

## MEANINGFUL EMPLOYMENT OF YOUNG ADULTS WITH INTELLECTUAL DISABILITIES IN LATVIA

Anna Broka<sup>1</sup>, Mg.Sc.pol.; Hanna Mihailova<sup>3</sup>, BA Pol.; Dace Demme-Vimba<sup>2</sup>, Mg.soc.sc.

<sup>1,2,3</sup>Vidzeme University of Applied Sciences, Institute of Social, Economic and Humanities Research

**Abstract.** Employment is a right of citizenship and one of quality of life determinants remaining low among the persons with disabilities, especially those with intellectual disabilities (ID). Initiated Deinstitutionalization (DI) process encourages for an open discussion whether there is a need for more radical change in shift from the individual or medical (more institutionalized) model towards the *social model of disability* in Latvia (DI action plan 2015-2020). Development and initiation of alternative social services goes in line with recognition and usefulness of social model of disability but lacks legal and even political voice in the process of its implementation. The aim is to assess the availability of meaningful employment opportunities for persons with ID in realm of DI action plan. It is an attempt to raise attention about the need for the *social disability model* signifying the practices for development of applicable comprehensive services for persons with ID in Latvia. Literature studies (research analysis on the topic) as well as empirical evidence (conducted in 2014-2016 from primary sources: in-depth interviews, life-stories, focus-group interviews with involved parties in DI process in Latvia, case study of Vidzeme region) raise a serious concern and demonstrate inconsistency in policy planning and its actions. Finally, preconditions for employment opportunities are discussed.

**Key words:** intellectual disability, deinstitutionalization, and meaningful employment

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### Introduction

"It is hard to achieve the EU overall target rate of 75 % employment without increasing employment rate of disabled people" (Priestley, May 11-12, 2015). Meaningful employment or daily activities for persons with intellectual disabilities (ID) is supportive service that is challenging human right activists, policy makers, service providers and even person's themselves (families and carers) in many countries. In Latvia Deinstitutionalization (DI) process (DI action plan 2015-2020) has initiated a hot debate among different interrelated groups regarding the development of appropriate services on local level in existing socioeconomic and cultural contexts (Broka, 2014; 2015; Rajevska et al. 2015; the Ministry of Welfare webpage).

The aim of the thesis is to assess the availability of meaningful employment, daily activity and supportive employment services for persons with ID taking into consideration DI action plan in Latvia.

In this study author's attempt is to apply M. Oliver's methodological indication that it is the researchers who have expertise or specific knowledge and skills, and should decide what topics should be researched, being in control of

the whole process of research production provoking change of social relations (Oliver 1992: 102). Instead of following the mainstream (medical and individual model of disability) the purpose is to introduce the most recent studies relating the *social model of disability*, i.e., to explain the relevance in use of the term "intellectual disability" instead of "mental retardation" and discuss it in realm of meaningful employment service development in Latvia.

Literature studies, secondary data analysis and theoretical reviews were conducted by selecting relevant articles on the topic from electronic academic databases and library (used terminology: "disability studies", "mental retardation", "intellectual disability", "deinstitutionalization" separately and in combination with "community-based services", "supports", "employment", "job", "work", "daily activities". Empirical evidence from primary sources conducted during the period from 2014-2016: in-depth interviews, life-stories, focus-group interviews with involved parties (social workers, charity organizations, representatives of disabled community in Latvia, case study of Vidzeme region, visits in Norway and Sweden). Research results raise a serious concern whether

DI process will improve quality of life of people with ID in near future, still observing inconsistency in policy planning, legal framework and mistakes made in actions on different levels?

### **1. Role of meaningful employment in the process of deinstitutionalization (DI)**

Deinstitutionalization (DI) Action plan (issued 2015-2020) implies the development of qualitative community based services and independent living opportunities for persons with mental disabilities (i.e., psychosocial and ID). At the moment it is rather difficult to identify the exact number of persons with ID (both residing in institutions as well as in other living arrangements), registered and not-registered in Latvia. In the end of 2015 there were at least 17758 persons registered with ID (according ICD-10 classification: mental retardation F70-79: mild, moderate and severe). The most of them are in working age group (15-17 years: 1115; 18 and older: 14262 persons) (The Centre, 2015). This might be the closest estimate as prevalence of ID is regarded being between 1 % and 2 % of the general population (Krahn, Fox, 2013). In 2015 there were 2163 adults (18 and older) with ID (F70-F73: mild, moderate and severe mental disorders) residing in institutions (LM 2015). Community-based living and day care arrangements were provided for at least 273 persons living in group houses, 811 persons in Day care centres and for 12519 persons in home care (Jasjko, 2015). Employment, e.g., meaningful activity, supported employment and daily activities of person with ID, is an important domain in transition to adulthood (school-to-work transition) (DISCIT January 2014; Holburn et al. 2000, 402-416). Therefore DI process shall take into consideration the state of young persons with ID not being living in their communities and families, but residing at primary and secondary special boarding schools, e.g., professional education institutions often located in rural, rather isolated areas with limited access to social life activities (Broka, 2014; Broka, 2015:56-70).

Previously mentioned assumptions regarding DI process are challenging the shift from *Individual or medical disability* model towards *Social model of disability* in Latvia; it is about to go against the post-socialist traditional attitude and culture, not being afraid to challenge the view of mainstream society favouring institutions, participating in discrimination or neglecting the rights of persons with disabilities (agreeing with M. Oliver's methodological considerations, 1992). Therefore the most recent debate about term *intellectual disabilities*, role of its application and contradictions in its use will be explained in the following paragraph. Then will be clarified the usefulness of *Social model* of disability with its additional attention regarding meaningful employment and other employment support services for persons with ID, strength and weaknesses in its application and practice. Finally, social services, supported employment and other related support mechanisms enhancing individuals right to meaningful employment are going to be presented.

#### **1.1. Defining and understanding "intellectual disability" (ID)**

Over the past 50 years important conceptualizations, assessments and observations have been introduced and influenced persons with ID life worldwide. Shift from such terms as "idiot", "imbecile" towards "mental retardation" and "intellectual disability" has the political, economical as well as cultural context. It is evident that inaccurate or misuse of the important terms may lead to fragility and inability for political, social or civic action. Authors attempt is to explain the most recent term "intellectual disability" - defined in disability studies and used in line with Human rights approach.

In the most recent publication group of experts from American Association on Intellectual and Developmental Disabilities (AAIDD) proposes to use "intellectual disability" as the new term for mental retardation (the two major classifications

of mental disorders: the ICD-10, primarily used by 194 WHO member countries, and the American Psychiatric Association (APA)'s Diagnostic and Statistical Manual of Mental Disorders have been revised) (Schalock et al. 2010). According to AAIDD definition:

*"Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18."*(Schalock et al. 2010)

Current debate is whether "intellectual development" should be considered as a disability or health condition. In many countries ICD categories are often used with an aim to define eligibility criteria for specific health care, educational or social services (Bertelli et al. 2016; Harris, Greenspan, 2016:11,17). In Latvia term "person with mental retardation" or "person with disorders of a mental nature" is most commonly used among professionals both for clinician judgment of person's state of functioning, self-advocacy, intelligence and adaptive criteria, as well in legal context regarding eligibility of particular social and employment services (Cabinet regulation No 288, Article 3.3, 3.4, 3.5, 3.6; 24.04.2008.; Taube, Leimane-Veldmeiere, 2007:19). Unfortunately "intellectual disability" term is totally missing in Latvian legislation, service provision and until now has been used only in few important publications (Open Society Institute, 2005; The Ministry of Welfare, 2015, NGOs "Saule", "Apeirons"; NGO "Rigas pilsetas rupju bernu").

"Intellectual disability" is a term aiming to understand person's environment, its social interface within the environment (the social model), not only emphasizing the person-centred neurobiological deficit (the medical model). The term "mental retardation" also is significant as it is clarifying the severity and persons limitations regarding intellectual functionings and adaptive behaviours, which cannot be seen in isolation

from certain environment (Schalock et al., 2002; 2010; Salvador-Carulla et al. 2011; Harris, Greenspan, 2016).

In Latvia "intellectual disability" and "mental retardation" are not used and understood as synonyms as may cover other diagnoses of psychiatric matter (Taube, Leimane-Veldmeiere, 2007). Additionally such terms like "mental retardation" or "psychiatric disorders", "persons with special needs", "person with disabilities", "functional impairments" or "disabilities due to mental illness" are even more confusing eligibility criteria for services.

The authors point out that the term *mental retardation* is the former construction viewing disability as the defect within the person, whereas the current *intellectual disability* term is viewing the disability as the fit between the person's capacities and the context in which the person is functioning. Still the condition (as in mental retardation) or the state of functioning shall be understood in terms of limitations in typical human functioning. Assessment of ID shall be conducted in order to state the diagnosis of disability, classify characteristics of it and plan individualized needed supports. Assessment tools and process shall stress both on limitations and those individualized support plans, being valid as possible and result orientated or useful practices. And resources and strategies aiming to promote the person's development, education, interests, and well-being shall enhance person's limitations (Schalock et al., 2002; 2010).

Missing term "intellectual disability" in general legislation and public policy restricts determining appropriate eligibility criteria and develop comprehensive *individualized supportive mechanisms*, e.g., systematic and continuous, long-term educational, social and health care, training, employment, income supports. This is the main reason why it is useful to introduce the importance of terminology and address it in realm of *Social disability model* as well.

## 1.2. Social disability model and meaningful employment

Environmental factors and supportive disability mechanisms are fundamental part of person's with intellectual disabilities everyday life. Furthermore, in its origins the *Social disability model* states that impaired person's exclusion from society depends on the way the society is responding to the person's needs (UPIAS, 1976:14). Disabling environments, economic, social and cultural barriers are of the same importance (social model) as the functional or individual inabilities, limitations (medical model), not excluding the need for appropriate medical interventions (rehabilitative, educational or employment initiatives) (Oliver, 1996). It has demonstrated political success and positive activism in UK, North America and Scandinavian countries, i.e., the Social relational model of disability, Nordic social relative model of disability and North American social model of disability (Owens, 2014:2-4). Thus *intellectual disability* term has been introduced and adapted as an umbrella for supported services in those countries.

Shift to this model is linked to transition from institutional care to self-determination, empowerment and autonomy (independent living) within DI process, evolving development of a variety of living arrangements (supported living) and supported employment and even supported parenting (Bradley, Knoll, 1995, in Harris, Greenspan, 2016:24-7).

T.W. Shakespeare (2006:214-221) highlights the usefulness and limitations of the *social disability model*. On the one hand, it is strengthening person's with disabilities political power and rights, encouraging for ideological change and developing new services. Still is a blunt instrument for explaining and combating the social exclusion, neglecting the complexity of disabled individual needs and experiences of the world. Finally, without strong theoretical foundation and well-defined practices the social

model is an utopian idea, hard to operationalize and generalize to common group.

For instance, lack of *social competences* of persons with ID - the way the person is functioning and interacting with environment, may become a real challenge for service providers and parents. Integrated work and living settings does not promise that person with ID will understand the diversity and rules of society, thus in the end being dependant from professional assistance and continuity of support settings. Person's life will remain vulnerable, experiencing high risk for social isolation or friendlessness, bullying, financial and even sexual exploitation. In society person with ID may be judged as aggressive, self-harming and expressing other problematic, "strange" behaviours (Andersson, 2014; Borthwick-Duffy, Greenspan, Ho, 2006 in Harris, Greenspan, 2016:28). In development of alternative social services and changing environments clear focus has to be both on the person's diagnosis, limitations (medical model) and his/her abilities in meeting the social world (Harris, Greenspan, 2016).

On the one hand, high institutionalization is the main reason why the community-based services are almost absent in supportive settings for persons with ID in Latvia. Children with ID are residing at special boarding schools, later in state long-term social care institutions, home care and living in isolation from society. On the other hand, transforming social service settings, high NGO engagement and best practices are confirming the slight movement towards social disability model. Even employment service models are developed for persons with severe ID (Broka, 2014; 2015; Rajevska et al. 2014; Taube, Leimane-Veldmeiere, 2007).

The reason for slow and inconsistent development of those comprehensive services for persons with ID relies in missing and misleading legislation. There is contradiction between ratified

international treaties, declarations, agreements and national legislation applied in practice.

One cruel mistake is found in UN Convention on the Rights of Persons with Disabilities, whereas well-known term for services available for persons with ID "habilitation" has been translated into Latvian language as "adaptation" (Article 26, in force since 31.03.2010). It states that:

*State Parties at the earliest possible stage shall take effective and appropriate measures, organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes in the areas of health, employment, education and social services. (...) It is a way the person should live independent, able to participate mentally, physically and socially. Furthermore, individual needs and strengths should be assessed in multidisciplinary manner. Multidisciplinary can be achieved if there is initial and continuing training for professionals and staff working in habilitation and rehabilitation service (Article 26).*

It is absolutely clear that *habilitation and rehabilitation* are two different terms and both terms refer to service settings available for persons with disabilities. Unfortunately, no one of main general national laws protecting and ensuring the rights of persons with disabilities have stated any services referring to "habilitation" or "adaptation" (Law on Social Services and Social Assistance, 12.12.2002., hereafter Social service law; Law on Disabilities 01.01.2011.). As one of the best practices of Social disability model should be mentioned law regulating Support and Service to Persons with Certain Functional Disabilities (LSS) in Sweden. It clearly defines the target group: persons with ID and people with autism or conditions similar to autism, persons with significant and permanent intellectual functional disabilities (children and adults). Accordingly the Habilitation centres, other related institutions and social partners are ensuring 10 forms of assistance and adapting

environment to person's capabilities (Stockholm lans landsting webpage; Table 1).

According to the LSS law Habilitation centres on county level assess individual needs (as early as possible), offer different treatments and expert help with in-depth knowledge of a certain disability, looking at all aspects of their life. The person can receive help from occupational therapists, counsellors/ social workers, speech therapists, psychologists, physiotherapists and special education teachers, curator working together to combine medical, psychological, social and educational perspectives. Parents and relatives are offered psychosocial support. Habilitation centres work in close collaboration with other related social partners (schools, preschools, work environments, residential care centres, governmental, medical and other partners) (Stockholm lans landsting webpage).

In Latvia available services and professionals are not functioning in the same manner and comprehensive team-work is absent. Parents and NGO representatives have admitted that they are missing the *one* person who would give correct advice, important information about services and further appointments (as *Curator* working with families in Habilitation centres in Sweden) (Interviews with parents, NGOs and representatives of person's with ID, Conducted in period 2014-2016, Vidzeme region, Riga).

*Meaningful employment or supportive employment* services for intellectually disabled person is not just a service *per se* but an important measure representing outcomes of other *Quality of life* dimensions across life domains (Felce, Perry 1995 Jan-Feb, 51-74; Felce April 1997, 126-35, in Broka 2015).

Furthermore, several international treaties and national legislation acknowledge those principles. Recognition of persons with disabilities to work on an equal basis with others is stated in the Disability right Convention (Article 27) and Labour Law (Article 7, in force 01.06.2002). Large share of responsibility in creation of working

environment, e.g., *inclusive and accessible, with general technical vocational guidance programmes, placement services and continuing training* (Disability Convention, Article 27) is an obligation of employer as far it is not putting unreasonable burden (Labour law, Article 7).

Case study in Sweden and Norway (2014) demonstrates that often job opportunities and working places are created in the public sector or public sector is using the services provided by the Social entrepreneurs hiring the persons with ID and other related syndromes (Autism, ADHD, Asperger etc.).

Table 1

**Assistance provided for persons with ID in Sweden**

No	Description	Service provider
1.	Advice and other personal support	Habilitation and rehabilitation services
2.	Personal assistance	Personally designed care in everyday life by professional
3.	Companion service (get out to leisure or cultural activities, or to participate in social life otherwise)	Personnel helping to
4.	Contact person	Friend giving personal support
5.	Relief service	Personnel comes to the family home in order to take care of the person with functional disabilities
6.	Short-term stays away from home (a short-term home, with a family or at a camp or similar)	Social activity ensured by social partners, local government etc.
7.	Short-term care (before and after school) for school children over 12	After-school clubs, in special groups or based on personal needs
8.	Living in family homes or housing with special services	Housing arrangements dependant with special services if the person is not able to live in his/her own family (children and young people)
9.	Housing with special services for adults or other specially adapted housing for adults	especially adapted housing, service housing or group housing
10.	Daily activities (for persons with ID, autism or functional disabilities following brain damage as an adult, Groups 1 and 2 as above).	At a day centre or at another place of work

**Source: Stockholm lans landsting webpage: LSS in brief.**

The empirical evidence from other countries demonstrates correlation between investments, supportive programmes and the positive outcomes – increasing person’s capacity to cope and function in social environments. The interventions shall be very carefully and individually designed (as they are not fitting for all persons with disabilities, and shall be different for each diagnosis) (Andersson 2014; visits in Norway and Sweden, 2014).

“Person-centred” and “family” centred planning offers alternative supportive system enclosing community channels, families and friends (Mansell, Beadle-Brown 2004, 1-9), nor neglecting existing educational or training, post-school activity settings (Broka 2015; Blacher 2001, 173-188; Neece et al. February 2009, 31-43). Meaningful employment activities may start

already in general education (class 7-9) or vocational/ professional training (class 10-12) or even during life-long learning (post-secondary) education in different periods of life. The main tasks are: (a) to identify person’s with ID strength, what she/he can do, specifying person’s interests and motivation, identifying the best adjustable practice/ training place in real work environment; (b) job development service or job finding, which may be fulfilled in close collaboration with National Employment Agency, Daily activities centres and Social support service providers; (c) job analysis, job matching or job (re) design shall be fulfilled by *occupational therapists, counsellors/ social workers and other careers involved (team work)*; (d) introduction to the workplace, training on the job tasks (*occupational therapists, ergo therapist*) and

*other careers involved (team work); (e) supportive mechanisms outside the work place (public transportation facilities, living arrangements and social activities)* (Author's suggestions in accordance with WASE, 2012; Scandinavian support service analysis; visits in working places in Norway and Sweden; Daily activity centres in Latvia). In Latvia the opportunity to assess the person's capabilities often depends on special schools and their ability to interfere with family environments (Interviews; Broka, 2015).

The professional education programmes offered for persons with ID are in highly institutional environment (isolated) and very restricted (Broka, 2014; 2015). Despite large investments for inclusive education (2007-2013) there are missing special integrated classes for persons with ID in mainstream schools (general or vocational training) (in comparison to Scandinavian countries, visit in Rud School, Norway).

To sum up, good initiatives relating inclusive education, professional training and their ability to interact with other professionals (speech therapists, physiotherapists, psychologists, and others when necessary) can be identified (Zake, 2013). Still professional shortages, teamwork and comprehensive planning model is absent. Authors encourage to make a bridge between "What is" and "What can be" and focus the educational and habilitation service system on reducing the gap between requirements and person's abilities (competences) (Thomson, 2009:135-146).

### **Research results and discussion**

On the one hand, M. Oliver invites to practice social model of disability by using available resources in more efficient way, not just creating special working places but adapt techniques the way of work can be carried out, making it more accessible for different groups (Oliver 1996, 2004, 18-31). On the other hand, still one of the

most vulnerable groups – persons with ID, remain in the end of supportive settings.

The main challenge is to create and adapt environments for person's with ID well-being in Latvia. The supported employment settings shall start already in school age, making transition of persons with ID easier in later stages. Rather high emphasis still follows the "pedagogical correction", "medical diagnosis" and "professional rehabilitation" doctrine. The habilitation services and supportive settings in collaboration with different social partners are fundamental in DI process.

The most of the Human right principles for persons with disabilities have been ratified after Latvia regained its independence in 1990s. Main legal instruments protecting the equal rights of persons with disabilities to employment are the Labour law (Article 7), and entitlement for services is specified in the Law on Disability, the Social service law, and binding Cabinet regulations. There are several state bodies and procedures assessing the person with ID in regard to different purposes. Funding for social service provision is divided between state and local authorities and has been identified as one of the problems in appropriate community-based service development (Interviews, 2016; Rajevska et al., 2015). Individuals and their families (parents, carers) are *"tired and exhausted in current assessment procedures that primarily looks out for medical diagnosis, identifying the person's inabilities and are useless, as again and again they just check into their forms what person is not able to do"* (Interviews, 2014; 2016;). In major assessment settings still dominating is *medical disability model* and identified practices in Vidzeme region are few, not exactly representing meaningful employment settings in community-based environments (Case study in Vidzeme region, 2015-2016). For instance *Day care centres* are not supposed to be Day activity centres whereas person can realize meaningful employment or daily activity; and

have restrictions for funding (differs from given example in Table 1; Interviews, 2015-2016).

The employability highly depends on community-based living arrangements, transportation facilities and careful application of DI Action plan that have been already initiated. Even though professionals and society are not ready: "*DI is alarming. We have no such experience, knowledge. Neighbourhood, society is stressful and experiencing fear*" (Interviews, 2016). Preliminary evaluation of planned DI actions in respect to the project "Vidzeme includes" ("Vidzeme ieklauj") demonstrates the challenges rather than opportunities.

To sum up, the *social model of disability* allows us to explore people with disability opportunities, experiences and abilities in more complex way, on different levels of analysis and interventions, including medical, social, economical, political and cultural experiences and interdisciplinary approaches.

### Conclusions, proposals, recommendations

1) DI Action plan (issued 2015-2020) implies the development of qualitative, community based services and independent living opportunities for persons with mental disabilities (i.e., psychosocial and ID). At this moment it is rather difficult to predict the results due to

several fundamental shortages in assessment procedures, general legislation and lack of comprehensive practices (team-work). There is a need for a coordinated set of supports for intellectual and social functioning of persons with ID (see Schalock et al., 2002; 2010).

- 2) The Social disability model is appropriate for interventions of community-based practices, still shall be carefully applied in line with individual model. Meaningful employment of person's with ID is a challenge due to their limitations in development of *social competences* and shortages in bridging "what is" and "what can be".
- 3) Assessment of person's abilities, capacities and motivations still has too high emphasis on "rehabilitation" and "pedagogical" correction (medical model) instead of evaluation of environments (social model). The habilitation services and team-work are a necessity for people with ID inclusion into society.
- 4) Professionals (local authorities, social workers, teachers) have no practical experience, while representatives of disability community have no political power to implement the DI plan, and actions influencing the person's with ID quality of life. There is a need for collaboration between all parties for one purpose.

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