinerstein, 2012).

Some countries have developed models that establish supported decision making, though they have not completely replaced the substitute decision-making model (Boundy & Fleischner, 2013). For instance, Canadian provinces including British Columbia, Manitoba, Yukon, and Alberta, have adopted different models that presume the capacity of persons with IDD, and established a system to allow them to make decisions on various issues, with or without court involvement. In Sweden, people with disabilities are no longer provided with guardianship; instead, they are provided with a court-appointed tutor to make decisions for the person following a "best interest" approach. Similar movements have also occurred in many other developed countries, including Australia, Germany, Norway, Scotland, England, and Ireland (Shogren et al., 2019).

## Effective practices: Role of guardianship in community living and employment

Guardianship plays an important role in community living and employment for individuals with IDD. When a guardian is appointed, he

or she becomes the legal representative for the person. Guardians are expected to make decisions with and on behalf of the individual with IDD with the goal to encourage and afford the individual with IDD the maximum level of independence or self-reliance. In making decisions on behalf of an individual with IDD, guardians must also exercise decision-making powers so that they are reasonable, safeguard the individual's rights and are based on a clearly established need for the individual with IDD and not for the convenience of the guardian. While this is the standard, actual application varies widely among guardians (Kleist, Hewitt, & O'Neill, 2019).

The guardian can be a strong advocate in supporting a person with IDD to get what they want or need. Effective guardians engage the individual with IDD in the decision-making process and spend time learning and understanding what is important to the individual and their dreams, goals and preferences. Effective guardians also advocate for services and supports that maximize inclusion in community life. Effective guardians have a relationship with the person and connect with them frequently.

## Role of the legal system in community living and employment

The use of guardianship as a tool to protect people with IDD continues; however there have been some reforms in guardianship that have benefited people with IDD. Some changes include the right to legal representation for the individual with IDD and annual reporting requirements for guardians. Additionally, every year the person with IDD under guardianship must be given notice that they have the right to ask the court to end the guardianship or appoint a new guardian.

## Opportunities for improvement

There are a number of opportunities for change emerging from ongoing advocacy efforts around the CRPD for improving how to best support individuals with IDD in decision making. Ongoing work to implement reforms in the legal system with respect to guardianship continues. Several states in the U.S. are actively pursuing formalizing alternatives to guardianship, such as the legally enforceable supported decision-making agreements found in Texas and Maine. In the years ahead, through ongoing efforts of self-advocates and their allies, the use of guardianship as the default for people with IDD will be replaced with alternative ways of supporting people to make their own decisions, e.g. supported decision making (Shogren et al., 2019).

In addition to legal reforms, there is a renewed focus on other approaches for supporting people in exercising their rights to make their own decisions. For example, research about self-determination provides a strong evidence for supported decision making. Additionally, practitioners of person-centered planning and practices are focused on developing and implementing strategies for including decision making support as part of an individual's person-centered plan (Burke, 2018).

All of these efforts will continue to push improvements in how guardianship is used with individuals with IDD.



## CASE STUDY 1

Charlotte's parents were advised during her annual educational transition IEP meeting to pursue guardianship when she turned 18. Charlotte relied on her parents and others to get through most of her daily routine. While Charlotte showed an interest in making some decisions about her life, she depended on her parents to provide decision making support, especially when she wasn't able to communicate with others what she wanted or needed. Listening and observing behavior as communication was important for understanding Charlotte's preferences and supporting her to make choices and decision based on what she wants. Just before her 18 birthday, Charlotte's parents contacted an attorney to help them navigate the guardianship process. After meeting with the attorney to assess Charlotte's need for a guardian, it was agreed that her parents were the most appropriate people to be appointed Charlotte's guardians because they knew what was important to her and were strong advocates for ensuring that she was included, engaged and socially connected in her community. As part of the court proceeding, Charlotte was appointed an attorney to represent her and a court visited interviewed her to learn if she had questions or concerns about the process or having a guardian. At the court proceeding, Charlotte and her parents were asked some questions about the need for guardianship and then granted the order to appoint Charlotte's parents as her guardians. Today, Charlotte's guardians support her to make as many decisions of daily life and continue to look for different ways to teach her to make bigger life decisions. Each year the talk to her about how they are doing as guardians and if she wants to change anything.



## CASE STUDY 2

Martin's adopted parents were appointed his guardians when he was 18. The need for guardianship was established because Martin had made a series of decisions that made him vulnerable and he resisted getting help from others. His parents felt that a guardianship was needed to protect his interests and allow them to advocate on his behalf when he was not able to. As his guardians, his parents helped Martin access services and supports including living in a group home with other people with IDD. They helped him make decisions about where to live, medical treatment and signing contract to buy a car. After about five years, Martin approached his parents about going back to court to become his own guardian. He wanted to move in with his grandmother. Martin's parents agreed that he had worked hard to build a support network of family and friends who he could rely on for help making decisions. They worked with an attorney and made a plan for supported Martin in decision making as his own guardian including drafting a living will for support with medical decisions. The court agreed with the plan and ordered that the guardianship be terminated, freeing Martin to make his own decisions with help with important people in his life.



## CASE STUDY 3

Being seen as independent is extremely important to Roberto. Despite professional's recommendations to Roberto's parents to pursue guardianship after a couple of situations where he made some poor decisions impacting his health and finances, Roberto and his family opted for using less restrictive alternatives to guardianship. They were adamant that he remain his own guardian because they have always supported him to make his own decisions even if that meant making some mistakes along the way. They supported him in moving into



his own apartment, getting a job at a medical supply, getting married (and divorced), saving money to buy a car and making decisions about medical care and treatment. They found that supporting Roberto to create a will, health-care directive and power of attorney worked best along with informal support. Roberto talks to his family every day and relies on them for support when making big life decisions. He will often ask their opinion and also seek out other's perspectives when that makes sense to him. For Roberto and his family, alternatives to guardianship makes the most sense to him.



## Tips & Strategies

- In a recent publication on community living, Kleist and colleagues shared 5 strategies for moving from guardianship to supported decision making including:
  - Identify opportunities from people with IDD to make decisions early on because, the earlier opportunities are provided, the better the outcomes.
  - Ensure opportunities for decision-making are included in educational planning, especially when planning for transition from high school to young adult life.
  - Look for and engage people with IDD to problem solve and learn to make decisions using person centered practices to figure out what the person with IDD wants to pursue in life and how best to support them to ensure what is important to them is present.
  - Watch for barriers and roadblocks in law and policy that get in the way of supported decision making because of concerns around liability, neglect and vulnerability.
  - Advocate for changes in how the system applies current guardianship laws by educating policy makers, judges and lawyers about supported decision-making (Kleist, Hewitt, & O'Neil, 2019).

## Resources

- [National Center on Supported Decision Making](#)
- [National Center for State Courts](#)

## References

- American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc (2016). *Joint position statement on autonomy, decision-making supports, and guardianship*. Retrieved from: [https://www.thearc.org/file/16-117-The-Arcs-Position-Statements\\_B3\\_Autonomy-Decision-Making-Supports-and-Guardianship.pdf](https://www.thearc.org/file/16-117-The-Arcs-Position-Statements_B3_Autonomy-Decision-Making-Supports-and-Guardianship.pdf)
- Blanck, P., & Martinis, J. (2015). The Right to make choices: The National Resource Center for Supported Decision-Making. *Inclusion*, 3(1), 35-39.
- Burke, S. (2016). Person-centered guardianship: How the rise of supported decision-making and person-centered services can help Olmstead's promise get here faster. *Mitchell Hamline Law Review*, 42(3). Retrieved from <http://open.mitchellhamline.edu/cgi/viewcontent.cgi?article=1030&context=mhrlr>
- Dinerstein, R. D. (2012). Implementing legal capacity under Article 12 of the UN Convention on the Rights of Persons with Disabilities: The difficult road from guardianship to supported decision-making." *Human Rights Brief*, 19(2), 8-12.
- Gotto, G.S., Reynolds, M. C., Palmer, S. B., & Chiang D. F. (2019). Supporting families through the charting the life-course framework. *Intellectual and Developmental Disabilities*, 57(1), 56-65.
- Jameson, M., Riesen, J., Polychronis, S., Trader, B., Mizner, S., Martinis, J., & Hoyle, D. (2015). Guardianship and the potential of supported decision making with individuals with disabilities. *Research and Practice for Persons with Severe Disabilities*, 40(1), 36-51. DOI: 10.1177/1540796915586189
- Kleist, B. A., Hewitt, A. S., & O'Neil, S. N. (2019). *Rights, choices, and supported decision making*. In Hewitt & Nye-Lengerman (Ed.) *A Community Life: Community Living and Participation for Individuals with Intellectual and Developmental Disabilities* (pp. 141-168). Washington, DC: Association of Intellectual and Developmental Disabilities.
- Kohn, N. Blumenthal, J., & Campbell, A. (2012). *Supported Decision-Making: A Viable Alternative to Guardianship?* Penn State Law Review 117:4.[http://www.penn-statelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20\(final\)%20\(rev2\).pdf](http://www.penn-statelawreview.org/117/4%20Final/4-Kohn%20et%20al.%20(final)%20(rev2).pdf)
- National Conference of Commissioners on Uniform State Laws, (2007). Uniform Guardianship and Protective Proceedings Act. Retrieved from [http://www.uniformlaws.org/shared/docs/adult\\_guardianship/UAGPPJA\\_2011\\_Final%20Act\\_2015feb4.pdf](http://www.uniformlaws.org/shared/docs/adult_guardianship/UAGPPJA_2011_Final%20Act_2015feb4.pdf)
- National Guardianship Association (2016). *Position Statement on Guardianship, Surrogate Decision Making and Supported Decision Making*. Bellefonte, PA. Retrieved from [http://guardianship.org/documents/NGA\\_Policy\\_Statement\\_052016.pdf](http://guardianship.org/documents/NGA_Policy_Statement_052016.pdf)
- Shogren, K.A., Wehmeyer, M.L., Martinis, J., & Blanck, P. (2019). *Supported decision-making theory, research, and practice to enhance self-determination and quality of life*. Cambridge, UK: Cambridge University Press.
- Smull, M, (2013). *Thinking About Risk*. Retrieved from <http://allenshear.com/wp-content/uploads/2016/10/risk-final.pdf>
- Tichá, R., Qian, X., Stancliffe, R.J., Larson, S., & Bonardi, A. (2018). Alignment between the Convention on the Rights of Persons with Disabilities and the National Core Indicators. *Journal of Policy and Practice in Intellectual Disabilities*, 15(3), 247-255.
- United Nations. (nd). *Convention on the Rights of Persons with Disabilities (CRPD)*, Division for Social Policy and Development. CRPD HomePage. Geneva, Switzerland. Retrieved from: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- Uekert, B.K., & Van Duizend, R. (2011). Adult Guardianships: A "Best Guess" National Estimate and the Momentum for Reform. In *Future Trends in State Courts*. Williamsburg, VA: National Center for State Courts. Retrieved from: [http://www.eldersandcourts.org/Guardianship/GuardianshipBasics/~/\\_media/Microsites/Files/cec/AdultGuardianships.ashx](http://www.eldersandcourts.org/Guardianship/GuardianshipBasics/~/_media/Microsites/Files/cec/AdultGuardianships.ashx)



# EMPLOYMENT

## CHAPTER 12

# Employment Opportunities in the Community

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### Guiding questions

- How do we assure that every human being has an opportunity to engage in a working life?
- What are the approaches and strategies to providing every human being with the opportunities for competitive integrated employment?

## Introduction: A working life

Why work? Consider the far-reaching impacts and possibilities of a working life! When a working-age youth or adult with a disability engages in competitive integrated employment, it drives and impacts his or her daily life routines, structures, and productivity. A competitive job in the community not only increases one's social inclusion and interactions with non-disabled adults, but provides earned wages, benefits, and discretionary income. Therefore, gainful employment increases other life choices about safe and affordable housing, recreational and leisure activities, and accessibility to other community involvements.

Competitive integrated employment means contributing one's talents and skills in a job that pays minimum or equitable wages and benefits, on the payroll of a business, and where the employee with a disability has regular social interaction with the company's co-workers, supervisors, and customers who do *not* have disabilities. We are not just talking about a job; we're talking about a life! Competitive integrated employment is a fundamental driver to individual contribution and productivity, lifestyle choices and self-determination, economic self-sufficiency, and emotional well-being.

In most cultures, working-age adults are not only encouraged, but expected to use their interests, skills, and experiences to earn a living. A competitive job not only improves quality of life through economic means, but also offers adults opportunities to contribute their talents and skills in support of the community and workforce where one lives. A job, therefore, not only contributes to goals of economic self-sufficiency and independence, but also contributes richly to one's self-esteem, self-confidence, social relationships, and overall emotional well-being (Nord, Timmons, & Lavin, 2015; Rogers, Lavin, Tran, Gantenbein & Sharpe, 2008; Griffin and Beamer, 2017).

While working in the community's workforce is a common expectation in most cultures, youth and adults who live with significant disabilities are often overlooked, even marginalized, concerning their perceived capacities to contribute. This is particularly true for youth and adults with intellectual and development disabilities (IDD). Despite enactment of progressive public laws and social policies (e.g., Americans with Disabilities Act - ADA), adults with disabilities tend to lag far behind their non-disabled peers in virtually all quality of life indicators. Of course, this includes participation in competitive integrated employment. To illustrate this point, national studies in the United States reveal that only a small minority of adults with significant disabilities work in the competitive labor force despite contemporary research documenting their ability to do so in the right job, and with access to the right measure of supports they need to succeed (Lengnick-Hall, Gaunt, & Kulkarni, 2015; Riesen, Morgan & Griffin, 2015; WINTAC & Y-TAC, 2017).

Recent public policy initiatives encourage more people with disabilities and their families to consider competitive integrated employment as the first and preferred option of publicly funded services. The underlying objective is to increase public support and funding of job seekers with disabilities to pursue and obtain competitive jobs through "Employment First" policy initiatives and services. "Employment First" means encouraging working-age youth and adults to: (1) consider the benefits and full range of possibilities in pursuing a working life, and (2) to choose evidence-based services and best practices that better support job seekers with disabilities and interested employers to make competitive employment both attainable and sustainable. Employment First policies recognize that pursuing gainful, equitable employment is an individual choice, but many people that choose to work still do not have adequate access to the assistance they need

to achieve their goal in attaining a working life. Employment First policies offer policy guidance so that no interested job seeker is denied the opportunity to pursue competitive employment because of his or her disability, no matter how severe or limiting.

## Navigating the workforce/ employment landscape

How much assistance will be needed by a job seeker with a disability? And who is available and has the essential knowledge and competencies to deliver the assistance that is needed?

Multiple employment development strategies and approaches can be used to support job seekers with disabilities in obtaining competitive integrated employment (with and without support). To illustrate, some job seekers with disabilities will require minimal or no assistance to interview and secure jobs that are well-aligned with their education, training, and work experience. However, some job seekers will benefit greatly from more active intervention with business leaders to engage helpful job supports (e.g., time-limited job coaching) or other accommodations that may be needed to ensure successful, on-the-job performance. Still others with more complex, significant disabilities may need intensive levels of assistance, and possibly, a formal negotiation, restructuring, or customization of job duties to better match the abilities of a job seeker. Finally, a small number of job seekers may choose to pursue entrepreneurial initiatives such as self-employment to create businesses that align best with their unique job interests, talents, and employment support needs.

In sum, there are many ways to earn a living and contribute one's strengths and talents within a community's workforce. For this reason, job seekers with disabilities, and those who love and support them (i.e. family members, educators, disability and employment

service professionals), must work together to support each job seeker in choosing a goal and plan of action that fits best with his or her job search needs and service availability.

While employment development approaches do vary and methods can be described in many ways, there are primarily three universal categories of job support. These include the following: (1) Pre-Employment Planning, (2) Employment Development, and (3) Post-Employment Support. Each service category is described briefly below:

### Pre-employment planning

This includes a wide range of activities, such as job or career exploration (i.e., use of job shadowing, business tours, person-centered discovery and assessment, researching job or career information, vocational counseling or career planning, etc.). Pre-employment planning can feature both a formal or informal assessment process. It is a process designed to guide the choosing of an individual job goal, or perhaps, the narrowing of employment interests or themes expressed by a job seeker. Pre-employment planning activities should explore a full range of possibilities, including examination of job availability, gaining a stronger understanding of a job seeker's preferred or ideal conditions of employment, identifying the types of job assistance (if needed), and establishing an individualized, written plan of action.

### Employment development

Employment development means contacting business leaders to discuss and negotiate opportunities for competitive integrated employment. This may include a wide range of activities such as:

- Responding to a specific employer job postings or advertisements
- Prospecting a local workforce for present or future employment opportunities

- Setting up targeted job interviews with employers in support of job seekers
- Arranging “informational interviews” to explore a range of employment possibilities for “customizing”
- Gaining an understanding of a company’s core values and workforce culture to determine its suitability to supporting an employee with a disability
- Discussing identified need(s) for job accommodations with business leaders
- Identifying opportunities for leveraging internal job training and natural supports at the company as well as external supports that may be needed (e.g., job coaching)
- Negotiating specific conditions of employment to enhance a job seeker’s safety, on-the-job performance, and related support needs

Note: Employment development could also include developing a business plan to support a small minority of job seekers choosing entrepreneurial pathways to competitive employment.

### Post-employment services

This includes a wide range of short-term, and possibly, long-term (ongoing) job support activities. For example, this might include: conducting co-worker/ supervisor training about disability conditions, assisting with new employee orientation, executing negotiated job or workplace accommodations, assisting with temporary on-the-job training or job coaching of a new employee, gradually “fading” on-the-job training/supports to a company’s supervisors/ owners, monitoring and responding to ongoing job assistance needs, and planning job retention and development services (e.g., supported employment) to ensure future job satisfaction, responsive problem-solving interventions, individual employee growth, and access to disability advocacy.

## Making the business case

A common argument made about why people with disabilities are unemployed in such high numbers is that employers tend to hold stereotypes and negative attitudes about hiring people with disabilities. This is not only an invalid argument, but is contrary to basic foundations of sound business practice. Employers want to hire job candidates with abilities, not disabilities. Private businesses and industries are not charities even when they are favorably disposed to charitable or civic interests. Most employers will be interested in learning about how a job seeker (with or without a disability) will help their company make money and how they can contribute to supporting real business interests and concerns. Are we up to this task of enlightening them?

Research studies with business leaders who are experienced in hiring job seekers with disabilities reveal that they are among the strongest champions in the employment of people with disabilities (LEAD, 2016; Siperstein, Romano, Mohler & Parker, 2006; Graffam, Smith, Shinkfield, & Polzin, 2002).

These employers report:

- Helpful access to talent recruitment, job customization, assistance with job training, and ongoing employment supports for their employee
- Positive impacts on productivity and profitability
- Positive impacts on workforce morale
- Increased workforce innovations and universal design (making their company and workplace more accessible to everyone)
- Increased employee job tenure and less expensive job turnover
- No concerns about job safety in comparison with other employees (without disabilities)
- Creating new business markets (customers) associated with hiring of people with dis-

abilities (i.e., people with disabilities, family members/relatives, disability advocates, and the general public).



## CASE STUDY

Ryan Richardson is a young adult who is diagnosed with Autism Spectrum Disorder (ASD). As a youth with significant disabilities, Ryan struggled to achieve academically during his elementary and secondary education years. In addition to academic challenges, he also struggled with social relationships and even bullying by his peers. Ryan was tormented by other youth with “name calling” and never truly “fit in” socially with other students in his classes.

Following high school graduation, Ryan was referred to and subsequently enrolled in a local community rehabilitation program designed to support individuals diagnosed with significant disabilities, particularly adults with intellectual and developmental disabilities. This non-profit agency specialized in a “sheltered employment” program in addition to offering other “center-based” services. The agency’s programs were predominantly characterized by segregation, limited job and life experiences, and long-term rehabilitation services. Ryan strongly objected to being supported in this sheltered workshop, and instead requested job assistance that better fit his interests and skills. Due to low expectations about his work and social skills, however, he was denied the opportunity to enroll in job placement services.

Ryan’s ongoing discouragement and strong dislike for being at a sheltered workshop led to his decision to quit and leave the agency’s services. For many months, Ryan languished at home. His time was characterized by despair, social isolation, and boredom according to Lori Richardson, Ryan’s Mom. Lori was growing increasingly concerned about Ryan’s overall well-being and his future. Yet she unwillingly coerced him into choosing a day service program

that shamed and discouraged him. The Richardson’s lived in a rural area, and therefore, did not have an abundance of service alternatives and resources to access. Through it all, Lori remained positive about exploring all possibilities so she could connect her son with the types of services and supports he needed to realize his life goals.

In 2014, Lori learned about an educational workshop entitled “Work is Possible” that was being offered to encourage family members and their loved ones with disabilities to consider pursuing a working life. The workshop, coordinated through a parent advocacy program, was designed to introduce emerging policies and best practices known to increase job placement opportunities in support of job seekers with disabilities, including those with significant disabilities. Lori decided to attend.

She was excited by what she was hearing but wondered aloud how Ryan could access such service innovations, particularly since the Richardson’s lived in a semi-rural area with such limited services. Lori engaged the workshop presenters about Ryan’s dilemma and was surprised by their response. She was encouraged to take control and consider the possibilities of achieving a fuller, integrated life by engaging a person-centered approach. Ryan was newly enrolled in case management strategy that encouraged self-direction and controlling the use of public funding in ways that would lead to person-centered goals and services.

With guidance, Lori and Ryan chose to hire an “employment consultant” trained in the delivery of a person-centered planning strategy called “Discovery.” During this period of Discovery, the employment consultant used a mix of observations, interviews with family members and people who know Ryan best, and additional tools/strategies to learn more about Ryan’s strengths. This included information about his unique interests, skills, talents, support needs,



and conditions where Ryan is at his best and able to showcase his strengths. The Discovery Process used resulted in an individual profile with robust information about Ryan. Further, this profile was used to consider a full range of possibilities for pursuing competitive integrated employment.

One of the predominant themes “mined” during Ryan’s Discovery process was his clear passion, almost obsession for airplanes and aeronautics. This theme, however, seemed like an unlikely pathway to employment given the rural area where the Richardson’s lived. How could Ryan’s knowledge and passion for airplanes result in a viable job?



Ryan’s unusual curiosity about airplanes and airports was evident by his surfing of Internet websites related to aeronautics. And it was Ryan’s Internet activities that led to information about a job fair being held by Sun Country Airlines at the Minneapolis/St. Paul airport. Ryan and his employment consultant decided to go to this job fair to learn more about job opportunities at the airline and to fully explore his own possibilities with the company’s representatives. Sun Country’s was immediately impressed by Ryan’s passion and knowledge. In fact, they were so impressed he was offered

an opportunity to work for Sun Country Airlines right on the spot!

Ryan’s job offer meant he would join a team of employees working to prep airplanes scheduled for departure at the airport. A long commute to and from work was necessary; however, Lori and Ryan worked out a plan that would enable him to realize a lifelong dream. He was now a proud employee of Sun Country Airlines earning competitive wages and benefits. And he was now working alongside co-workers who had similar job interests and skills. He was so excited to be an included member of the team working to clean, stock, and ready the planes for departure to destinations around the world.



By introducing a new foundation of high expectations, persistence, and innovative practices, Ryan had successfully navigated an improbable journey from the basement of his home to a competitive, strengths-based job. Lori was thrilled and shared how Ryan was a changed individual in every way possible. His self-esteem, self-confidence, and quality of life were dramatically improved by what could only be described as his “dream job.”

For three years, Ryan worked successfully at Sun Country Airlines until the unimaginable happened. Sun Country Airlines was sold to a new owner! And this change in ownership at the airline company resulted in a disbanding of

his department and outsourcing of duties once held by Ryan and his co-workers. Now what?

Life happens. After disappointment and discouragement, Lori and Ryan worked together to pick up the pieces. Ryan updated his resume and began exploring job possibilities with other airline companies. He was contacted by Ground Airline Transportation (GAT) regarding his interest in arranging a job interview. GAT is based in Atlanta, Georgia, but provides contracted services for Alaska Airlines at the Minneapolis/St. Paul Airport. As before with Sun Country, GAT's airline representatives were highly impressed by Ryan's knowledge and passion about the airline industry. Within 10 minutes, GAT had offered Ryan an opportunity to join the airline company. However, this time as a Ticket Agent!! Now Ryan would be working directly in customer service, and the job would include a major shift in job duties and responsibility.

As a condition of hire, Ryan was required to participate in a formal staff development training program and pass a test designed for Ticket Agents in Seattle, Washington. Acknowledging that Ryan had special learning needs, GAT arranged for tutoring assistance to support him with his learning challenges and passing a mandatory test. The team of Ticket Agent trainees who were sent to Seattle for training were also highly supportive of Ryan. In fact, several of them indicated—"We're not leaving until Ryan also passes the employment test." With persistence and accommodations, Ryan finally passed the test!

Ryan has been working for GAT and Alaska Airlines for one and half years now as a Ticket Agent. He earns competitive wages and comparable benefits with other Ticket Agents employed by GAT. Recently, Lori and Ryan moved their home residence to a location more accessible to the Minneapolis/St. Paul Airport, so he has a much shorter commute time. Ryan's co-workers are highly supportive and contribute to his job accommodations especially with tasks where writing skills are essential. Ryan

and his co-workers are a functional team and complete a wide array of tasks in ways that support customer service excellence.



Sometimes when one door closes, another door opens. Ryan's ongoing journey has resulted in securing a new job that pays more money and features customer service in an industry well-suited to his passion. This successful employment outcome was unexpected and unforeseen by many for an adult who continues to live with significant barriers related to his disability.

Was Ryan's hire a charitable act by his employer? Not a chance! In fact, his supervisor said recently she would like to "clone" Ryan—meaning he's a model employee who is highly reliable and exceeding job performance expectations.





## Tips & Strategies

- You may find the following ideas helpful to encouraging, planning, and advancing competitive integrated employment outcomes:
  - The earlier the better!--Begin thinking about and encouraging competitive integrated employment with youth at the earliest age possible. For parents/educators—set job expectations early by assigning tasks and responsibilities to youth so they learn helpful responsibilities and skills.
  - Reward performance and encourage new tasks and skills.
  - See ABILITY not disability. See opportunities not barriers.
  - Pay attention to unique interests and talents. Encourage youth and adults to use their innate interests and strengths.
  - Advocate for Employment First policies to encourage competitive integrated employment as the first, preferred outcome of secondary education and adult services.
  - Infuse person-centered thinking and strategies to encourage possible pathways to competitive integrated employment.
  - Consider how best practices and emerging technologies can increase independence and enhance on-the-job performance.

- For NGO's—Retrain disability support professionals with workforce and employment development competencies to ensure availability of best practices and strategies.
- For NGO's—Rethink “brand.” Transform organizations so they are brokers of talent vs. caretakers of people with disabilities.
- Engage business leaders as strategic partners and champions of employment—active partners in providing job training and skills development, work experience programs, and customized/supported employment.
- Engage educators and adult service providers in a shared vision and partnership to increase opportunities in the competitive workforce.
- Communicate employment success stories with all stakeholders (i.e., people with disabilities, family members, educators, NGO's, employers, others) to shift old paradigms to a new way of thinking—“People with disabilities can be economic assets and a working life is possible.”

## Resource

- [National Center on Leadership for the Employment and Economic Advancement of People with Disabilities \(LEAD\)](#)

## References

- Graffam, J., Smith, K., Shinkfield, A., & Polzin, U. (2002). Employer benefits and costs of employing a person with disability. *Journal of Vocational Rehabilitation, 17*, 251–263.
- Griffin, C. & Beamer, S. (Eds.) (2017). *Customized Employment: Stories and Lessons from the Field*. Florence, MT: Griffin-Hammis Associates.
- Lengnick-Hall, M.L., Gaunt, P.M., & Kulkarni, M. (2008). Overlooked and underutilized: People with disabilities are an untapped human resource. *Human Resource Manager, 47*, 255–273.
- Nord, D., Timmons, J., & Lavin, D. (2015). Building economic opportunity through community development. *Journal of Vocational Rehabilitation, 42*, 241-245.
- Riesen, T., Morgan, R.L., & Griffin, C. (2015). Customized Employment: A Review of the Literature. *Journal of Vocational Rehabilitation, 43*, 183-193.
- Rogers, C., Lavin, D., Tran, T., Gantenbein, A., & Sharpe, M. (2008). Customized employment: Changing what it means to be qualified in the workforce for transition-aged youth and young adults. *Journal of Vocational Rehabilitation, 28*, 191-207.
- Siperstein, G.N., Romano, N., Mohler, A., & Parker, R. (2006). A national survey of consumer attitudes towards companies that hire people with disabilities. *Journal of Vocational Rehabilitation, 24*, 3–9.
- The Workforce Innovation Technical Assistance Center (WINTAC) and the Youth Technical, Assistance Center (Y-TAC) (2017, June). *The Essential Elements of Customized Employment for Universal Application*. Retrieved from <http://www.leadcenter.org/resources/tool-manual/essential-elements-customized-employment-universal-application>
- The National Center on Leadership for the Employment and Economic Advancement of People with Disabilities (LEAD) (2016, January). *Information Brief—Perspective of Employers on Customized Employment*. Retrieved from [http://www.leadcenter.org/system/files/resource/downloadable\\_version/CE\\_Info\\_Brief\\_Employer\\_Perspective\\_0.pdf](http://www.leadcenter.org/system/files/resource/downloadable_version/CE_Info_Brief_Employer_Perspective_0.pdf)



## CHAPTER 13

# Employment of People with Disability in the Russian Federation

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## Daily life and opportunities of the average client of Life Route Foundation programs

What does the week of an average young person, participating in the Life Route Foundation programs consists of? Twice a week – attending a specialized vocational college, once a week - equine therapy, once a week - individual classes with an artist, and once a week - a daytime program or a workshop.

Every week is pre-planned with a busy, comprehensive schedule. However, this is not a work or a study course “like everyone else has”. Finding a daily workload of any kind, more so a regular job in Moscow is very difficult and almost impossible. Therefore, parents are forced to visit several organizations and employ private tutors.

After graduating from a vocational college, only 10% of youth find employment in specialized shops, and about 3% enter employment available in the labor market. Moscow is a huge metropolis with long distances, high rental costs and numerous labor migrants, who consent to employment in simple low-paying jobs without social benefits (people with disabilities could apply for such jobs, but in some people’s opinion labor migrants can handle this type of work better and present fewer challenges).

There are several specialized shops in Moscow (e.g., “Special Ceramics”, “Artel of the Blessed”, “Naive? Very”, “Trunk”, “KTO”) that make recognizable and popular products. However, these shops employ a limited number of people, usually adults with less pronounced behavioral problems, since the productivity of such shops needs to be high enough to assure self-sufficiency. There are not many people in the shops, who require help for the duration of their working hours. They are hired only with a personal aid.

## Creating a path toward work for clients of Life Route Foundation with a project called Training Apartment

Having discovered that most of the adults with disabilities, who came to the Training Apartment project by the Life Route Foundation were not sufficiently employed, we created our own culinary workshop. The Church of St. John of Kronstadt, located within a walking distance from the training apartments, and its superior, Father Alexander, lets us conduct a workshop at the church. Currently, the workshop is held twice a week for three hours. Eight to 10 adults with disabilities can work there at the same time. There are plans to expand the workday hours.

The workshop creators came up with the workshop idea that all the people at the training apartments, even the “difficult” ones, will be able to master some part of the process of making pelmeni and vareniki. While observing the trainees and the process, the teachers came to the following conclusions:

1. Adults with disabilities are not able to work for three hours without a break for lunch. Some of the workers are busy preparing food “for now,” not for future sales. A shared lunch unifies and motivates everyone to work.
2. Aids are required at a 1:1 ratio. This makes it possible to accept people with complex behavior needs in the project. It is especially difficult and essential for such individuals to find suitable activities. Participants supported by aids improve the quality of work and create truly excellent, competitive products. Aids also help individuals with disabilities to organize themselves when they work together in a small workshop room.
3. It is important to factor in the capabilities of all the workshop participants and invent new recipes and final products based on

the interests and abilities of each of the young people. Therefore, with time, it was not enough to just make pelmeni. By the summer, the workshop also started making homemade marmalade, apple pies, jams, and meringues. Participants mastered a lot of recipes for everyday meals. Sports warm-ups were added during the breaks.

4. For all participants of the culinary workshop, the motive is not the work or the money-making, but the communication with the people and participating in the workshop.

## Future goals

The plan for the next academic year is to divide the participants into two groups. Prospective successful workers are to be included in the labor market: cafes, bakeries (at this time we are looking for places in the community run by friends). The workshop can become a place of training. At first, mentors will accompany the graduates of the workshop to work. The group of participants with more pronounced challenges will remain engaged in the workshop. The goal is to gradually shift their motive from being engaged in communication to work. It may be necessary to also start new programs for communication purposes only to help young people with both needs but divide these groups into “going to work” and “meeting for joy”.





## CHAPTER 14

# Introduction to Customized and Supported Employment

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### Guiding questions

- What are essential characteristics of customized and supported employment?
- What processes guide customized and supported employment?

## Reasons for customized and supported employment for people with disabilities

- Center-based programs operated by non-governmental organizations (NGO's or non-profit agencies) often to lead to long-term segregation and dependency of adults with significant disabilities. Research documents only a small fraction of those supported in center-based programs (approximately 20%) will obtain person-centered, competitive integrated employment.
- Traditional job development approaches are ineffective for many job seekers with significant disabilities and rarely lead to competitive integrated employment results. This is especially true for those with the most complex disabilities.
- *Qualified vs. Quality Job Seekers*—In legacy practices of job development: qualified job candidates are matched to the requirements and conditions of a competitive employment position (formal job descriptions). In practices of customized and supported employment, competitive employment positions are often customized and negotiated to fit the unique, known strengths of quality job candidates.
- Customized and supported employment feature tools and best practices to increase competitive integrated employment outcomes—one job seeker, one employer at a time. These tools and strategies offer innovative ways to create competitive integrated employment as well as essential supports for job seeker,s who are traditionally underserved and underrepresented in the competitive labor force.

## Customized employment tools and strategies

*Customized Employment* is “a flexible process designed to personalize the employment relationship between a job candidate and an employer in the way that meets the needs of both.” (ODEP & USDOL, 2002)

Customized employment can be used to assist and benefit job seekers with complex disabilities who have been traditionally underserved in the competitive workforce. The individual employee's unique interests, skills, and preferred conditions of employment are identified through an assessment called “Discovery.” This information gained through Discovery is organized, analyzed, and presented in an individual job seeker profile. The profile is then used to: (1) plan individual employment opportunities, and (2) map and negotiate employment possibilities (positions), job supports, and workplace conditions with interested employers (Marc Gold & Associates, 2014a,b; Hall, Keeton, Cassidy, Lovannone, & Griffin, 2018).

Customized employment, therefore, is a voluntary, flexible, non-comparative, and interest-driven employment negotiation between an individual job seeker and an employer. It is a person-centered, strengths-based strategy designed to negotiate competitive jobs in ways that fit the known abilities and potential contributions of a job seeker. In summary, customized employment is a formal process designed to plan and negotiate real jobs at competitive wages and benefits one job seeker, one employer at a time.

Customized employment fosters new ways of thinking about the employability of individuals who are highly underserved in the competitive workforce and unlikely to benefit from traditional or legacy models of job development (e.g., where job seekers compete for established employment positions with formal job requirements and qualifications). A few commonly used strategies for planning, nego-

tiating, and customizing jobs includes but are not limited to the following:

- **Job carving**—this strategy means the carving of tasks or restructuring of job duties from existing employment positions to fit the skills and abilities of a job seeker.
- **Job creation**—this strategy means suggesting new tasks, duties, or jobs that directly contribute in meaningful ways to existing work processes (or perhaps a new work process) of a company's business operations and bottom line.
- **Self-employment**—this means supporting a job seeker with unique interests, strengths, and skills to launch an entrepreneurial business plan that will result in economic opportunities through self-employment.
- **Business within a business**—this strategy includes entrepreneurial innovations such as introducing a self-contained microenterprise within an already established business. A business with a business contributes meaningfully to an existing company's business operations or enhances its customer services (e.g., introducing a coffee kiosk enterprise inside an existing bakery) (Griffin & Beamer, 2017).

## Supported employment services

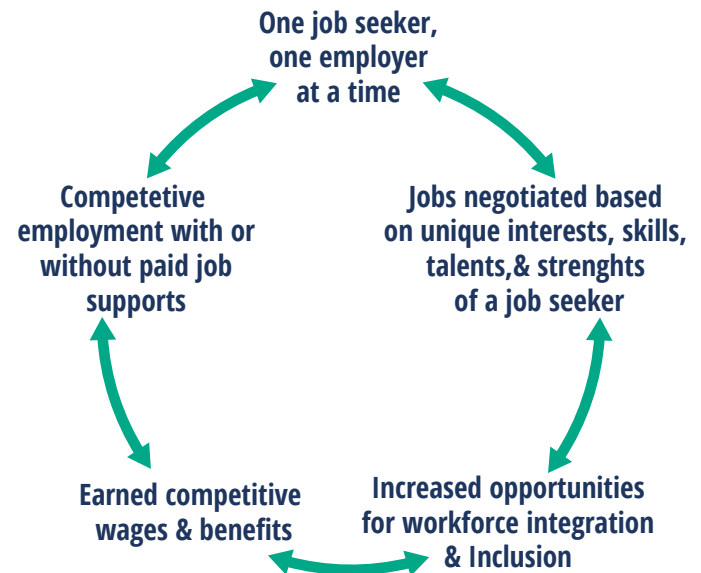
Supported Employment means..."competitive integrated employment, including customized employment or employment in an integrated setting, in which an individual with the most significant disability, including a youth with a most significant disability, works at competitive wages and benefits...consistent with the unique strengths, abilities, interests, and informed choice of the individual. Supported Employment means having access to ongoing job supports for individuals with the most significant disabilities." (OSERS/RSA, 2016; USDOL, 2016).

Stated simply, supported employment embeds the innovative practices of customized

employment, but also features access to short-term and long-term (ongoing) job supports that may be needed by some employees with complex disabilities and their employers.

The diagram below provides a visual illustration of shared principles of customized and supported employment.

### Shared principles of customized and supported employment



## Navigating the community workforce/employer landscape using customized employment

Since customized employment involves a voluntary and non-comparative approach to finding and negotiating jobs in support of job seekers with the most significant disabilities, this employment development strategy does not typically respond to local labor markets in conventional ways. In other words, the job seeker is not likely to be competing in a pool of job candidates for employment vacancies in traditional ways.

Once an intensive, formal assessment process called Discovery is completed on behalf of a job seeker, the goal is to create a composite profile that identifies employment “themes” as well as possible pathways to competitive integrated employment. The consideration of employment themes helps to explore a full range of opportunities and potential contributions by a job seeker. The process, therefore, is guided by an individual employment profile that showcases unique interests, strengths, talents, and skills, as well as other helpful information (e.g., times of the day and places where the job seeker is at his or her best). Also, the profile may suggest specific tasks or contributions consistent with an identified employment theme (e.g., washing cars in an automotive theme). The identified employment themes give each job seeker, and those supporting him or her, a helpful framework for targeting specific businesses in the local workforce that either need or may benefit from a job seeker’s potential work contributions.

Think about it—“What types of businesses in your community’s workforce can benefit from a job seeker’s potential contributions?” It is helpful to create a written list of these businesses as well as possible contacts we know to navigate or steer the job search.

Trained practitioners of customized employment do not set out immediately to schedule job interviews. Instead, they identify a robust list of businesses that are well-aligned with a job seeker’s identified employment theme(s). Then, “informational interviews” are commonly scheduled to explore opportunities with business leaders. Informational interviews with a targeted job seeker can lead to real possibilities for proposing and negotiating a customized job. In addition, they can lead to unforeseen directions guided by our business contacts (e.g., “*Who else should we talking to about this job seeker’s employment interests?*”)

As customized employment is a voluntary process, it is an arrangement built on trust and

relationships. The list of businesses, as well as their representatives to contact, often flows from our “social capital” or the many connections we or others may have with people who own, work, or have decision-making authority at a targeted company.

Once we engage an interested employer, a customized employment position can be formally proposed and/or negotiated. This means advancing formal agreements about position descriptions such customizing assigned tasks or duties, competitive wages and benefits, internal job supports, and other employment conditions (e.g., supported employment services) to a written form. Creating access to Supported Employment (ongoing job follow-up and support) offers a formal strategy for regular review, changes, and updating of agreements. In addition, formalizing access to Supported Employment encourages discussions about future job growth (e.g., adding job duties) as well as planning job progression (i.e., learning new skills, adding more work hours, earning more money) over time.

### CASE STUDY 1

Jessica Knoepfler is a 30-year-old female diagnosed with an intellectual disability and attention deficit/hyperactivity disorder (ADHD). As a child, Jessica’s family reports she was very introverted. She was uncomfortable in most social situations and went out of her way to avoid talking to people. It was only when Jessica persuaded her parents to buy and bring home their first dog, Abby, did her parents notice a change in their daughter. “Abby really brought Jessica out of her shell,” said Jessica’s father, Joel. “Soon everything was about dogs - Jessica spent much of her time with Abby, she did research on breeds and even presented a periodic chart of dogs to her classmates - something very out of character for Jess.”

By the 9th grade, Jessica was already sure she wanted a career working with dogs. For this reason, Jessica's individualized education plan (IEP) included career exploration activities to examine potential pathways in working with dogs. As a part of her transition from high school, Jessica and her family analyzed opportunities for employment as well as enrollment in post-secondary education programs. Initially, Jessica was provided with job placement assistance and secured a job with a large dog grooming franchise. The company offered their new employees dog groomer training with a goal of providing full-time employment once they completed the training.

Jessica has a history of struggles with short-term memory. Also, she requires repetition with new concepts to store information in her long-term memory. For these reasons, access to customized and supported employment was considered important to obtaining and maintaining a successful employment outcome. The company that hired Jessica observed high productivity standards by requiring their dog groomers to service a minimum of eight dogs per day. Jessica found it challenging to keep up and manage this heavy workload. In addition, the company's management was not receptive to partnering with Jessica's employment consultant to examine how possible job accommodations might increase her productivity. Sadly, Jessica was terminated at the end of her 90-day probationary period.

After losing this job, Jessica was assisted in finding a job with a second dog grooming corporation in the area. Jessica worked at this second franchise company for almost three years, but they limited her job role to only bathing dogs. To Jessica, this was disappointing, as she loves grooming the animals. To complicate matters, the company's management had experienced considerable turnover, disrupting plans for Jessica's internal supervision and support. In

time, Jessica left a second job developed on her behalf.

After losing two consecutive jobs, many in Jessica's circle of support began to question whether dog grooming was the right career for her. The truth was, Jessica was always capable of doing a great job - she just needed more time and customized support to learn.

Jessica did not give up on her career goal. She and her support team agreed the next best step was to enroll in independent dog grooming school to certify her knowledge and skills. Jessica received tutoring assistance from her employment consultant to better support her learning needs. Also, her job development plan was amended in consideration of workplace factors believed to be critical to her future success. Jessica's best chance to showcase her talents and strengths was believed to be within a smaller, neighborhood-oriented business.

After completing training and obtaining certification, Jessica was interviewed and hired by the owner of "Just Paws," a dog grooming salon in a small neighborhood strip mall in Minneapolis!

"Working for Brenda at Just Paws was the turning point for Jess," said Jessica's mother, Janet. "Brenda was a patient shop owner who was willing to mentor Jess. She had excellent suggestions about job accommodations to help Jess through her learning period. For example, a whiteboard was used to write out instructions for her daily cuts. In addition, the salon's shampoos and chemicals were now stored in color-coded containers with measured markings so Jess could perform her duties as independently as possible."

Jessica was now a productive, engaged employee. She had finally found a company where she could showcase her passion and skills. The casual atmosphere of the salon provided the right environment to support Jessica's learning and growth. And under Brenda's mentor-

ing and supervision, Jessica was making new strides in her career development.

Two years after Jessica was hired, however, a co-worker purchased the salon from Brenda. This change was unfortunate because it wasn't long after the purchase the new owner stopped showing up to work, started missing appointments, and barely communicated with the salon's staff. It was a time of big challenges and uncertainty. Jessica was encouraged by her employment consultant and family to continue doing her job as best she could.

Out of necessity, Jessica began to take on responsibility for the everyday running of the business. Along with grooming several dogs per day, Jessica began making the appointments, keeping up the shop, ordering supplies, and cleaning. While the situation was incredibly stressful, it was during this time that Jessica began to really shine. She always had a sense of responsibility and a great work ethic, but the emerging chaos forced Jessica to grow in order to save the business.

In May of 2015, Jessica's parents, Joel and Janet Knoepfler, bought and became the official owners of Just Paws. "Jess had proven herself as responsible and committed, and we wanted to provide an opportunity for our daughter to continue to thrive." Jessica, with support from her parents, hired a second groomer to help at the salon. "If Jessica's teachers could see her today, they wouldn't believe it was her," says Janet. "She has come so far!"

Jessica's parents helped by managing the financial books for Just Paws. However, Jessica took on day-to-day responsibility of running the new family-owned enterprise with intermittent assistance (supported employment) from her employment consultant. The employment consultant often serves an intermediary between Jessica and her family to ensure all aspects of the business were being managed successfully. The employment consultant also provided encouragement to nurture her self-confidence.

All things considered, success for Jessica was about finding the right business and level of support she needed to succeed.

However, Jessica's story continues to evolve in new and exciting ways. Five years ago, she met Diego Vega at a dinner party. He was seated across from her at the table where they spent the evening discussing travels to Cabo San Lucas. Their engaging conversation turned into a scheduled date and within months Jessica was in love. In December of 2016, Diego proposed to Jessica at her home on Christmas Eve.

Jessica had experienced a significant period of career and social growth the year she had to step up and take on the role of owner at the grooming salon where she works. She was required to interact with customers in ways that made her uncomfortable, but she did so to save the business. Those who love and know Jessica best continue to marvel about how she became more skilled by interacting with others and attempting new skills on the job.

Jessica was thrilled to become engaged, and she knew this commitment meant the time had come to share some very personal information with Diego. This really made her nervous. "I still remember the day I decided to tell Diego about my disability. I sat him down on the couch and cried as I tried to find the words to tell him. I was so worried of what he'd think of me." She wanted to be sure Diego understood her specific challenges and how it affects her everyday life.

Diego admits today that he already knew of Jessica's disabilities when she sat him down. "Jessica is such a loving, honest and genuine person and that is why I am in love with her," he explained. "These great qualities say more about her than a disability ever will."

On October 6, 2017, loved ones gathered to witness the wedding. That evening, Jessica calmly and confidently approached Diego at the altar. “The night of the wedding was extremely gratifying for me as her father,” said Joel. “To see her shine like that and to be so controlled while in the spotlight...” His voice trailed off for a moment. “I can see that all of her hard work is paying off.”

Finding the right job is often about improving quality of life. Just Paws gave Jessica the opportunity to do what she had been dreaming about since the beginning of high school. “When she was given this chance to fulfill her dream,” said Joel, “Jessica’s confidence grew in all facets of her life.”



## CASE STUDY 2

Helen Deverehunt is a 65-year-old woman diagnosed with intellectual and developmental disabilities including a condition of dyslexia. Helen had experienced a long history of involvements with formal disability services in Minnesota throughout her lifetime. For many decades, she lived at home with her family. And she participated in several center-based, community rehabilitation programs. Most of these programs were designed to support adults with significant disabilities in group service arrangements, and generally, they were lacking in a delivery of person-centered services. When new public policies and service opportunities were introduced in Minnesota, Helen decided she wanted to change her life in new ways and self-direct her services and community living goals.

Helen wanted more independence in her life as well as a desire to be more active in her community. With technical support by her legal guardian and county case manager, Helen was able to find and connect with service providers that embrace her vision of a working life. These providers specialize in the delivery of person-centered services that can

lead to competitive integrated employment as well as inclusive community living. Helen and her service team worked together to plan and build life outcomes she always desired. Her core goals included living in an apartment of her very own and finding a part-time job that fit with her interests and skills. As Helen was approaching retirement age, she desired a part-time job offering opportunities for daily structure, social interaction, and discretionary income to support her many leisure and recreational activities.

Helen’s service providers worked collaboratively to plan and build a comprehensive plan of support so she could realize her community living outcomes. The community living provider helped Helen find an affordable apartment where she could live independently with periodic supported living services. She now lives independently and has a few friends within her apartment building apartment that she enjoys spending time with. Helen has several leisure and hobby interests she enjoys such as sewing, knitting, “going out for tea” with her friends, and cheering on her favorite baseball team, the Minnesota Twins.

In addition to living on her own, Helen also wanted to secure a part-time job. Her employment provider used a Discovery Process to help Helen think about her interests, strengths, skills, as well as the types of work environments where she might excel. Helen and her support team agreed she would be best suited by working for a business culture that was open to customizing employment and creating a job that included tasks she is able to perform. The Discovery Process also examined “where” these skills might be needed in the workforce close to the geographic location where she lived.

By happenstance, one of these employers identified was the agency responsible for delivering Helen’s supported living services! The office headquarters for this organization is located only a short commute from her home.



With this knowledge, Helen's employment consultant worked closely with the company's leadership to propose, negotiate, and customize a job that aligned with two of Helen's employment themes--doing office related work and connecting socially with others.

When Helen began working at this private company, she was only looking for a handful of hours. The company identified a few tasks around the office that Helen had the skills to assist with. Job training assistance (e.g., job coaching) was provided to support Helen with learning these new tasks as well as offering tips to the employer for her supervision and support.

Today, Helen sits at the front desk of the company during her shifts. She does a variety of office related tasks such as opening and delivering mail, copying documents, stamping payroll envelopes, and welcoming visitors who arrive at the company. Helen's job title is Office Assistant. She earns competitive wages and she's fully integrated and included with other staff who work at the company's headquarters.



It took only a short period of time for this company's management to notice that Helen had a unique talent for connecting with people and appeared to thrive in social interactions associated with her job. During this time, the company was busy conducting interviews for employment vacancies (e.g., Supported Living Professionals) when it occurred to Helen's supervisor that she might make a helpful addition to the company's interview panel. Helen would bring a service recipient perspective and would essentially be helping the company to hire staff that impact the quality of their supported living services.

"At our company, we have a long-standing vision to ensure the folks we support are as active as possible in designing their own supports," said the company's human resources manager. "Being a long-time service recipient herself, Helen has seen quite a few staff come and go over the years. We thought she'd be a perfect fit for the role." The company presented the idea to Helen who agreed to the opportunity, but she immediately felt tense over the upcoming new experience.

With access to supported employment services, Helen continued to meet with her employment consultant to talk over arising job issues and plan for future job growth. Over the next few weeks, Helen and her employment consultant spent time reading through interview questions and discussing what each one might reveal about a job candidate. Helen spent a lot of time reading the questions to assess which she would choose as hers, because in Helen's words, "It's important that I figure out who is best. I need to pick someone who I would feel comfortable with." Once Helen made her selections, the company reworded the questions so that it came directly from her. Then, she practiced reading these questions aloud so she would feel confident as a panel member for the company's interview team.

Helen has now been a part of many interviews and admits there were a few candidates that didn't feel right. "Helen has a good read on if someone is being genuine or just running through the questions," said her employer. "She has a great sense if they're going to be a good match for delivering supported living services to many vulnerable adults." Helen says that she plans to continue participating in the interviewing because it makes her feel happy to be hiring good people.



## Tips & Strategies

- You may find the following ideas helpful to encouraging, planning, and advancing competitive integrated employment outcomes using customized employment and supported employment policies and practices:
  - Advance an "Employment First" policy so anyone with a disability, including those with the most significant disabilities, are offered real opportunities to work in the community's competitive workforce.
  - Invest time and resources in "person-centered thinking" and "person-centered planning" training with families, educators, NGO's, adult service agencies, and others to change the mindset that only group service models are necessary to deliver assistance to people who live with significant disabilities.
  - Remember, best practices in Customized Employment and Supported Employment are delivered one job seeker, one employer at a time.
  - Consider the value of informational seminars with people with disabilities, family members, guardians, disability advocates, public policymakers, and others to encourage full consideration of risks vs. rewards of a working life.
  - Plan and deliver staff development training in the knowledge and compe-

tencies of Customized and Supported employment so job seekers with the most significant disabilities have real opportunities to use their skills and strengths in creative, innovative ways. (See Chapter 4)

- Consider the value of self-employment and entrepreneurial approaches within the menu of possibilities if appropriate to a job seeker's skills and support needs.
- Transform communications—use “conditions of employment” in place of “job barriers” to advance resolutions that need to be addressed (e.g., job barrier = no transportation vs. condition of employment=job seeker needs car-pooling options).
- Consider multiple ways to partner with business leaders such as participating in business-based: (1) job shadowing and work exploration, (2) on-the-job training programs, (3) informational job interviews, and (4) other “hands on” experiences so employers learn firsthand about the possibilities and business benefits of hiring youth and adults with disabilities.
- Encourage “natural job supports” (business-based supports) so supervisors, co-workers, and others learn skills they will fully need to support employees with disabilities possible.
- Encourage workforce innovations that benefit all employees such as use of

universal design principles, systematic instruction, assistive/adaptive technologies, and workplace modifications that enhance human functionality and on-the-job performance.

- Share employment success stories via multi-media with all stakeholders to build content knowledge and confidence that a working life is possible (i.e., prospective job seekers, family members, service team members, governmental officials, employers, and others).
- Establish helpful alliances and partnerships with business champions to encourage other business leaders to consider the benefits of hiring job seekers with disabilities.

## Resource

- [National Center on Leadership for the Employment and Economic Advancement of People with Disabilities \(LEAD\)](#)

## References

- Griffin, C. & Beamer, S. (Eds.) (2017). *Customized Employment: Stories and Lessons from the Field*. Florence, MT: Griffin-Hammis Associates.
- Hall, S., Keeton, B., Cassidy, P., Lovannone, R., & Griffin, C. (2018, December). *Discovery Fidelity Scale*. Griffin-Hammis Associates, Center for Social Capital.
- Marc Gold & Associates (2014, January). Documenting Discovery: Developing a Descriptive Profile to Guide Employment Plans Pathways to Employment Resource Center (PERC) Curriculum. *Report Brief*. Retrieved from <https://static1.squarespace.com/static/57fa78cd6a496306c83a2ca7/t/5cdad9524a694c78f4604f8/1557846933241/Documenting+Discovery+5-2019.pdf>

- Marc Gold & Associates (2014, January). *Employer Negotiation Strategies in Customized Employment, Report Brief*. Retrieved from <https://static1.squarespace.com/static/57fa78cd6a496306c83a2ca7/t/5cd4ebb2eb39313ebc35e441/1557851059369/Employer+Negotiation+Strategies+for+JD+in+CE+5-2019.pdf>
- Office of Disability Employment Policy & US Department of Labor (2002, June 26). *Definition of Customized Employment*. Federal Register, Vol. 67. No. 123, p. 43154 -43149.
- OSERS/RSA Publication (2016). *Overview and Discussion of Federal Regulations on Supported Employment. Workforce Innovations & Opportunities Act of 2016, Sections 7 (38) of the Act and 363.1 (b) of the Regulations*, U.S. Department of Education, Office of Special Education, Rehabilitation Services Administration, Washington, D.C.
- U.S. Department of Labor (2016). *Supported Employment Definitions and Practices Under the Final Rules of the Workforce Innovations & Opportunities Act, Title IV*, Washington, D.C.



## CHAPTER 15

# The Core Knowledge & Skills of Employment Consultants

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### Guiding questions

- How do job seekers with disabilities access the types of services and supports they need and want to secure competitive integrated employment?
- What are the roles of an Employment Consultant in guiding a job seeker with disabilities through the process of finding and securing a job in the community?

## Introduction

When job seekers begin their relationship with an employment service, they are often coming with a past filled with low expectations and great focus on their disability. Not surprisingly, when the idea of a job is discussed, they are quick to list their disabilities and explain how they negatively impact their lives. Shifting this view to see their abilities instead can be quite a struggle. If they cannot see their own abilities, imagine how they might present themselves to a potential employer. Many individuals have found it beneficial to work with a support person who can help them discover their abilities, skills and interests and assist in presenting them in the best possible light. An employment consultant is a professional who is well-trained in the knowledge and skills necessary to assist job seekers in searching for and obtaining long term successful competitive integrated employment in the community's workforce. The core knowledge and competencies of the employment consultant can be grouped to support job seekers and employees with disabilities within three primary service categories. They include:

- Employment planning
- Employment development
- Post-employment success

## Employment planning

When an employment consultant is first matched with a job seeker, they establish a working relationship by getting to know each other. During this initial meeting, the consultant will introduce an assessment process called Discovery. Discovery is a strengths-based approach to planning employment where the goals are to identify unique interests, strengths, and conditions of employment for the job

seeker seeking services (WINTAC & Y-TAC, 2017; Hall, Keeton, Cassidy, Lovannone & Griffin, 2018).

While the employment consultant drives the process, the individual is expected to be an active participant all the way to job acquisition. Through home and neighborhood observations, interviewing those who know them well and skills testing, trained employment consultants develop several strong themes that encompass the skills and passions of the job seeker. These themes are ultimately used as guides to search for employment and businesses that may potentially benefit from the interests, skills, and contributions of a job seeker. These themes guide the "mining" and "mapping" of opportunities within a community's workforce. Through informational meetings, employment consultants, job seekers, and their circle of supporters work together to find an employer and job match that fits these themes. These types of job matches have been shown to result in successful, fulfilling long term employment in the community for both the job seeker and the employer (Marc Gold & Associates, 2014; Griffin & Beamer, 2017).

## Employment development

Employment development is both a formal and informal process of mapping, prospecting, interviewing, negotiating, and securing competitive integrated employment in support of job seekers with disabilities. An employment search can be conducted with minimal to intensive levels of support depending on the wishes and needs of the individual job seeker. The knowledge and skills of an employment consultant (job developer) are often helpful to an effective job search because of the wide complexities associated with the employment development process.

Most employment development strategies are used to develop "wage employment", but self-employment is also a useful approach for

some job seekers with unique interests and job-related talents.

## Post-employment

When a job match is found, the employment consultant has an open conversation with the job seeker about what kind of employment support they would like going forward. Will it be short term or for the duration of the job? How “hands on” would they like their consultant to be? Would they like the consultant to visit the job site or continue a relationship after work hours? It is important for everyone to be on the same page and also to be open to a change of opinion once the job seeker begins a job.

With different disabilities and personalities, there is a wide range of possibilities related to individual preferences and needs. What might this look like? Let’s take a look at two examples.

- Mary has asked her employment consultant to attend her job training. Her consultant sits with her, taking notes about the responsibilities and expectations of Mary. Mary is someone who cannot read or write so the employment consultant helps Mary fill out her paperwork. Throughout training, the consultant checks in with Mary and may reword or emphasize the important details. For the first week of Mary’s employment, her consultant is with her every day, observing Mary, encouraging her along and pointing out missed details. After the first week, Mary becomes more self-confident and self-assured making decisions without her consultant. At this point, the consultant decides to let Mary start days on her own and will instead stop in halfway through the shift. At every check in they visit with both Mary and her supervisor. Eventually, a regular pattern of check in visits happen every other week. Sometimes Mary will call on the phone if something comes up, otherwise the open, regular, proactive communications with

Mary and the employer set her up for long term success.

- John would like to attend his orientation by himself. He feels that he would benefit from having employment supports in his life but he would rather the consultant refrain from visiting the actual job site. During his break or after a hard shift, he will send a text or make a phone call to his consultant to discuss something that has happened that upset him. His consultant helps him talk it through and think about what options he has. Together, they come to decide what might result in the best outcome. John hangs up, feeling confident in how he would like to handle the situation on his own. A few weeks later, John and his consultant meet at a coffee shop during one of his days off. They discuss how work is going, transportation issues and even future goals.

As you can see, employment consultant support will look differently for every individual and every job. It is important that a consultant remains flexible and willing to look at new ways to support each individual.

Formalized training and education for employment consultants is beginning to emerge in the United States in recognition of the essential skills and competencies that are basic to obtaining competitive integrated employment outcomes, particularly for job seekers with the most complex and significant disabilities (APSE, 2019; WINTAC & Y-TAC, 2017).

This demand for universal knowledge and skills for employment consultants has resulted in the development of a professional certification standards (e.g., Association of Community Rehabilitation Educators—ACRE) to ensure minimum standards for professional practice and ethics in the delivery of customized and supported employment services (ACRE, 2019).

The fundamental knowledge and skills or competencies required to deliver effective, person-centered employment planning, em-



ployment development and post-employment services include the following:

### **Content knowledge:**

- Information about the individual job seeker
- Understanding about disabilities as well as how they commonly manifest in human, social, educational, employment, and community settings
- Grasp of public policies related to employment and disability services; including supported employment regulations for services and reporting.
- Understanding of person-centered thinking, services, and practices including use of Discovery and assistive technologies.
- Information about supported employment and vocational resources in the local community or region
- Information about the community's workforce including types of businesses, career opportunities, and range of employment/job prospects, etc.
- Knowledge about how competitive employment and wages impact on disability benefits and access to healthcare
- Understanding of public and private transportation systems and resources
- Information about employment and vocational resources in the local community or region
- Information about the community's workforce including types of businesses, career opportunities, and range of employment/job prospects, etc.
- Knowledge about how competitive employment and wages impact on disability benefits and access to healthcare
- Understanding of public and private transportation systems and resources
- Knowledge of multiple job development practices effective in securing competitive integrated employment, one job seeker, one employer at a time.
- Knowledge about guiding supported employment policies and standards (i.e., national, state, local, etc.)
- Knowledge about effective job training methods (e.g., systematic instruction) and job coaching strategies (e.g., transfer and fading supports to internal business)
- Knowledge about supported businesses including its products and services, leadership and supervision structure, company policies, business culture, etc.

### **Core skills and competencies:**

- Ability to build trust and build a good rapport with the job seeker and important people at the job site.
- Skills in working with home supports and other team members to prepare the individual for correct hygiene, work dress code (e.g., uniform) and adaptive tools if necessary, for success.
- Skills to coordinate individual transportation plans (e.g., bus or mobility training) as well as helping new employees identify a mentor at the job (to foster natural supports).
- Skills to help teach a variety of job duties to individuals with different learning styles; this includes using specialized teaching methods (e.g., systematic instruction) to support learners with complex learning disabilities.
- Ability to build and sustain strong relationships with the individual employee and business supervisors in order to avoid potential upsets. These skills include job visit preparation and securing high quality feedback to manage the job assistance needs of both parties.
- Skills for regular, honest communication with the employees' support team (i.e. case manager, home supports, educators, family,

- etc.) to facilitate conversations regarding work issues and gathering feedback and advice from those who know them well.
- Ability to address the individual's disability benefits and how a job, a pay raise or extra hours could potentially affect him or her.
  - Ability to observe the individual on the job and suggest ways he or she can build on quality or quantity of work.
  - Ability to observe and identify if the job is well integrated in the company work processes-culture; offering suggestions if there are ways to increase integration/inclusion.
  - Skills to advocate for an individual in regard to additional hours, increasing tasks and opportunities for personal growth both on and off the job.
  - Skills to lead discussion about goals for the job, help to craft goals into measurable objectives, and continue data collection for regular review and plan updates.
  - Skills to conduct a task analysis and break down the tasks to smaller steps to enhance learning (e.g. systematic instruction)
  - Skills to create and embed naturally supported business prompts to help the individual learn and stay on track (i.e. check list, photos, etc.). Recommending assistive technologies or other supports helpful to on-the-job performance.
  - Ability to be sensitive to changing needs as the individual develops new desires and skills or as life circumstances change.
  - Skills in building natural job supports with company supervisors and co-workers. Skills to step up and/or back down job supports as the situation requires.
  - Remaining vigilant to changes in business management, supervision structure, company policies, etc. impacting the supported employee
  - Uses of multiple tools and strategies to conduct Discovery & Customized Employment
  - Ability to interview a wide variety of people and secure information that is helpful to the Discovery Process
  - Skills in behavior observation, recordkeeping, and identifying job seeker talents, strengths, and skills
  - Ability to identify unique patterns and themes that can be used to prospect for employment
  - Skills in creative problem-solving and ability to transform barriers to conditions of employment
  - Skills in vocational and employment counseling including ability to be a positive messenger about work as a possibility
  - Skills in facilitating team meetings, building consensus, and coordinating division of labor
  - Skills in writing individual job seeker profiles with themes, goals, and action plans.
  - Uses of multiple tools and strategies to conduct Discovery & Customized Employment
  - Ability to identify a wide range of businesses that need or can potentially benefit by the identified skills or potential contributions of a job seeker
  - Ability to schedule job interviews and engage business leaders about the hiring of job seekers with disabilities
  - Skills in marketing, persuading, and negotiating to engage business leaders in the customization of jobs, tasks, and/or use of accommodations
  - Skills in creative problem-solving and ability to transform barriers to conditions of employment
  - Skills in identifying job accommodations in support of individual job seekers such as assistive technologies, job coaching, workplace modifications, interpreters, etc.
  - Skills in employer, supervisor, and co-worker education to enhance job orientation, inter-

nal training, and acceptance/inclusion of job seeker

- Skills in supporting individual job seekers with employment applications, resumes, or use of employment profiles with goals and action plans.
- Skills in customizing jobs using common practices such as job carving, job creation, self-employment, and other strategies.



## CASE STUDY

Helen, whom we met in the other chapter, has a great story that involves several levels of supports which led to successful, integrated employment in the community. Let's dive in and see how the knowledge and skills of her Employment Consultant assisted in the overall success of Helen's job placement.

When Helen initially began her job search for a part time position, she insisted on a job which allowed her to work from home. When she was asked to explain why, Helen told her consultant that she did not like crowds. Her Employment Consultant, who had been working with her for over twelve years, knew Helen very well.

Over the years, she had noticed Helen's dislike for large crowds, but if you got her in a small group or one on one, she flourished and could talk forever. Living alone and avoiding crowds had led Helen into a fairly solitary life, and ultimately, the results of so much alone time did not fare well for her. During initial interviews with Helen's support team (case manager, sister and former home staff), the emerging picture was clear: Helen often got lonely. Most of those interviewed mentioned Helen spending much of her alone time reaching out to socialize via Facebook and phone. Helen's consultant explained that there were so many different work environments out there. Helen's desire for small groups or one on one

work opportunities was possible out in the community with the right job match.

During the initial stage of discovery, Helen and consultant drove around her neighborhood, mapping nearby businesses that were aligned with her desire for office work. One of the places Helen pointed out was the organization in which Helen received Supported Living Services. The consultant took note and later her made a phone call to the agency's office manager. From the moment they began their conversation, the consultant could sense a deep connection and concern for Helen's well-being. They had a sewing hobby in common and shared several deep conversations about life over the last year they had known each other. As the consultant's conversation worked further into the type of work that Helen was searching for, there was a pause on the phone. The manager mentioned her organization potentially needing administrative help and that she would need to talk with the others. A week later, the consultant received a phone call from Helen exclaiming that she got a job offer for a part time office assistant position and she wanted to accept it!

Helen's consultant read through the position description and found several of Helen's discovery themes within social interaction, office environment and teamwork. Her consultant agreed; this job sounded quite promising.

The following week, Helen's employment consultant met with Helen and her support team (case manager, guardian and direct support staff) at her home to discuss transportation options, related funding, and the training likely to be needed. Helen insisted on taking the city bus and explained that she knew how to use the system. The employment consultant asked Helen to do bus training with her before the first day of employment. The consultant would merely sit next to Helen and let her

practice making the decisions necessary to get off the bus at the correct stop. That day, the bus drove right past her employer's building and Helen didn't move an inch. Her consultant learned that "knowing the bus system" meant that Helen knew how to take the bus to her sister's home, but she didn't have the skills to take it just anywhere. After four unsuccessful bus training days, the employment consultant connected with her support team to share the training results. Everyone was concerned about Helen's safety. It was decided, with Helen's approval, that she would be best served using a ride service that picked her up from her front door and dropped her off directly at her employer's building.

To help alleviate nervousness for her first day of work, Helen's consultant rode with her to work. The first part of the day was spent in a conference room where Helen, her consultant and Helen's direct supervisor went over the tasks she would be assigned. When asked if she had any questions, Helen answered "no". At this point, the consultant began asking more probing questions necessary to set Helen up for success. These were questions such as: "What office tools would she be using to complete her tasks?" and "For her filing responsibility, does she need to be able to alphabetize?" The consultant was making sure that Helen had the dexterity and skills necessary to complete these tasks as is.

It turned out that by asking these questions, it was uncovered that Helen has dyslexia which made recognizing letters difficult, especially when she'd have to alphabetize based on last name. To make the task easier, the consultant asked if an alphabetizing document sorter was available in the office. There was. When it came to that task, the consultant spent time helping Helen understand how to use this Sorter as a way to prep the documents for another employee. With this tool, Helen was able to alphabetize every letter with the exception of

x. "Where will Helen be performing this task on a regular workday?" the consultant asked. The supervisor explained that there were several stations which Helen could use and that she had a choice of locations. The consultant noticed that one of the workstations was up at the front desk, sitting side-by-side with another employee. This was a perfect opportunity to set Helen up for some one on one interactions. The consultant pointed that out, and Helen took it.

Going back to the task of alphabetizing, at this point the consultant met with the front desk attendant and slowly through conversation realized that this employee would serve very well as a natural support to Helen. "Would it be OK if Helen checked in with you if she has a question about a letter?" The response was enthusiastic and clear, "Absolutely!"

Over the course of the next few months, Helen became quite friendly with the front desk attendant. Whenever the consultant visited, she found them chatting comfortably the way colleagues and friends commonly would. In addition, Helen's desk mate smoothly stepped into a natural support role and turned into someone Helen regularly ate lunch with.

After the initial job training, the consultant noticed that natural supports were working wonderfully, so she decided to scale back in-person supports to every other week. The consultant noticed that Helen spoke more honestly about her feelings when she wasn't in her employer's presence, so they began having regular tea dates where they sat at a table, sipping tea and talking about the latest work drama. This not only allowed Helen to speak freely without the listening ear of her supervisor, it also continued to strengthen the relationship and trust Helen has with her consultant.

While Helen and her consultant meet offsite, the consultant continues to connect with the employer in the supervisor's preferred mode of communication. Most days, the supervisor replies with a glowing report. During one partic-

ular exchange the supervisor shared that they'd noticed how much Helen enjoys and excels in social situations. They were considering Helen as a potential interviewer on a panel for ongoing interview needs at their business!

Helen was very excited for the opportunity, though after the initial "yes" she became very nervous about being in the spotlight. The consultant asked the business for their list of interview questions and brought it to Helen's home. They read through them and then the consultant turned to Helen. "These interviews are meant to hire direct support staff that could potentially support you in your home. If you could ask one question about your future staff, what would it be?" This new perspective helped Helen choose a question rather quickly and so she began reciting the question with her consultant as the audience. With every read, the consultant noticed there were two words that kept tripping Helen up. They worked together to reword the question with Helen's own voice. After that, Helen read the question with confidence and was soon in the conference room, interviewing job candidates. This kind of personal growth made a visible difference in Helen's work satisfaction and overall self-esteem. She was making important decisions and working alongside directors at her business. This small group situation in a community job was working out splendidly.



## Tips & Strategies

- Relationships are the foundation to long term job success. Relationships build trust and trust will allow individuals, employers and employment consultants to remain open and honest with each other. This kind of communication will foster teamwork that can many times save a job.
- Be an excellent listener! Try to see arising issues and concerns from the unique perspectives of all stakeholders.
- Communicate regularly with the job seeker's support team! Hearing what is happening at home can shed light into why you are seeing an unusual behavior or general difficulty on the job. Be proactive!
- The quality of a supported employment job site visit is directly related to the quality of questions asked of the employer and employee. Consider the following general question to an employer: "How are things going?" Consider improving the quality of this question by asking: "Is this employee meeting your company's standards for job productivity and quality?"
- Never let "professional services and supports" replace natural, business-based supports that can be delivered by supervisors, co-workers, and others.
- Learn creative problem-solving skills because it is impossible to anticipate every problem that may arise.

- Join professional trade associations to stay current in best practices and network with others who deliver competitive, customized, and supported employment services.
- Learn from the best! Identify potential mentoring relationships with experienced professionals known to deliver high quality services.
- Read professional journals and stay current with research on evidence-based practices.
- Never give up on individuals. There is a suitable job for most everyone who chooses to work.
- Recognize the power in alliances in all aspects of the employment consultant.

National Association of People Supporting Employment First (APSE) (2019, January). *Universal employment competencies*. Retrieved from <https://apse.org/wp-content/uploads/2019/03/Apse-universal-Comps-FINAL3-15-19.pdf>.

The Workforce Innovation Technical Assistance Center (WINTAC) and the Youth Technical Assistance Center (Y-TAC) (2017, June). *The essential elements of customized employment for universal application*. Retrieved from <http://www.leadcenter.org/resources/tool-manual/essential-elements-customized-employment-universal-application>.

## Resource

- [National Association of People Supporting Employment First \(APSE\)](#)

## References

- Association of Community Rehabilitation Educators (ACRE, 2019). *Types of certificates*. Retrieved from <http://www.acreducators.org/certificates>.
- Griffin, C., & Beamer, S. (Eds.) (2017). *Customized employment: Stories and lessons from the field*. Florence, MT: Griffin-Hammis Associates.
- Hall, S., Keeton, B., Cassidy, P., Lovannone, R., & Griffin, C. (2018, December). *Discovery fidelity scale*. Griffin-Hammis Associates, Center for Social Capital.
- Marc Gold & Associates (2014, January). Documenting discovery: Developing a descriptive profile to guide employment plans Pathways to Employment Resource Center (PERC) Curriculum. *Report Brief*. Retrieved from <https://static1.squarespace.com/static/57fa78cd6a496306c83a2ca7/t/5cdadb9524a694c78f4604f8/1557846933241/Documenting+Discovery+5-2019.pdf>

## Institute on Community Integration, University of Minnesota, Minneapolis, Minnesota, USA

The Institute on Community Integration (ICI) is a University Center for Excellence in Disabilities (UCED). Along with its allied centers, including the Research and Training Centers on Community Living and Home and Community-Based Services Outcome Measurement and the Global Resource Center on Inclusive Education, ICI is part of a national federally-supported network of University Centers on Disabilities and other federally funded disability research and training efforts at universities across the United States. The Institute's mission is to improve the quality of life and community inclusion of persons with disabilities as well as the professional services and social supports available to individuals with disabilities and their families. The Institute is currently implementing over thirty research, training, and technical assistance projects fund-ed by the federal and state government, and private foundations. The project topics include self-determination, social inclusion of students with disabilities, facilitating their transition into adulthood; enabling access to high-quality services and supports, and promoting living within inclusive communities. ICI not only serves, but employs individuals from numerous ethnic and disability backgrounds. ICI staff have collaborated on projects not only locally and nationally, but also across the globe, including in Russia, the Czech Republic, India, Costa Rica, Bhutan, Ukraine, Armenia, Kazakhstan, Zambia, Liberia, Micronesia, and New Zealand.

Institute website: <https://ici.umn.edu>

## Life Route Foundation, Moscow, Russian Federation

The Life Route Foundation is a non-governmental organization established in 2009 to support people with disabilities realize their rights to education, communication and a decent life in the community. The founders of the organization are parents raising children with disabilities as well as the Center for Curative Pedagogy, one of the most respected non-profit organizations in Russia that provides assistance to children with developmental disabilities and their families in Moscow and its regions.

Founded on humanistic values, a social model of disability and high standards of services and supports, the foundation began to develop programs with a goal is to improve the quality of life of people with intellectual, developmental, and multiple developmental disabilities in Russia. At present, the foundation supports integrated employment, educational accommodations and inclusion, daytime programs for people with significant developmental disabilities, volunteer projects for social adaptation in boarding schools in Moscow, and projects for social inclusion. In addition, the foundation's specialists advise families on legal issues and share experiences of successful practices with other regions of Russia.

Life Route Foundation website:  
<https://liferoute.org/>