



European Association of Service providers  
for Persons with Disabilities

# Models of promising practices on independent living and inclusion in the community for people with significant support needs



# Research on models of promising practices on independent living and inclusion in the community for people with significant support needs

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Author: Dr. Arch. Jasmien Herssens, founder fourmind

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for Persons with Disabilities



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### 3. Abbreviations

EC	European Commission
EEG	European Expert Group
EU	European Union
IL	Independent Living
ISF	Individual service funds
NCIL	National Council of Independent Living
PAS	Personal Assistant
SDG	Sustainability Development Goals
SDS	Self-Directed-Support Act (Schotland)
SGVV	Sociale Gereguleerde VastgoedVennootschap
VIPA	Vlaams Infrastructuurfonds voor Persoonsgebonden Aangelegenheden
QoL	Quality of Life
UNCRPD	United Nations Convention on the Rights of People with Disabilities

## 4. Abstract

Recent insights on the living environment of people with disabilities highlight the need for a smart transformation of support services towards better quality that creates empowerment and person-centred forms for Independent Living (IL) in the community. Different acts and policy reforms already underline a required change to improve IL. However, there is a gap between theory and practice and this study aims to clarify certain causes as well as exemplify five promising practices in different welfare states. First ‘people with significant support needs’ are defined and the complexity of the topic is developed by a conceptual framework for models of support in IL. Secondly, promising models are investigated. Findings prove that a diversity of perspectives, definitions, and approaches on the topic contribute to a lack of common definitions and knowledge. The five promising models demonstrate the invisible interactions between different actors, variables and factors that determine a support model for IL.

## 5. Introduction

### ▪ State of the art

As society respecting human rights, it is our full responsibility to include all people as full citizens, and to support all individuals, with and without disabilities, to participate fully in life.<sup>1</sup> The main goal of this research is to provide useful data, concepts, and analysis of models of promising practices in the context of independent living for persons with significant support needs, which includes people with multiple, complex, and intersecting impairments, facing multiple barriers such as environmental, attitudinal, financial, communicative, among others. The National Council of Independent Living (NCIL) argues a higher risk of institutionalisation and exclusion of this group<sup>2</sup> and urges to improve their lives.

Although Article 19 of the UNCRPD already underlines *the right of people with a disability to live independently and to take full part in society*<sup>3</sup>, its actual adoption and implementation shows an extremely slow progress and sometimes even a decline. In response, the UN has recently adopted additional guidelines on deinstitutionalisation, including in emergencies.<sup>4</sup> Crisis situations, such as the Covid19-pandemic, the war in Ukraine, the economic crisis in Europe, the increasing ageing society and the climate crisis, accelerate the need to revisit our current models of support for Independent Living (IL). Indeed, crisis conditions are the best test cases to reveal and locate the actual limits within

<sup>1</sup> UN 2007. Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly. In: NATIONS, U. (ed.) A/RES/61/106. New York: UN General Assembly.

BUNTINX, W. H. & SCHALOCK, R. L. 2010. Models of Disability, Quality of Life and Individualized Supports: Implications for Professionals Practice in Intellectual Disability. *Journal of policy and practice in intellectual disabilities*, 7, 283-294, HARPUR, P. 2012. From disability to ability: changing the phrasing of the debate. *Disability & society*, 27, 325-337, SCHALOCK, R. L., LUCKASSON, R. & SHOGREN, K. A. 2020. Going beyond Environment to Context: Leveraging the Power of Context to Produce Change. *International journal of environmental research and public health*, 17, 1885.

<sup>2</sup> NCIL. 2022. *The National council of Independent Living* [Online]. Available: <https://ncil.org/> [Accessed 10/9/2022 2022], VON DER LEYEN, U. 2021. State of the Union Address 2021: Strengthening the soul of our Union. In: COMMISSION, E. (ed.). Brussels: European Commission.

THOMPSON, J. R., BRADLEY, V. J., BUNTINX, W. H., SCHALOCK, R. L., SHOGREN, K. A., SNELL, M. E., WEHMEYER, M. L., BORTHWICK-DUFFY, S., COULTER, D. L., CRAIG, E. P., GOMEZ, S. C., LACHAPPELLE, Y., LUCKASSON, R. A., REEVE, A., SPREAT, S., TASSE, M. J., VERDUGO, M. A. & YEAGER, M. H. 2009. Conceptualizing supports and the support needs of people with intellectual disability. *Intellect Dev Disabil*, 47, 135-46.

<sup>3</sup> UN 2007. Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly. In: NATIONS, U. (ed.) A/RES/61/106. New York: UN General Assembly.

<sup>4</sup> OHCHR 2022. Draft Guidelines on Deinstitutionalization, including in emergencies Committee on the Rights of Persons with Disabilities. In: NATIONS, U. (ed.). Geneva, Switzerland: United Nations.

CRPD, U. 2022. Convention on the Rights of Persons with Disabilities: Guidelines on deinstitutionalisation, including in emergencies. UN.



guidelines and treaties. In general, practice shows a lack of knowledge of the concept of inclusion and support models.

## ▪ Research aim

Apart from a positive and growing awareness transformation, through political models, treaties, guidelines and successful advocacy work, research shows that the complexity of support models for independent living requires more study and a holistic approach so as to comply with the UNCRPD. Frequently, unsuccessful stories are used to justify the existence of segregated residences and services. Arguments often focus on people's condition as opposed to the ambition to start from their choices and voice as generated by human rights. This study focuses on models that address the need for support to empower people for IL, starting from people's self-determination, choice and participation.

In their 2022-2025 strategy, EASPD<sup>5</sup> highlights the need for a smart transformation of support services towards better quality, empowering and person-centred forms of support, for independent living. It is guided and supported by human rights treaties and policy strategies:

- The UN committee on the Rights of persons with disabilities: guidelines on deinstitutionalisation (OHCHR, 2022)<sup>6</sup>;
- The UN CRPD, Convention on the Rights of persons with disabilities (2007)<sup>7</sup>;
- The UN Sustainable Development Goals<sup>8</sup> (UN SDG);
- The European Commission (EC) 'Union of Equality Strategy for the Rights of Persons with Disabilities (2021-2030)<sup>9</sup>;
- The EU Care Strategy (2022)<sup>10</sup>.

The scope of the research was clearly identified by EASPD in two parts:

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<sup>5</sup> SIGNAL, T., BERTRANA, I. & LEVENTI, K. 2021. EASPD position paper on EU Care strategy. *In*: EASPD (ed.). Brussels..

<sup>6</sup> OHCHR 2022. Draft Guidelines on Deinstitutionalization, including in emergencies Committee on the Rights of Persons with Disabilities. *In*: NATIONS, U. (ed.). Geneva, Switzerland: United Nations.

<sup>7</sup> CRPD, U. 2022. Convention on the Rights of Persons with Disabilities: Guidelines on deinstitutionalisation, including in emergencies. UN..

<sup>8</sup> UN. 2015. *Sustainability Development Goals* [Online]. Available: <https://sdgs.un.org/> [Accessed]..

<sup>9</sup> EUROPE, C. O. 2016. The Council of Europe Disability Strategy 2017-2023. Council of Europe..

<sup>10</sup> EUROPEANCOMMISSION. EU Care Strategy. *In*: EASPD, ed. Webinar on Stakeholders' Initial reactions, 2022 online webinar, September 9th 2022..

1. define “people with significant support needs” and
2. find five promising examples for good models on independent living for people with significant support needs within five different welfare states.

Subsequently, this study aims to determine the processes and characteristics for quality, empowerment and inclusion in support services that empower people on independent living.

## ▪ Research Approach & Set-up

This research is articulated around two main axes, theoretical and empirical. Before proceeding with the selection of promising practices, it is recommended to define a conceptual framework for understanding the main processes and determinants of an IL support model for people with significant support needs. Although many researchers in disability studies frequently refer to “people with significant support needs”, there is no worldwide common definition. A clear definition of the key terms defining “people with significant support needs” is necessary to ensure consistency. Similarly, there is no actual definition of independent living in the context of people with significant support needs. Therefore, this research starts with a systematic literature review<sup>11</sup> in which the following research questions will be examined:

- How can we define people with significant support needs?
- What are the conditions that allow us to refer to people with significant support needs?
- What is considered as independent living?
- What are the different requirements or characteristics that justify independent living?

Based on a cross-sectional analysis of systematic literature review, common definitions on ‘people with specific support needs’ and ‘independent living’ are defined, taking into account an inclusive approach of the human-centred model.. Furthermore, the outline of a conceptual framework was developed. The diversity and relations between support and its variables and factors are key in this framework that will also serve as a tool for the final selection of the five case studies in the empirical track.

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<sup>11</sup> SIDDAWAY, A. P., WOOD, A. M. & HEDGES, L. V. 2019. How to Do a Systematic Review: A Best Practice Guide for Conducting and Reporting Narrative Reviews, Meta-Analyses, and Meta-Syntheses. *Annu Rev Psychol*, 70, 747-770.

The design of the empirical track, using a qualitative case study methodology, starts from a human-centred approach that highlights and supports people's voices and choices, equally to the vision and ambition of the UN CRPD.

The investigation on models of promising practices on independent living and inclusion in the community for people with significant support needs, starts with contacting experts, practitioners, organisations, and users in person. Every contact receives a personal call or email in which they are invited to give their most promising examples in context of this research. This network of stakeholders represents all continents of the world and covers all countries in Europe. This approach is consistent with the ambition to screen five models in five different welfare states as required by EASPD and acknowledges the impact of welfare states on independent living.<sup>12</sup> This research methodology also aspires to contribute towards a success rate of a diversity of models and a raise of the actual number of promising practices.

During a time-span of two months, we received a total of 102 examples from 22 different countries in the world representing 4 different continents. All these examples were listed in an excel-file and categorised according to the welfare states, countries, a small description, and the style of the support. Each example has been thoroughly examined within the scope of this research. The main criteria for the first selection were:

- Representative for article 19 of the UNCRPD
- Best examples for each welfare state
- Different styles of services

Based on these criteria, 18 examples were introduced to EASPD. The final selection resulted out of the main parameters that came out of the theoretical track. Indeed, after the data collection of both tracks, a cross-analysis from the theoretical and empirical track was conducted and led to the first outline of a conceptual framework for models supporting IL. These 18 examples were thoroughly examined for a second time based on received documents, additional calls, and their websites.

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<sup>12</sup> In 1973 Andersen and Newman created a simplified model of reality in IL organised along three types of determinants: 1. Individual characteristics; 2. Facilitating factors; 3. Welfare system. In: ANDERSEN, R. & NEWMAN, J. F. 1973. Societal and individual determinants of medical care utilization in the United States. *The Milbank Memorial Fund Quarterly. Health and Society*, 51, 95-124.

The final selection of five examples, was made based on concepts, references, documents that demonstrate pioneering work and guarantees a human-centred approach with respect for peoples' voice. The directors of the models were contacted by email with an invitation letter and context of the research. Each case study research consists out of two parts: an interview with the staff members and video testimonials with the people with significant support needs. For the first part, semi-structured interviews were conducted with staff-members of the practice. Each interview was recorded by video and transcriptions during a video call. For the second part, staff members were invited to make video testimonials of three users asking them basic questions about their experiences of the practice. The videos were recorded by the staff, the Personal Assistant (PAS) or their legal counsellor. All data of the semi-structured interview was analysed and organised within a similar template. The video-testimonials proved the participation, autonomy, and self-determination of the users. Subsequently, data of conceptual theoretical framework, the semi-structured interviews and video-testimonials has been triangulated and revealed patterns of support models and interdependence and interactions in between variables and factors of a conceptual framework. The framework reveals the complexity of independent living and how, what and why support is required.

*We immediately move to the findings for the definitions and refer to Annex 1 for the profound details on the methodology of the theoretical track.*

## 6. Theoretical conceptual framework

A theoretical framework is the first objective since a common language and interpretation is recommended to find comparable parameters for selecting promising examples. Systematic literature review<sup>13</sup> reveals that the term “people with significant support needs” has not yet been defined within academic literature. In general, the term has often been used in relation to people with multiple disabilities, a countable number of disabilities<sup>14</sup> or the value of a person’s degree of disabilities.<sup>15</sup> Remarkably, this interpretation starts from the actual abilities or disabilities of people, a medical model approach. However, this research fits in a human centred model approach in which the diversity of people is honoured and “needs” are linked to personal choices instead of abilities. Therefore, this research starts to define “people with significant support needs” in the light of the UN CRPD and a human centred model approach.

Questioning who might be categorised under “people with significant support needs” could unintentionally result in a debate exploring the segregation between “them” and “we”. The act of defining may give the impression that, there is a form of labelling.<sup>16</sup> As this study is embedded in the human centred approach regarding inclusion,<sup>17</sup> defining people with significant support needs is part of this research process towards a workable conceptual framework to value potential promising models. Regardless the fact that insights and definitions can cover the role of generators and gatekeepers for policy making,<sup>18</sup> it is not the main objective of this study. Accordingly, this process of defining must be considered as necessary clarification in the context of a continuous shift towards a more inclusive society, in which language may act as a generator. First, we define the different terms

<sup>13</sup> SIDDAWAY, A. P., WOOD, A. M. & HEDGES, L. V. 2019. How to Do a Systematic Review: A Best Practice Guide for Conducting and Reporting Narrative Reviews, Meta-Analyses, and Meta-Syntheses. *Annu Rev Psychol*, 70, 747-770.

<sup>14</sup> LITVAK, S. & ENDERS, A. 2001. Support Systems: The Interface between Individuals and Environments. In: GARY, A., KATHERINE, S. & MICHAEL, B. (eds.) *Handbook of Disability Studies*. Thousand Oaks: SAGE Publications, Incorporated.

<sup>15</sup> Ibid.

<sup>16</sup> It is a common perception by many that a label can solve a problem, unfortunately it is still too often the starting point for exclusion because it is used in a non-appropriate context or way.

<sup>17</sup> Although this process of defining, aims for inclusion, it still requires statements, and we recommend to be aware of this political sensitivity. Definitions and concepts are always time related and evolving, especially on disability. We invite our readers to mind yourself during reading that this process is a form of exercise in transformation.

<sup>18</sup> DE BRUIJN, J., BUNTINX, WIL, TWINT, BRIAN 2014. *Verstandelijke beperking: definitie en context*, Amsterdam, Uitgeverij SWP Amsterdam.

and subsequently we put the definition in a context of Independent Living. The chapter closes with an outline of a conceptual framework for models of support.

## ▪ People with significant support needs

The term “people with significant support needs” lacks a common definition. Therefore, it has been unravelled to first analyse each term separately and finally compile its general meaning maintaining the UNCRPD’ ambition to empower people’s choice. Need is the first subject to discuss because it specifies who this research refers to. If it is known ‘why’ they need something and ‘what’ they need, it is more evident to subsequently zoom in on the necessary support that characterises the needs. Finally, the adjective ‘significant’ has been explained in the context of this research.

### Need(s)

Literature study reveals different interpretations of the term “need” and outlines a dichotomy. Definitions vary according to research domain or area of expertise, and whether need is defined as something to have<sup>19</sup> or as what people want<sup>20</sup> to respectively have a satisfactory or comfortable life.<sup>21</sup> In general, the concept always refers to life conditions of an individual and its actual interpretation immediately relates to ‘why?’ people need something. We distinguish four categories:

1. Need for survival;
2. Need to fit the norm or meet expectations;
3. Need: what people want, or desire for;
4. Need as a Quality of Life;

<sup>19</sup> The definition of Cambridge Dictionary covers the diversity in perspectives very well in a general explanation: “*the things that a person must have in order to have a satisfactory life.*”. (Cambridge Dictionary, 2022a)

<sup>20</sup> Oxford Dictionary defines “needs” as: “*the things that somebody requires in order to live in a comfortable way or achieve what they want*”

<sup>21</sup> OXFORDDICTIONARY. 2022a. *Oxford Dictionary* [Online]. Oxford: Oxford University Press. Available: [https://www.oxfordlearnersdictionaries.com/definition/english/need\\_2](https://www.oxfordlearnersdictionaries.com/definition/english/need_2) [Accessed].

## 1. Need for survival

Being “in need” means that someone requires help. Consequently, an extensive number of studies use the word as an aspect required for survival.<sup>22</sup> One of the best-known conceptualisations of needs, based on human basic needs, is that of the psychologist Abraham Maslow (1970)<sup>23</sup> who described human behaviour in relation to specific human requirements (physiologic, safety, love and belonging, esteem, self-actualisation needs).<sup>24</sup>

## 2. As something to fit the norm

According to cultural perspectives or scientific frameworks, someone can fit a norm or deviate from it. For example, in a classical medical approach,<sup>25</sup> needs can arise when people deviate from the norm.<sup>26</sup> Similarly, in the domain of sociology, a “need” is sometimes used as a requirement in life to succeed.<sup>27</sup> This perspective starts from a normative evaluation based on checklists, evaluating what people ‘have’.

## 3. As expectations or aspirations

Another approach is to define needs as what people ‘want’ or ‘desire’ for<sup>28</sup>, one’s expectations or aspirations. From a psycho-analytical point of view, Sigmund Freud has

<sup>22</sup> In the Dictionary of Sociology “need” is defined as “something that is deemed necessary for the survival of a person, organisation or whatever and the concept is widely used in the social sciences related to human needs”. In MARSHALL, G. 2022. Need. In: MARSHALL, G. (ed.) *A Dictionary of Sociology*. Oxford: Oxford University Press.

<sup>23</sup> MASLOW, A. 1970. *Motivation and personality*, New York, Harper & Row

<sup>24</sup> Although his research has often been contested<sup>24</sup>, it offers a clear overview of human’s basic needs. Using the pyramid as a metaphor and starting with the basic needs as a fundament, towards the more visceral and cognitive needs that contribute to self-actualisation, the pyramid construction represents an evolving process of needs in which a next level can only be achieved when the founding underlying needs are covered. In the self-determination theory, which is a macro-theory of human motivation that focuses on self-determined behaviour as well as a set of basic psychological needs, needs are defined as: autonomy, competence, and relatedness.<sup>24</sup> These needs are a requirement for a healthy, vital, human functioning in life that enhance wellbeing. This theory starts from the perspective of humans as active organisms.

<sup>25</sup> Within a medical model approach, a health need is essentially value laden. Health has an objective element defining a normative state of nature and an evaluative element, wellbeing. The classical medical approach is that needs arise when the medical norm is uncovered, referring to the “functional ability” as a bodily or mental status of an individual.

<sup>26</sup> For example, in medicine, needs are put in relation to the clinical state of the individual and definitions are based on the scientific knowledge. The main objective is to cure illness and save life or ensure and attain health. NORDENFELT, L. 2007. The concepts of health and illness revisited. *Medicine, health care, and philosophy*, 10, 5-10., p.6

<sup>27</sup> However, this can be related to the fact that norms hold a perspective of equity, whereas in a human rights approach we move towards equality, based on personal objectives and choice.

<sup>28</sup> MARSHALL, G. 2022. Need. In: MARSHALL, G. (ed.) *A Dictionary of Sociology*. Oxford: Oxford University Press.

explained the movement<sup>29</sup> that leads from need to desire.<sup>30</sup> Needs are thus considered as stimuli for aspirations and means of survival.

#### 4. As part of the Quality of life- construct

Increasingly studied in different fields and research areas<sup>31</sup> is the Quality of Life (QoL) framework, developed in different fields (economics, medicine, social sciences, design, etc.),<sup>32</sup> and its outcome is considered as part of welfare.<sup>33</sup> A QoL framework embraces needs as both subjective and objective life conditions and offers people a perspective on their position regarding culture, value systems, goals, expectations, aspirations, standards, and concerns.<sup>34</sup> A detailed description is not within the scope of this study,<sup>35</sup> but interestingly a QoL perspective structures the complexity of needs in a life context.

<sup>29</sup> Freud justifies the term “needs” as: “a drive stimulus that does not arise from the external world, but from within the organism itself” and acts as a constant force, and he states that a better term for ‘drive stimulus’ is ‘need.’ This has put the basis for Freud’s two new theories that explain the levels of complexity within needs and desires.

<sup>30</sup> Freud, (1900) in GOLSE, B. 2022. Primary Need. *International Dictionary of Psychoanalysis*. Cengage.

<sup>31</sup> CLAES, C., VAN HOVE, G., VAN LOON, J., VANDEVELDE, S. & SCHALOCK, R. L. 2010b. Quality of Life Measurement in the Field of Intellectual Disabilities: Eight Principles for Assessing Quality of Life-Related Personal Outcomes. *Social indicators research*, 98, 61-72, HAMBLETON, P., KEELING, S. & MCKENZIE, M. 2009. The jungle of quality of life: Mapping measures and meanings for elders. *Australasian journal on ageing*, 28, 3-6, VAN HECKE, N., CLAES, C., VANDERPLASSCHEN, W., DE MAEYER, J., DE WITTE, N. & VANDEVELDE, S. 2018. Conceptualisation and Measurement of Quality of Life Based on Schalock and Verdugo’s Model: A Cross-Disciplinary Review of the Literature. *Social indicators research*, 137, 335-351, SCHALOCK, R. L. & VERDUGO, M. A. 2002. *Handbook on quality of life for human service practitioners*, Washington, American Association on mental retardation.

<sup>32</sup> Each research field also has its proper QoL-definitions and concepts.

<sup>33</sup> NORDENFELT, L. 2007. The concepts of health and illness revisited. *Medicine, health care, and philosophy*, 10, 5-10.

<sup>34</sup> WHOQOLGROUP 1995. The World Health Organization Quality of Life Assessment (WHOQOL): Position paper from the World Health Organisation. *Social Science and Medicine* 41, 1403-1409.

<sup>35</sup> For extensive research on QoL see literature: CLAES, C., VAN HOVE, G., LOON, J., VANDEVELDE, S. & SCHALOCK, R. L. 2010a. Eight principles for assessing quality of life-related personal outcomes. *Social Indicators Research*, 98, 61-72, HAMBLETON, P., KEELING, S. & MCKENZIE, M. 2009. The jungle of quality of life: Mapping measures and meanings for elders. *Australasian journal on ageing*, 28, 3-6, SCHALOCK, R. L. & VERDUGO, M. A. 2002. *Handbook on quality of life for human service practitioners*, Washington, American Association on mental retardation, NUSSBAUM, M. C. 2011. *Creating Capabilities: The Human Development Approach*, Cambridge, Harvard University Press, DE MAEYER, J., VANDERPLASSCHEN, W. & BROEKAERT, E. 2010. Quality of life among opiate-dependent individuals: A review of the literature. *The International journal of drug policy*, 21, 364-380, BUNTINX, W. H. & SCHALOCK, R. L. 2010. Models of Disability, Quality of Life and Individualized Supports: Implications for Professionals Practice in Intellectual Disability. *Journal of policy and practice in intellectual disabilities*, 7, 283-294, DE WAELE, I., VAN LOON, J., VAN HOVE, G. & SCHALOCK, R. L. 2005. Quality of Life versus quality of care: implications for people and programs. *Ibid.*, 2, 229-239, GRABOWSKA, I., ANTCZAK, R., ZWIERSZCHOWSKI, J. & PANEK, T. 2021. Individual quality of life and the environment - towards a concept of livable areas for persons with disabilities in Poland. *BMC public health*, 21, 740-15, SHOGREN, K. A., BONARDI, A., COBRANCHI, C., KRAHN, G., MURRAY, A., ROBINSON, A., HAVERCAMP, S. M., THE NISONGER, R. O. H. & FUNCTION 2021. State of the Field: The Need for Self-Report Measures of Health and Quality of Life for People With Intellectual and Developmental Disabilities. *Journal of policy and practice in intellectual disabilities*, 18, 286-295, THOMPSON, J. R., BRADLEY, V. J., BUNTINX, W. H., SCHALOCK, R. L., SHOGREN, K. A., SNELL, M. E., WEHMEYER, M. L., BORTHWICK-DUFFY, S., COULTER, D. L., CRAIG, E. P., GOMEZ, S. C., LACHAPPELLE, Y., LUCKASSON, R. A., REEVE, A., SPREAT, S., TASSE, M. J., VERDUGO, M. A. & YEAGER, M. H. 2009. Conceptualizing supports and the support needs of people with intellectual disability. *Intellect Dev Disabil*, 47, 135-46, VAN HECKE, N., CLAES, C., VANDERPLASSCHEN, W., DE MAEYER, J., DE WITTE, N. & VANDEVELDE, S. 2018. Conceptualisation and Measurement of Quality of Life Based on Schalock and Verdugo’s Model: A Cross-Disciplinary Review of the Literature. *Social indicators research*, 137, 335-351, WHOQOLGROUP 1995. The World Health Organization Quality of Life Assessment (WHOQOL): Position paper from the World Health Organisation. *Social Science and Medicine* 41, 1403-1409.



The first foundations for a QoL framework were defined by Maslow (1943)<sup>36</sup> In 1970 Brill and Krauss list nine personal needs that extends the vision and encompasses a broader categorisation (see Figure 4).<sup>37</sup> However, two of the most influential models are: the World Health’s Organisation’s Quality of Life Model<sup>38</sup> (WHOQOL, 1995) and the Schalock and Verdugo QoL-model (2002)<sup>39</sup> which many authors continued working on to create a “Quality of Life” assessment instrument.<sup>40</sup>

Maslow (1943) human needs	Brill & Kraus (1970) personal needs	WHOQOL, 1995 QoL framework	Schalock & Verdugo (2002) QoL framework: domains	Nussbaum (2011) human capabilities
physiological	comfort	physical health	personal development	life
safety	autonomy	psychological health	self determination	physical health
belonging and love	stimulation	social relationships	interpersonal relationships	physical immunity
esteem	cognition	environment	social inclusion	sensitive perception
cognitive	function		rights	feelings
aesthetic	novelty		material well-being	practical reason
transcendental	order		emotional wellbeing	social bonding
	affiliation		physical wellbeing	respecting other biological species
	privacy			game
				designing your own environment

Figure 1 Overview on the categorisation of needs in the context of QoL

Recently, Martha Nussbaum (2011) introduced human needs as ten basic interacting capabilities which she considers as required and guaranteed within a civil society.<sup>41</sup> Remarkably, Nussbaum’s

<sup>36</sup> MASLOW, A. 1954. *Motivation and personality*, New York, Harper.; MASLOW, A. 1943. A theory of human motivation. *Psychological Review*, 50, 370-396.  
 MASLOW, A. 1970. *Motivation and personality*, New York, Harper & Row Maslow’s research has been contested, partly due to the pyramid structure in which he wanted to capture the metaphor of dynamics between different needs. This metaphor remained quiet rigid.  
<sup>37</sup> BRILL, M. & KRAUSS, R. Planning for Community Mental Health Centers. In: SANOFF, H. & COHN, S., eds., 1970 Edmonton. EDRA.  
<sup>38</sup> The Physical domain refers to the person’s perceptions on their physical status, the psychological domain refers to a person’s perceptions on their cognitive and affective state and the social domain relies to the interpersonal relationships and social roles.  
<sup>39</sup> SCHALOCK, R. L. & VERDUGO, M. A. 2002. *Handbook on quality of life for human service practitioners*, Washington, American Association on mental retardation.  
<sup>40</sup> CLAES, C., VAN HOVE, G., VAN LOON, J., VANDEVELDE, S. & SCHALOCK, R. L. 2010b. Quality of Life Measurement in the Field of Intellectual Disabilities: Eight Principles for Assessing Quality of Life-Related Personal Outcomes. *Social indicators research*, 98, 61-72.  
<sup>41</sup> NUSSBAUM, M. C. 2011. *Creating Capabilities: The Human Development Approach*, Cambridge, Harvard University Press, NUSSBAUM, M. C. 2006. *Frontiers of justice: disability, nationality, species membership*, Cambridge, Mass, Belknap Press.

work not only starts from people’s personal aspirations, but from the recognition of human rights in society and dignity towards our planet earth, calling for respecting all living species on earth.<sup>42</sup> She links the validation of human rights to the GNP (Gross National Product).<sup>43</sup> Researchers state that this classification is integrally applicable for people with disabilities.<sup>44</sup> Indeed this honours diversity in all areas and is therefore a sustainable vision, which intrinsically generates the ambition of the UN CRPD. Insight in ‘why’ we need and ‘what’ we exactly may need in life, offers opportunities to categorise what forms of support are required and hence support can meet needs and is determined by needs.

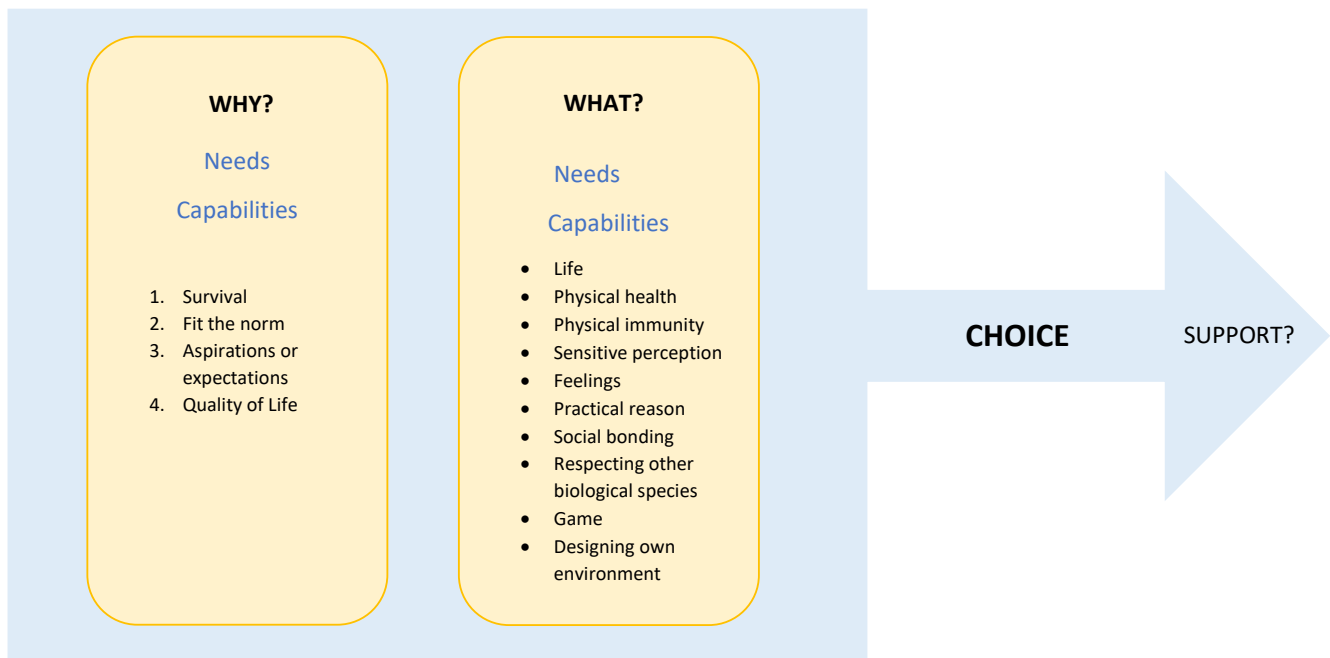


Figure 2 Scheme outlining how choice bridges needs and support

<sup>42</sup> NUSSBAUM, M. C. 2011. *Creating Capabilities: The Human Development Approach*, Cambridge, Harvard University Press.

<sup>43</sup> SEN, A. 2004. Capabilities, Lists, and Public Reason: Continuing the Conversation. *Feminist economics*, 10, 77-80. Economic growth is no longer the only standard because people’s rightful capabilities are included. In SEN, A. 2004. Capabilities, Lists, and Public Reason: Continuing the Conversation. *Feminist economics*, 10, 77-80 and NUSSBAUM, M. C. 2011. *Creating Capabilities: The Human Development Approach*, Cambridge, Harvard University Press.

<sup>44</sup> VAN GENNEP, A. T. G. 2009. Verstandelijke beperkingen als sociaal probleem? Kansen of bedreigingen vnan het burgerschapsparadigma. *Nederlands Tijdschrift voor de Zorg aan mensen met verstandelijke beperkingen.*, 35, 101-124.

## Support

In the context of independent living, “support” is related to the enjoyment of human rights that make independent living possible and enables one to carry their daily life, gain access to their world, and participate as citizen.<sup>45</sup> In other words supports cover the needs as defined for the individual and can be a matter of survival in crucial situations. There is a diversity of explanations of the term support, and consequently a range of possible interpretations.<sup>46</sup> Research proves an existing gap<sup>47</sup> between perception, use and the actual nature of support because the term is often interchangeably used with ‘care’ and ‘services’. Whereas “care” generally implies the assistance of others, support refers to the specific style of service preferably based on choice.<sup>48</sup> In some countries, different meaning is given to services and supports, and pitted against each other.<sup>49</sup> Depending on the language and the used terminology, different use of words is adopted and sometimes services are meant as part of the support whereas in other contexts, it refers to the whole support system.

Support is in many contexts considered as a single intervention but can also be considered as a dynamic support system, and each of us holds a personalised system based on the basic elements: personal assistance (cooperation), assistive technology (tools) and adaptive strategies (strategies).<sup>50</sup>

Our literature study unfolds the following general requirements for support in the context of Independent Living:

1. The form of support always contributes to the improvement of a person’s quality of life;
2. Support is unconditional: the supported person doesn’t have to meet certain conditions and receives support based on personal choice

<sup>45</sup> LITVAK, S. & ENDERS, A. 2001. Support Systems: The Interface between Individuals and Environments. In: GARY, A., KATHERINE, S. & MICHAEL, B. (eds.) *Handbook of Disability Studies*. Thousand Oaks: SAGE Publications, Incorporated.

<sup>46</sup> CAMBRIDGEDICTIONARY 2022b. Support. Cambridge: Cambridge University Press.

<sup>47</sup> LITVAK, S. & ENDERS, A. 2001. Support Systems: The Interface between Individuals and Environments. In: GARY, A., KATHERINE, S. & MICHAEL, B. (eds.) *Handbook of Disability Studies*. Thousand Oaks: SAGE Publications, Incorporated., p.725

<sup>48</sup> EEGTICC, E. E. G. O. T. F. I. T. C.-B. C. 2019. Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community based service. Brussels: European Commission.

<sup>49</sup> ENDERS, A. Personal Assistance Services and Assistive technology: Allies or Adversaries. RESNA, 1995 Arlington, VA. RESNA, 584-586, LITVAK, S. & ENDERS, A. 2001. Support Systems: The Interface between Individuals and Environments. In: GARY, A., KATHERINE, S. & MICHAEL, B. (eds.) *Handbook of Disability Studies*. Thousand Oaks: SAGE Publications, Incorporated.

<sup>50</sup> LITVAK, S. & ENDERS, A. 2001. Support Systems: The Interface between Individuals and Environments. In: GARY, A., KATHERINE, S. & MICHAEL, B. (eds.) *Handbook of Disability Studies*. Thousand Oaks: SAGE Publications, Incorporated.

3. A social network is very important: both formal and informal is regarded as social inclusion.<sup>51</sup>

More specifically different forms of support referring to specific needs can be determined:

practical support (running the household), cognitive support, facilitative support, educational support, emotional dialogue, advisory support (e.g. finance, communication), intervening, inclusion oriented and advocacy support.<sup>52</sup> Support can be obtained offered by public, private, and non-governmental providers.

Support can apply to everyone; and this study refers to a distinction by designating it as significant. What makes support significant?

## Significant

Significant is an adjective highlighting the actual content that follows and indicates the actual required support as 'important or noticeable'<sup>53</sup> in relation to the needs. Sometimes "significant" is used to stress the degree of disabilities<sup>54</sup>, however in the context of the UN CRPD we look at the significance of the choices requested and their level of impact on daily life instead of a person's abilities.

Interestingly, in American English the word has a dynamic connotation indicating that it can lead to a

<sup>51</sup> ZAAGSMA, M., VAN DE VELDE, D., KONING, M. H. M., VOLKERS, K. M., SCHIPPERS, A. P. & VAN HOVE, G. 2021. 'When I need them, I call them and they will be there for me'. Experiences of independently living people with intellectual disabilities with 24/7 available online support. *Disability & society*, ahead-of-print, 1-24, VAN GENNEP, A. T. G. 2009. Verstandelijke beperkingen als sociaal probleem? Kansen of bedreigingen vnan het burgerschapsparadigma. *Nederlands Tijdschrift voor de Zorg aan mensen met verstandelijke beperkingen.*, 35, 101-124, VAN GENNEP, A. T. G. 2000. *Emancipatie van de zwaksten in de samenleving: Over paradigma's van verstandelijke handicap*, Amsterdam, Boom, TANAKA, E. 2009. Independent living and Life Resources for People with Disabilities. 46-70, TANAKA, E. 2018. Diversity of Independent Living. *Journal of disability studies*, 14, 35-53, ROETS, G., DERMAUT, V., BENOOT, T., CLAES, C., SCHIETTECAT, T., ROOSE, R., VAN LANCKER, W. & VANDELDE, S. 2020. A Critical Analysis of Disability Policy and Practice in Flanders: Toward Differentiated Manifestations of Interdependency. *Journal of policy and practice in intellectual disabilities*, 17, 108-115, REMMERY, M., ROETS, G., BENOOT, T., VERVLOESEM, E., DERMAUT, V. & ROOSE, R. 2021. Ruimte voor zorg: Reflectie- en inspiratiekader de-institutionalising. Gent: UGent, IRIARTE, E. G., MCCONKEY, R. & VILDA, D. 2021. Family experiences of personalised accommodation and support for people with intellectual disability. *Journal of intellectual disabilities*, 25, 476-489, MCCONKEY, R. & COLLINS, S. 2010. The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of intellectual disability research*, 54, 691-700, MCCONKEY, R. 2007. Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Ibid.* 51, 207-217, DESROCHES, M. L., FISHER, K., AILEY, S., STYCH, J., MCMILLAN, S., HORAN, P., MARSDEN, D., TRIP, H. & WILSON, N. 2022. Supporting the needs of people with intellectual and developmental disabilities 1 year into the COVID-19 pandemic: An international, mixed methods study of nurses' perspectives. *Journal of policy and practice in intellectual disabilities*, 19, 48-63, CLAES, L., DE SCHAUWER, E. & VAN HOVE, G. 2013. Disability studies and social geography make a good marriage: Research on life trajectories of people with intellectual disabilities and additional mental health problems. In: WAPPET, M. & ARNDT, K. (eds.) *Emerging perspectives on disability studies*. London: Palgrave Macmillan, CASALEIRO, T., CALDEIRA, S., CARDOSO, D. & APÓSTOLO, J. 2022. Spiritual aspects of the family caregivers' experiences when caring for a community-dwelling adult with severe mental illness: A systematic review of qualitative evidence. *Journal of psychiatric and mental health nursing*, 29, 240-273.

<sup>52</sup> VAN GENNEP, A. T. G. 1997. *Paradigmaverschuiving in de visie op zorg voor mensen met een verstandelijke handicap*, Utrecht, NIZW, DRAAK, M. D., MARANGOS, A. M., PLAISIER, I. & KLERK, M. D. 2016. *Wel thuis? Literatuurstudie naar factoren die zelfstandig wonen van mensen met beperkingen beïnvloeden*, Den Haag, Sociaal en Cultureel Planbureau.

<sup>53</sup> CAMBRIDGEDICTIONARY. 2022a. *Cambridge Dictionary* [Online]. Cambridge: Cambridge University Press. Available: <https://dictionary.cambridge.org/dictionary/english/need> [Accessed].

<sup>54</sup> LITVAK, S. & ENDERS, A. 2001. Support Systems: The Interface between Individuals and Environments. In: GARY, A., KATHERINE, S. & MICHAEL, B. (eds.) *Handbook of Disability Studies*. Thousand Oaks: SAGE Publications, Incorporated.

different result or change over time.<sup>55</sup> In this study significant is considered as ‘important’ support that deviates from personal choices and self-determination and may change over time.

Based on the definitions drawn from the literature study this study understands **people with significant support needs as:**

*Individuals who experience an important amount or a high degree of (cap)abilities or disabilities within themselves or at a micro-, meso- or macro-level of the environment requiring a specific style of service based on personal choice, that empowers or disables themselves in processing their “Quality of Life” These (cap)abilities or disabilities are time-related and defined by a dynamic relationship in between individual choices, time, context, and funding. It may require encouragement, help or maintenance in a material or immaterial way. The choice of the individual is always at the heart of this requirement.*

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<sup>55</sup> UNKNOWN 2022. Significant. *Cambridge Academic* Cambridge: Cambridge University Press.

## ■ Independent Living in a human centred model approach

Independent living is a human right. The UN CRPD, legally binding for State parties, strives towards the right of inclusion, personal autonomy, and participation, and encourages empowerment and personal choice on IL. Despite the ratification of this convention by all EU member states, many researchers and policymakers note a lack of proper implementation as originally foreseen. Based on literature<sup>56</sup>, this study argues that a common definition is missing for Independent Living, what results in different interpretations and executions of the UN CRPD. Consequently, research shows opposite outcomes than originally intended. Systematic literature review demonstrates that:

1. IL is often reduced to the inclusion or exclusion of people in an institution, leaving a building or leaving the personal network.<sup>57</sup> Focus is put on the institute represented by a physical building; hence independent living is considered as the certainty of the psychological and physical nest. However, IL is not restricted to a personal property, but it encompasses the different aspects that determine life.
2. The process of deinstitutionalisation unintentionally contributes to the disappearance of autonomy, self-determination, and participation of people with disabilities.<sup>58</sup> Consequently, people with several disabilities are less likely to successfully experience inclusion,<sup>59</sup> because they experience exclusion, stigma, and isolation<sup>60</sup> and are therefore defined as part of the most vulnerable group for institutionalisation.<sup>61</sup>

<sup>56</sup> TANAKA, E. 2018. Diversity of Independent Living. *Journal of disability studies*, 14, 35-53.

<sup>57</sup> AZUMI, J., MASYUKI, O., FUMIYA, O. & SHINAYA, T. 2012. Raw Techniques. 3, 9, DRAAK, M. D., MARANGOS, A. M., PLAISIER, I. & KLERK, M. D. 2016. *Wel thuis? Literatuurstudie naar factoren die zelfstandig wonen van mensen met beperkingen beïnvloeden*, Den Haag, Sociaal en Cultureel Planbureau, TANAKA, E. 2018. Diversity of Independent Living. *Journal of disability studies*, 14, 35-53.

<sup>58</sup> EGTICC, E. E. G. O. T. F. I. T. C.-B. C. 2019. Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community based service. Brussels: European Commission, REMMERY, M., ROETS, G., BENOOT, T., VERVLOESEM, E., DERMAUT, V. & ROOSE, R. 2021. Ruimte voor zorg: Reflectie- en inspiratiekader de-institutionalisering. Gent: UGent, UN 2007. Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly. In: NATIONS, U. (ed.) *A/RES/61/106*. New York: UN General Assembly.

<sup>59</sup> BEADLE-BROWN, J., MANSELL, J. & KOZMA, A. 2007. Deinstitutionalisation in intellectual disabilities. *Current opinion in Psychiatry*, 20, 437-442, MANSELL, J. 2006. Deinstitutionalisation and community living: Progress, problems and priorities. *Journal of Intellectual and developmental disability*, 31, 64-76.

<sup>60</sup> BEADLE-BROWN, J., MANSELL, J. & KOZMA, A. 2007. Deinstitutionalisation in intellectual disabilities. *Current opinion in Psychiatry*, 20, 437-442, MANSELL, J. 2006. Deinstitutionalisation and community living: Progress, problems and priorities. *Journal of Intellectual and developmental disability*, 31, 64-76, BREDEWOLD, F., TONKENS, E., TRAPPENBURG, M. J., GOVERNANCE, U. L. R. U. P. M. P., MANAGEMENT, GOVERNANCE, P. & MATTERS, U. L. R. U. P. 2016. Urban encounters limited: The importance of built-in boundaries in contacts between people with intellectual or psychiatric disabilities and their neighbours. *Urban studies (Edinburgh, Scotland)*, 53, 3371-3387.

<sup>61</sup> In 2019, a European Expert group on the Transition from Institutional to Community-based Care was established and developed a checklist for evaluation of EU-funding to avoid misuse. In this document they also refer to what has been the most vulnerable group for institutionalisation (EGTICC, 2019) as follows: children and young adults with a disability, people with a disability and psychological disabilities, elderly people with a disability, homeless people.

3. People with significant support needs are often the last people who move out of institutions and the first to move back into institutions: re-institutionalisation<sup>62</sup> and again the level of vulnerability has been used to motivate these acts.
4. Research also shows a pure practical fact, more precisely a lack of good support and services adapted to the needs of people with support needs<sup>63</sup> and it puts both the informal and formal network under pressure.<sup>64</sup>
5. The UN CRPD has often become an awareness creator and generator for deinstitutionalisation, but this process sometimes results in even more segregation and stigma as a result of categorisation in language and communication. For example, research of Draak et al. (2016) states that IL is frequently connected to people with disabilities and categorised into three groups:
  - Care and caring (people who need care, elderly, and people with dementia),
  - People with a disability (people with cognitive, physical, sensitive, and multiple impairments),
  - People with a psychiatric disorder.<sup>65</sup>
6. IL's meaning can vary depending on the country, state, and its respective welfare state, cities, and communities.<sup>66</sup> Dominating institutional culture, concepts, and socio-cultural embedded frameworks<sup>67</sup> mark a country or society and influence the performance of

<sup>62</sup> MANSELL, J. 2006. Deinstitutionalisation and community living: Progress, problems and priorities. *Journal of Intellectual and developmental disability*, 31, 64-76, REMMERY, M., ROETS, G., BENOOT, T., VERVOESEM, E., DERMAUT, V. & ROOSE, R. 2021. Ruimte voor zorg: Reflectie- en inspiratiekader deinstitutionalisering. Gent: UGent, ROETS, G., DERMAUT, V., BENOOT, T., CLAES, C., SCHIETTECAT, T., ROOSE, R., VAN LANCKER, W. & VANDELDE, S. 2020. A Critical Analysis of Disability Policy and Practice in Flanders: Toward Differentiated Manifestations of Interdependency. *Journal of policy and practice in intellectual disabilities*, 17, 108-115.

<sup>63</sup> FAKHOURY, W. & PRIEBE, S. 2007. Deinstitutionalization and reinstitutionalization: major changes in the provision of mental healthcare. *Psychiatry (Abingdon, England)*, 6, 313-316, PRIEBE, S. 2004. Institutionalization revisited - with and without walls. *Acta psychiatrica Scandinavica*, 110, 81-82.

<sup>64</sup> KOSTER, M. 2014. Bridging the gap in the Dutch participation society: New spaces of governance, brokers and informal politics. *Etnofoor*, 26, REMMERY, M., ROETS, G., BENOOT, T., VERVOESEM, E., DERMAUT, V. & ROOSE, R. 2021. Ruimte voor zorg: Reflectie- en inspiratiekader deinstitutionalisering. Gent: UGent, MOREL, N. 2007. From subsidiarity to "free choice": Child and elder-care policy reforms in France, Belgium, Germany and the Netherlands. *Social policy & administration*, 41, 618-637.

<sup>65</sup> DRAAK, M. D., MARANGOS, A. M., PLAISIER, I. & KLERK, M. D. 2016. *Wel thuis? Literatuurstudie naar factoren die zelfstandig wonen van mensen met beperkingen beïnvloeden*, Den Haag, Sociaal en Cultureel Planbureau.

<sup>66</sup> KROMTHOUT, M., FEIJTEN, P., VONK, F., DE KLERK, M., MARANGOS, A. M., MENSINK, W., DEN DRAAK, M. & DE BOER, A. 2014. De Wmo in beweging. Evaluatie Wet maatschappelijke ondersteuning 2010-2012. Den Haag: Sociaal en Cultureel planbureau, TANAKA, E. 2009. Independent living and Life Resources for People with Disabilities. 46-70, TANAKA, E. 2018. Diversity of Independent Living. *Journal of disability studies*, 14, 35-53.

<sup>67</sup> CAMPBELL, F. K. 2009. *Contours of Ableism: The production of Disability and Aabledness*, New York, Palgrave MacMillan, DEVLIEGER, P. 2016. *Rethinking disability : world perspectives in culture and society*, Antwerp, Garant, UN 2007. Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly. In: NATIONS, U. (ed.) A/RES/61/106. New York: UN General Assembly.

deinstitutionalisation.<sup>68</sup> For example, different disability models<sup>69</sup> have been designed to capture the diversity of socio-cultural perspectives, regarding people with disabilities. In a medical or social model approach, people with disabilities are still too often perceived as “special” or “in need”, excluding their freedom of choice.<sup>70</sup> Considering the UNCRPD, this study acknowledges the human rights approach<sup>71</sup> or cultural model approach<sup>72</sup> in which the identity of the person is core, the driver is inclusion and human diversity is celebrated. It is the most recent and modern disability model. Despite the historical origin of these models, they can appear next to each other in the same era and in between different cultures. Consequently, the dominating model can influence the actual implementation of IL.

7. Research shows that although societies may be very progressive, people with disabilities are still confronted with severe social and cultural trailing that impacts their wellbeing and meaning of life<sup>73</sup> and reveals a huge impact at societal level because people are sometimes unwilling to include people with disabilities in their community.<sup>74</sup> Too often the advantages are questioned<sup>75</sup> and this lack of knowledge, fears, and disadvantages, calls for more insights to improve the actual systems generating inclusion so the uncertainty for people with disabilities disappears.

Consistency within the objectives of this study requires a correct meaning of IL and therefore its meaning is briefly explained and outlined in the following section.

<sup>68</sup> EEGTICC, E. E. G. O. T. F. I. T. C.-B. C. 2019. Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community based service. Brussels: European Commission, MURPHY, K. & BANTRY-WHITE, E. 2021. Behind closed doors: Human rights in residential care for people with an intellectual disability in Ireland. *Disability & society*, 36, 750-771, UN 2007. Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly. In: NATIONS, U. (ed.) *A/RES/61/106*. New York: UN General Assembly.

<sup>69</sup> DEVLIEGER, P. 2016. *Rethinking disability : world perspectives in culture and society*, Antwerp, Garant.

<sup>70</sup> UN 2007. Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly. In: NATIONS, U. (ed.) *A/RES/61/106*. New York: UN General Assembly.

<sup>71</sup> Ibid.

<sup>72</sup> DEVLIEGER, P. 2016. *Rethinking disability : world perspectives in culture and society*, Antwerp, Garant.

<sup>73</sup> DE WISPELAERE, J. & CASASSAS, D. 2012. Handicap, vrijheid en overheersing. Een republikeins perspectief op het gehandicaptentbeleid. *Ethiek en maatschappij*, 13, 53-78.

<sup>74</sup> For example, in the Netherlands, the last twenty years, many people with disability moved from institutions to the residential areas. In general, studies prove that the quality of the person with a disability has improved, however social integration is still an issue and not yet the case. In: *ibid*.

<sup>75</sup> DRAAK, M. D., MARANGOS, A. M., PLAISIER, I. & KLERK, M. D. 2016. *Wel thuis? Literatuurstudie naar factoren die zelfstandig wonen van mensen met beperkingen beïnvloeden*, Den Haag, Sociaal en Cultureel Planbureau., p.15



## Defining Independent Living

As a concept appropriated by the “disability rights movement” in the 1960s, IL evolved into the independent living movement. Therefore, it is frequently associated with a worldwide movement, striving for equal opportunities, self-determination, and self-respect. In this context, some researchers already consider it as a service to help.<sup>76</sup>

IL is not a synonym for “help” or “doing things for yourself” or being “self-sufficient”<sup>77</sup> but refers to people being able to make choices and decisions as to where they live, who they live with and how they organise their daily life.<sup>78</sup> This study follows the definition of Litvak & Enders in which *“Independent living means self-determination. It means being in control of one’s life, choosing one’s own goals and activities, and ultimately defining one’s own support system, including the tools, strategies, and cooperation (people or animals) necessary to any given task to objective in all the environments in which the support system is needed.”*<sup>79</sup> So IL evokes the opposite experiences of an institution that can be defined as a place or a setting in which: 1. people with a disability are obliged to live together, or isolated from society or segregated in a residential facility, 2. There is a lack of control for residents’ daily decisions, 3. Priorities of the institution are put forward instead of the needs of the residents.<sup>80</sup>

Whereas social life in institutions often takes place on site or within the walls of an institution, this is different in IL because a network changes when living in the community. The psychological experience of having a personal space, meaningful activities and belonging is as important as the

<sup>76</sup> ROSKEN, A., CROSBY, N. & FUZESI, P. 2020. From institution to community living: collection of Models of Good practice in deinstitutionalisation for people with high support needs/multiple disabilities including practices on how assistive technology can support inclusive living. Brussels: EASPD.

<sup>77</sup> UN 2007. Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly. In: NATIONS, U. (ed.) A/RES/61/106. New York: UN General Assembly.

<sup>78</sup> BULIC, I., ANGUELOVA-MLADENOVA, L., GYLLENSTEN, L. & MULHEIR, G. 2012. Common European Guidelines on the Transition from Institutional to Community-based Care. In: CARE, E. E. G. O. T. F. I. T. C.-B. (ed.). Brussels: European Expert Group on the Transition from Institutional to Community-based Care., p.31

<sup>79</sup> LITVAK, S. & ENDERS, A. 2001. Support Systems: The Interface between Individuals and Environments. In: GARY, A., KATHERINE, S. & MICHAEL, B. (eds.) *Handbook of Disability Studies*. Thousand Oaks: SAGE Publications, Incorporated., p.725

<sup>80</sup> BEADLE-BROWN, J., MANSELL, J. & KOZMA, A. 2007. Deinstitutionalisation in intellectual disabilities. *Current opinion in Psychiatry*, 20, 437-442, MURPHY, K. & BANTRY-WHITE, E. 2021. Behind closed doors: Human rights in residential care for people with an intellectual disability in Ireland. *Disability & society*, 36, 750-771, REMMERY, M., ROETS, G., BENOOT, T., VERVLOESEM, E., DERMAUT, V. & ROOSE, R. 2021. Ruimte voor zorg: Reflectie-

en inspiratiekader de-institutionalisering. Gent: UGent.

actual physical home.<sup>81</sup> Hence, the UN CRPD (Article 19) explains that: “*independent living is often used interchangeably with “community living”*”.

Based on the foregoing insights we define independent living as follows: ***Independent living is a state of being in which individuals, based on their capabilities, live in a setting of their own choice by means of support needs and systems of their own choice, how and who they live with. The state of independency relates to both material as well as immaterial aspects in life that guarantee a satisfying level of quality of life.***

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<sup>81</sup> MCCONKEY, R. & COLLINS, S. 2010. The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of intellectual disability research*, 54, 691-700, *ibid.*, PILLA, D. & PARK-TAYLOR, J. 2022. “Halfway Independent”: Experiences of formerly homeless adults living in permanent supportive housing. *Journal of community psychology*, 50, 1411-1429.

## ■ A conceptual framework for models of support

To find the right promising models endorsing inclusion and IL, a conceptual framework that outlines the characteristics determining a support model on independent living in the community, is developed to verify the values of the practices with the ambitions of the UNCRPD. Based on the findings in the literature review, we have mapped out the different elements and actors that intervene on a model for independent living. Mapping enables us to clarify the relations and interactions between the different characteristics and ensures the level of inclusion at IL.

In this conceptual framework, independent living is considered as a personal system that should be specifically defined for every person following their choices and conditions. According to *'The checklist to ensure EU-funded measures contribute to IL'*, being included in the community versus being segregated in an institution is based on control over one person's life, location and style of service.<sup>82</sup> This study respectively defines this as choice, context and style of service. Additionally, time and funding are included as variables that influence the style of service.

More precisely, support can come in different forms and these forms are just one of several aspects that characterise a style of service. In addition to forms, our literature study reveals the following factors:

- Approach
- Kind of assistance
- Network availability

The actual support or style of service can vary depending on the choice of people, time, context, and funding.

In the following section, the different aspects that characterise a style of service as well as the variables that can influence the style of service are explained and mapped.

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<sup>82</sup> EEGTICC, E. E. G. O. T. F. I. T. C.-B. C. 2019. Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community based service. Brussels: European Commission, REMMERY, M., ROETS, G., BENOOT, T., VERVLOESEM, E., DERMAUT, V. & ROOSE, R. 2021. Ruimte voor zorg: Reflectie- en inspiratiekader de-institutionalisering. Gent: UGent, UN 2007. Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly. In: NATIONS, U. (ed.) *A/RES/61/106*. New York: UN General Assembly.

## Style of service

### 1. Factors of style: approach, kind of assistance, forms of support and network

Based on the literature we distinguish different factors of the style of service as follows:

approach	kind of assistance	forms of support	network availability
material immaterial	<b>human</b> PAS (personal assistant) professional (consultant, trainer, ...) family, friends, neighbours animals <b>technological</b> AT (assistive technology) + AI platform <b>organisational</b> AS (assistive strategy)	practical support cognitive support facilitative support educational support emotional dialogue advisory support intervening inclusion oriented support financial advocacy support	informal formal

Figure 3 Overview on the factors that determine the style of service.

A first factor defines the link between support and its approach: material (income, house,...) or immaterial (status, network,...).<sup>83</sup> The second factor, is the used medium or kind of assistance through which support has been offered: human (family, friends, neighbours, personal assistance services (PAS), professionals, animals) or technological (a platform, assistive technology, artificial intelligence) or organisational (assistive strategy (AT)).<sup>84</sup> A style of service can be defined by the offered forms of support<sup>85</sup>: practical, cognitive, facilitative, educational, emotional, advisory, intervening, inclusion oriented, financial, advocacy. Finally, the available network will contribute to the style of service. Whether people can rely on an informal or formal network<sup>86</sup>, its actual size and their inclusive approach will affect support. Literature proves that living in a home environment with family has no

<sup>83</sup> DRAAK, M. D., MARANGOS, A. M., PLAISIER, I. & KLERK, M. D. 2016. *Wel thuis? Literatuurstudie naar factoren die zelfstandig wonen van mensen met beperkingen beïnvloeden*, Den Haag, Sociaal en Cultureel Planbureau., p.13

<sup>84</sup> LITVAK, S. & ENDERS, A. 2001. Support Systems: The Interface between Individuals and Environments. In: GARY, A., KATHERINE, S. & MICHAEL, B. (eds.) *Handbook of Disability Studies*. Thousand Oaks: SAGE Publications, Incorporated.

<sup>85</sup> VAN GENNEP, A. T. G. 1997. *Paradigmaverschuiving in de visie op zorg voor mensen met een verstandelijke handicap*, Utrecht, NIZW, DRAAK, M. D., MARANGOS, A. M., PLAISIER, I. & KLERK, M. D. 2016. *Wel thuis? Literatuurstudie naar factoren die zelfstandig wonen van mensen met beperkingen beïnvloeden*, Den Haag, Sociaal en Cultureel Planbureau.

<sup>86</sup> MOONEN, X. 2014. Visie op ondersteuning. In: DE BRUIJN, J., BUNTINX, WIL, TWINT, BRIAN (ed.) *Verstandelijke beperking: definitie en context*. Amsterdam: Uitgeverij SWP Amsterdam.

guarantee for inclusion as people can still experience a form of exclusion or segregation due to existing social and cultural models and concepts: “institutionalisation at home”<sup>87</sup> or “trans-institutionalisation”<sup>88</sup>, “community institutions and institution-like practices within community care”<sup>89</sup>, or “asylum without walls”.<sup>90</sup>

All different factors of the style of service will offer insight into the availability of the services.

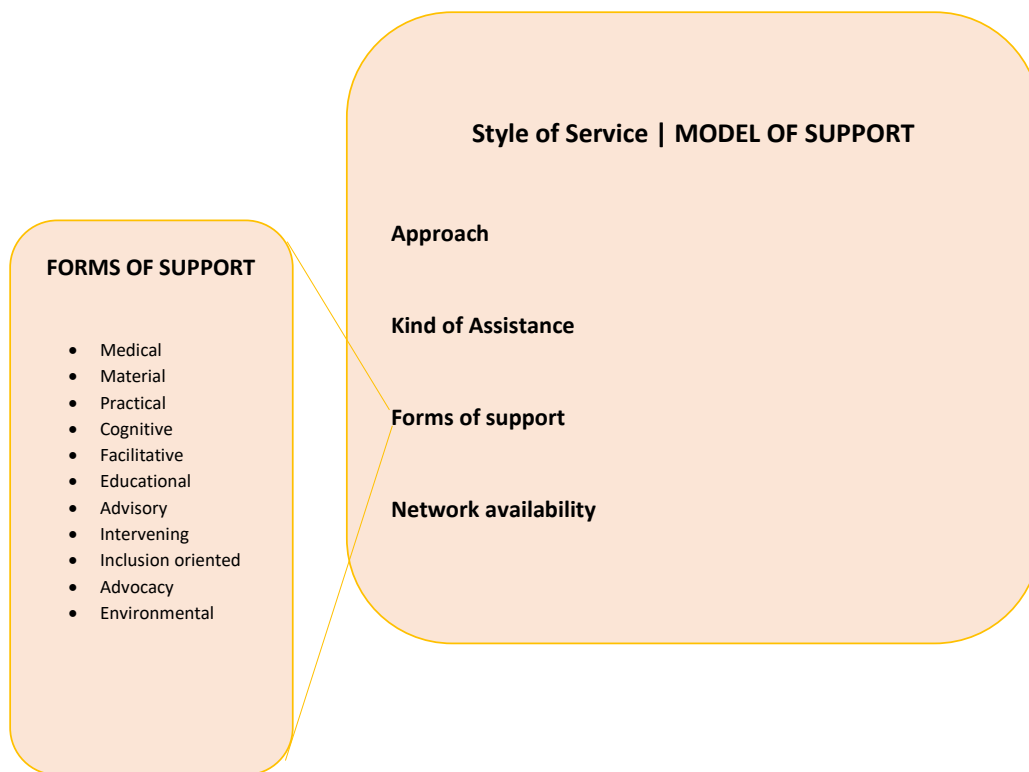


Figure 4 Scheme indicating 'Forms of Support' as a factor in the Style of Service or Model of support

<sup>87</sup> REMMERY, M., ROETS, G., BENOOT, T., VERVLOESEM, E., DERMAUT, V. & ROOSE, R. 2021. Ruimte voor zorg: Reflectie- en inspiratiekader de-institutionalisering. Gent: UGent, BEADLE-BROWN, J., MANSELL, J. & KOZMA, A. 2007. Deinstitutionalisation in intellectual disabilities. *Current opinion in Psychiatry*, 20, 437-442, VERVLIET, M., REYNAERT, D., VERELST, A., VINDEVOGEL, S. & DE MAEYER, J. 2019. “If You Can’t Follow, You’re Out.” The Perspectives of People with Mental Health Problems on Citizenship. *Applied Research in Quality of Life*, 14, 891-908.

<sup>88</sup> HÖGSTRÖM, E. 2018. It used to be here but moved somewhere else: Post-asylum spatialisations- A new urban frontier? *Social and Cultural Geography*, 19, 314-355.

<sup>89</sup> TØSSEBRO, J., BONFILS, I. S., TEITTINEN, A., TIDEMAN, M., TRAUSTADÓTTIR, R. & VESALA, H. T. 2012. Normalization Fifty Years Beyond-Current Trends in the Nordic Countries. *Journal of policy and practice in intellectual disabilities*, 9, 134-146.

<sup>90</sup> Dear & Wolch, 1987 in HALL, E. 2005. The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health & place*, 11, 107-115.

## 2. Variables determining the style of service: choice, time, context, and funding.

According to Moonen (2014): *the support needs of persons are the result of the individual capacities, wishes and desires on the one hand and on the other hand the context in which someone functions.*<sup>91</sup> In other words it depends on choice and the context: location or environment. Based on our literature review time,<sup>92</sup> and funding are also considered as influential variables.

context	time	funding
location	day	public
political	night	private
welfare state	long-term	non-governmental
community	short term	
architecture/ urban	temporarily	
	biorythm	

Figure 6 overview of variables determining the style of service

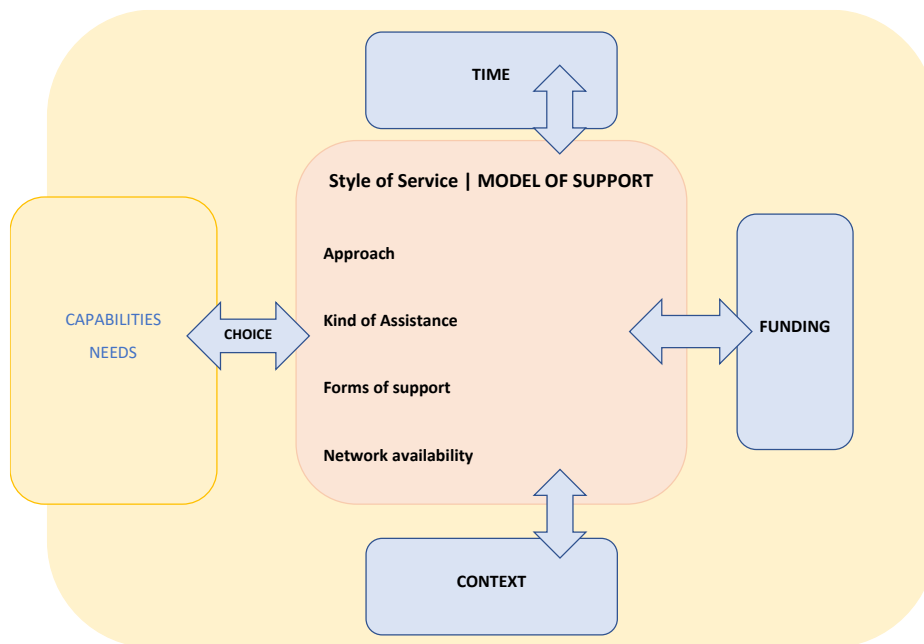


Figure 5 Conceptual framework outlining the four variables in relation to the Style of Service or the Model of Support

<sup>91</sup> MOONEN, X. 2014. Visie op ondersteuning. In: DE BRUIJN, J., BUNTINX, WIL, TWINT, BRIAN (ed.) *Verstandelijke beperking: definitie en context*. Amsterdam: Uitgeverij SWP Amsterdam., p.118

<sup>92</sup> In the actual categorisation of services, attention has been given by the EEG towards 1. the individual personal needs and preferences, 2. the time-related aspects, 3. the network. In EEGTICC, E. E. G. O. T. T. F. I. T. C.-B. C. 2019. Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community based service. Brussels: European Commission.

## Support in dialogue with choice

The act of choice will influence the style of service. As explained before, every person holds a personal set of needs that are at the basis of a personal choice. It determines ‘what’ and ‘why’ they need support. If other people make this choice, the style of service will be influenced by their determinants different from the person who requires the support. Since this study focuses on personal choice, other options are left out to build up this conceptual model.

## Support in dialogue with time

The aspect of time brings in a dynamic that is rather new to existing frameworks. People can be permanent or temporarily<sup>93</sup> disabled, during day, night or night and day. Consequently, support can be day-care or long-term care, it can be permanent or temporarily, and it can be linked to one’s biorhythm. People can have short term needs or long term needs and thus abilities can change over time. It is possible to change in all stages of life the enclosure of inclusion.<sup>94</sup> This makes us aware that, based on time, the experience and perception of people with disabilities may differ from those of their social networks as well as policy institutes.<sup>95</sup>

Besides the changing timeline of the individual, there is also a changing timeline for each location they reside in on this planet. A location can change over time and is influenced by its context: physical, social, cultural, political. Nussbaum explains it as follows: *“All countries are developing countries although that phrase is used to refer to poorer countries: every nation has a lot of room for*

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<sup>93</sup> To give an example, a mother who gave birth to her child might need significant support during maternity period. This is a temporarily time setting in a special context and this time restricted period might ask structured support. There are no fix needs or a checklist to tick the box for all mothers in maternity leave as it depends on the context of the mother, her environment in a social, cognitive, cultural, political, and physical sense. The same counts for elderly people. You can have people who are 94 years old and still need no support while someone in their sixties may need significant support.

<sup>94</sup> VAN HECKE, N., CLAES, C., VANDERPLASSCHEN, W., DE MAEYER, J., DE WITTE, N. & VANDEVELDE, S. 2018. Conceptualisation and Measurement of Quality of Life Based on Schalock and Verdugo’s Model: A Cross-Disciplinary Review of the Literature. *Social indicators research*, 137, 335-351. JASKULSKI, T. M., LAKIN, K. C. & ZIERMAN, S. A. 1995. The journey to inclusion. A resource guide for state policymakers. Washington: President's Committee on Mental Retardation.

<sup>95</sup> For example, in some countries they put an “age of onset” to cognitive impairments. The main objective to do this is to make a difference and create a line between cognitive impairments and developmental problems with different aetiologies in SCHALOCK, R. L., BORTHWICK-DUFFY, S. A., BRADLEY, V. J., BUNTINX, W. H. E., COULTER, D. L., CRAIG, E. M., GOMEZ, S. C., LACHAPPELLE, Y., LUCKASSON, R. & REEVE, A. E. 2010. Intellectual Disability. Definition, Classification, and Systems of Supports. . *The 11th Edition of the AAIDD Definition Manual*. . Washington DC: AAIDD., pp.27-28

*improvement in delivering an adequate quality of life to all its people.*<sup>96</sup> Summarised, time can be an influential aspect because it relates to personal time and as well as contextual time.

#### Support in dialogue with environment and location

Support interacts with the environment and location and will influence the style of service due to its interdependence with personal experiences.<sup>97</sup> For example, architecture will contribute to the actual form of independent living<sup>98</sup> and will support or undermine the performance of Independent Living. Hence, physical locations or environments can create barriers too and avoid people to live independently.<sup>99</sup> This is an approach that hasn't been investigated enough in relation to the aspect of support needs for people. Besides the physical material environment Nussbaum distinguishes the political environment, as the space in which the right and freedom of speech and participation are considered (10<sup>th</sup> capability: "designing your own environment") and which can also influence the funding of the person. This section clarifies that location does contribute to the accessibility of IL.

#### Support in dialogue with funding

Unfortunately, disabilities are still drivers for disadvantages in modern society: poverty, unemployment, mobility, housing, education, health, ...and on top there is still an exclusion for this group in society.<sup>100</sup>

<sup>96</sup> NUSSBAUM, M. C. 2011. *Creating Capabilities: The Human Development Approach*, Cambridge, Harvard University Press., p.X

<sup>97</sup> BUNTINX, W. H. & SCHALOCK, R. L. 2010. Models of Disability, Quality of Life and Individualized Supports: Implications for Professionals Practice in Intellectual Disability. *Journal of policy and practice in intellectual disabilities*, 7, 283-294, DE BRUIJN, J., BUNTINX, WIL, TWINT, BRIAN 2014. *Verstandelijke beperking: definitie en context*, Amsterdam, Uitgeverij SWP Amsterdam, GRABOWSKA, I., ANTCZAK, R., ZWIERSCHOWSKI, J. & PANEK, T. 2021. Individual quality of life and the environment - towards a concept of livable areas for persons with disabilities in Poland. *BMC public health*, 21, 740-15, KAPEDANI, E. 2021. *Indoor Environmental Comfort - Integrating Universal Design & Energy Efficiency in Home Renovations*, KAPEDANI, E., HERSENS, J. & VERBEECK, G. 2017. Comfort in the Indoor Environment: A Theoretical Framework Linking Energy Efficiency and Universal Design. *Advances in Design for Inclusion*. Cham: Springer International Publishing, MOONEN, X. 2014. Visie op ondersteuning. In: DE BRUIJN, J., BUNTINX, WIL, TWINT, BRIAN (ed.) *Verstandelijke beperking: definitie en context*. Amsterdam: Uitgeverij SWP Amsterdam, ROOS, J., KOPPEN, G., VOLLMER, T. C., VAN SCHIJNDEL-SPEET, M. & DIJKXHOORN, Y. 2022. Unlimited Surrounding: A Scoping Review on the Impact of the Built Environment on Health, Behavior, and Quality of Life of Individuals With Intellectual Disabilities in Long-Term Care. *HERD*, 15, 295-314, SCHALOCK, R. L., LUCKASSON, R. & SHOGREN, K. A. 2020. Going beyond Environment to Context: Leveraging the Power of Context to Produce Change. *International journal of environmental research and public health*, 17, 1885.

<sup>98</sup> REMMERY, M., ROETS, G., BENOOT, T., VERVLOESEM, E., DERMAUT, V. & ROOSE, R. 2021. Ruimte voor zorg: Reflectie- en inspiratiekader de-institutionalisering. Gent: UGent.

<sup>99</sup> SCHALOCK, R. L., LUCKASSON, R. & SHOGREN, K. A. 2020. Going beyond Environment to Context: Leveraging the Power of Context to Produce Change. *International journal of environmental research and public health*, 17, 1885.

<sup>100</sup> BECKER, L. C. 2005. Reciprocity, justice, and disability. *Ethics*, 116, 9-39, DE WISPELAERE, J. & CASASSAS, D. 2012. Handicap, vrijheid en overheersing. Een republikeins perspectief op het gehandicaptenbeleid. *Ethiek en maatschappij*, 13, 53-78.



The last decades there is a shift in many Western countries from a welfare state built on needs towards an increasing privatisation of welfare services built upon what one can afford.<sup>101</sup> The term ‘needs’<sup>102</sup> is often used in political and policy debates. In general, basic needs are often agreed upon but the specification of needs and the level of requirements is complex and linked to political visions and opinions. A welfare state engages itself to include people with significant support needs as full citizens and takes responsibility for their social life.<sup>103</sup> Therefore, a constitution and organisation of a welfare state can influence the actual performance of residents upon independent living in different countries as well as the approach towards people with significant support needs. More precisely, depending on the funding systems, researchers state that people without choice will often move in institutions as well as residents in countries with a care-oriented approach<sup>104</sup> instead of an inclusive human centred approach.

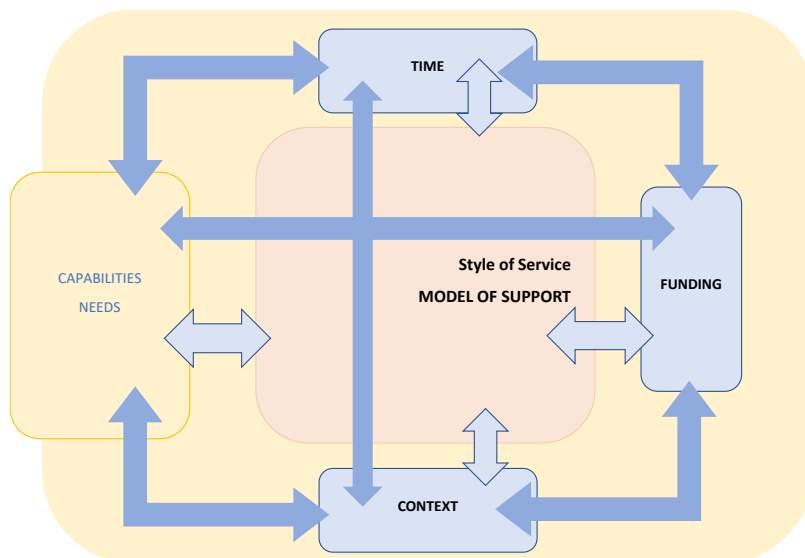


Figure 7 Scheme outlining the different dynamics in between the different variables and factors in the context of a Model of Support for IL

<sup>101</sup> OXFORDDICTIONARY 2022b. Welfare, Sociology of Welfare. *Dictionary of Sociology*. Oxford: Oxford University Press.

<sup>102</sup> From a sociological point of view, “needs” are prior linked to welfare or the sociology of welfare. To enhance individual or group welfare, the needs are defined within the domain of policy and linked to the concept of “needs”.

<sup>103</sup> HARPUR, P. 2012. From disability to ability: changing the phrasing of the debate. *Disability & society*, 27, 325-337, BUNTINX, W. H. & SCHALOCK, R. L. 2010. Models of Disability, Quality of Life and Individualized Supports: Implications for Professionals Practice in Intellectual Disability. *Journal of policy and practice in intellectual disabilities*, 7, 283-294.

<sup>104</sup> BEADLE-BROWN, J., MANSELL, J. & KOZMA, A. 2007. Deinstitutionalisation in intellectual disabilities. *Current opinion in Psychiatry*, 20, 437-442, REMMERY, M., ROETS, G., BENOOT, T., VERVOESEM, E., DERMAUT, V. & ROOSE, R. 2021. Ruimte voor zorg: Reflectie- en inspiratiekader de-institutionalisering. Gent: UGent, DRAAK, M. D., MARANGOS, A. M., PLAISIER, I. & KLERK, M. D. 2016. *Wel thuis? Literatuurstudie naar factoren die zelfstandig wonen van mensen met beperkingen beïnvloeden*, Den Haag, Sociaal en Cultureel Planbureau.

### 3. Models of support

In this study we refer to models of promising practices as systems, tools, strategies, or cooperation enabling inclusion and IL for people with significant support needs in an affordable, accessible, and available way.<sup>105</sup> A system can for example refer to: “A personal support system, based on individual’s choices and resources, serving as the actual interface between the individual and all the different aspects and variations of his or her multiple environments.”.<sup>106</sup> Tools are for example training platforms, governmental platforms, checklists for evaluation,... while organisational, operational, business governmental strategies can contribute to a management model of support.

By means of mapping out a conceptual framework for evaluating the IL-models, the interactions and interdependence between the different factors are visualised. Literature review reveals four main variables that can determine and impact people’s support models: choice, context, time, and funding. Each personal support system will be characterised by these four variables. The frameworks of “quality of life”, already showed the relations between several domains and the interconnectedness.<sup>107</sup> Based on our findings, each personal support system can be considered as specific, like a fingerprint, defined by the four pillars which are connected in a dynamic exchange system. In the following section, some examples are given for each variable.

#### Dynamics of choice

In evaluating the possibilities and choices of an individual for independent living, research demonstrates that both professional and personal network can apply different perspectives.<sup>108</sup> Needs

<sup>105</sup> EUROPEANCOMMISSION. EU Care Strategy. In: EASPD, ed. Webinar on Stakeholders' Initial reactions, 2022 online webinar, September 9th 2022.

<sup>106</sup> LITVAK, S. & ENDERS, A. 2001. Support Systems: The Interface between Individuals and Environments. In: GARY, A., KATHERINE, S. & MICHAEL, B. (eds.) *Handbook of Disability Studies*. Thousand Oaks: SAGE Publications, Incorporated.

<sup>107</sup> SCHALOCK, R. L. & VERDUGO, M. A. 2002. *Handbook on quality of life for human service practitioners*, Washington, American Association on mental retardation.

<sup>108</sup> IRIARTE, E. G., MCCONKEY, R. & VILDA, D. 2021. Family experiences of personalised accommodation and support for people with intellectual disability. *Journal of intellectual disabilities*, 25, 476-489, MCCARTHY, M., FRAWLIE, P., OLOIDI, E. O., NORTHWAY, R. & PRINCE, J. 2022. 'People with intellectual disabilities living in the communities is bad enough let alone having sex': Exploring societal influence on social care workers' attitudes, beliefs and behaviours towards support for personal and sexual relationship needs. *Journal of applied research in intellectual disabilities*, 35, 1037, ROOS, E. & SØNDENAA, E. 2020. Improving the transition process to independent living for adolescents with profound intellectual disabilities. Experiences of parents and employees. *BMC health services research*, 20, 1133-1133, ROOS, J., KOPPEN, G., VOLLMER, T. C., VAN SCHIJNDEL-SPEET, M. & DIJKXHOORN, Y. 2022. Unlimited Surrounding: A Scoping Review on the Impact of the Built Environment on Health, Behavior, and Quality of Life of Individuals With Intellectual Disabilities in Long-Term Care. *HERD*, 15, 295-314, ZAAGSMA, M., VAN DE VELDE, D., KONING, M. H. M., VOLKERS, K. M., SCHIPPERS, A. P. & VAN HOVE, G. 2021. 'When I need them, I call them and they will be there for me'. Experiences of independently living people with intellectual disabilities with 24/7 available online support. *Disability & society*, ahead-of-print, 1-24.

can be considered within the conceptual framework and linked with the possibilities. Similarly, Nusbaum's capabilities approach starts from the questions: "What are people capable of doing and being?" and "What opportunities are available to them?",<sup>109</sup> professionals can link the needs by finding opportunities in relation to other variables. This also motivates whether the actual self-awareness of related choices is a requirement for IL or not. Based on the findings in this study and following Tanaka this should not be a required ability.<sup>110</sup> This model covers "independence through dependence" referring to the support of others that is guaranteed.<sup>111</sup>

#### Dynamics of context

Recent literature motivates and explains the shifts on needs from a personal problem, defined as an "impairment within the individual", towards conditions in the interactions within the environment.<sup>112</sup> Consequently, an interaction flow in between needs, and context is evident.

#### Dynamics of funding

Research also proves the impact of social care and social protection systems on the preferences and possibilities to live independently.<sup>113</sup> However, there is a research gap on this research topic these existing interactions, and it is recommended conducting research on how the processes of people who live independently evolve and how financial changes can influence decisions.<sup>114</sup>

#### Dynamics of time

Apart from the impact of time on personal experiences, time is also context related. For example, there is a noticeable historical evolution in disability models and society's perception of people with

<sup>109</sup> NUSSBAUM, M. C. 2011. *Creating Capabilities: The Human Development Approach*, Cambridge, Harvard University Press., p.X

<sup>110</sup> TANAKA, E. 2018. Diversity of Independent Living. *Journal of disability studies*, 14, 35-53., p.1

<sup>111</sup> Ibid.

<sup>112</sup> BUNTINX, W. H. & SCHALOCK, R. L. 2010. Models of Disability, Quality of Life and Individualized Supports: Implications for Professionals Practice in Intellectual Disability. *Journal of policy and practice in intellectual disabilities*, 7, 283-294, DE BRUIJN, J., BUNTINX, WIL, TWINT, BRIAN 2014. *Verstandelijke beperking: definitie en context*, Amsterdam, Uitgeverij SWP Amsterdam, UN 2007. Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly. In: NATIONS, U. (ed.) *A/RES/61/106*. New York: UN General Assembly.

<sup>113</sup> COTE, A. 2021. Social protection and access to assistive technology in low- and middle-income countries. *Assistive technology*, 33, S102-S108, DRAAK, M. D., MARANGOS, A. M., PLAISIER, I. & KLERK, M. D. 2016. *Wel thuis? Literatuurstudie naar factoren die zelfstandig wonen van mensen met beperkingen beïnvloeden*, Den Haag, Sociaal en Cultureel Planbureau.

<sup>114</sup> COTE, A. 2021. Social protection and access to assistive technology in low- and middle-income countries. *Assistive technology*, 33, S102-S108, DRAAK, M. D., MARANGOS, A. M., PLAISIER, I. & KLERK, M. D. 2016. *Wel thuis? Literatuurstudie naar factoren die zelfstandig wonen van mensen met beperkingen beïnvloeden*, Den Haag, Sociaal en Cultureel Planbureau.

disabilities. Consequently, these perceptual shifts change over time. It is proven that this evolution is considered important in the constant engagement between people with a disability, their social network, and professionals.<sup>115</sup>

An awareness of these constant interactions in between different pillars clarifies the complexity of the Independent Living models and creates space for a more holistic approach.

The style of service of the support consists out of the approach, kind of assistance, forms of support and the available network. Interestingly, it is noticed that in between the factors of these style of service different interactions and interrelations exist. For example, looking at the kind of assistance, one may choose to rely on different kinds of assistance and when different kinds of assistance exist, these are also interconnected as a dynamic system within the larger conceptual framework.<sup>116</sup>

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<sup>115</sup> MOONEN, X. 2014. Visie op ondersteuning. In: DE BRUIJN, J., BUNTINX, WIL, TWINT, BRIAN (ed.) *Verstandelijke beperking: definitie en context*. Amsterdam: Uitgeverij SWP Amsterdam.

<sup>116</sup> With Universal Design you can change the size and the shape of the inner triangle shape. "When support systems for disabled people are described by professionals, the larger context of the human accomplishment triangle is sometimes forgotten or ignored. The focus turns primarily and solely on the more specialised elements of a support system. (...) One of the problems with focusing primarily on an individual's disability is that professionals can forget that everyone, including people with disabilities, lives in a larger generic support envelope. Too often, the focus gets restricted to the part related to the "special needs" (...) Isolated support systems for disabled people may produce de facto discrimination" (Litvak & Enders, 2001, p. 723)

## ■ Findings Theoretical Track

Our society is in a transformation towards inclusion and this invisible process impacts our contextual perspectives in society. It is argued that the complexity and sensitivity of the subject ‘Independent living for people with significant support needs’ also contributes to a lack of consistent language in general. Therefore, multiple definitions and interpretations exist throughout the world, which makes a clear approach and communication difficult. Consequently, this study argues a lack of:

- Common grounds and a definition on ‘people with significant support needs’ as well as ‘independent living’
- Knowledge on inclusive processes generating successful models of Independent Living.
- Knowledge on the interdependence and interactions in between different actors and models of support (for example the impact of personal budget and its implications<sup>117</sup>).

This theoretical study began with a conceptual analysis of the terminologies of people with significant support needs in a context of independent living. By identifying the definitions, concepts, and terms, patterns of underlying models can be revealed. With a focus on a people-oriented model approach and the UN CRPD, a conceptual framework has been developed that respects people's autonomy, self-determination, and participation. The conceptual framework shows an ecosystem of independent living that starts from peoples’ capabilities or QoL-framework, determining their choice.

The conceptual framework puts people at the heart of every decision as one of the four main variables, besides context, time and funding that influence a support model or style for Independent Living. Choice, context, time, and funding may vary depending on the person for whom the support model is intended, as this study states that independent living is a state of being supported by a

<sup>117</sup>Several countries shifted towards a personal budget, often pushed by new policies and governments. In some cases, this resulted in a more consumer-controlled and consumer-directed personal assistance services<sup>117</sup> whereas in other countries it met its goals, so governments can reflect on the impact and make changes.

MLADENOV, T. 2020. What is good personal assistance made of? Results of a European survey. *Disability & society*, 35, 1-24, MLADENOV, T. 2012. Personal assistance for disabled people and the understanding of human being. *Critical social policy*, 32, 242-261, YATES, S., DICKINSON, H., SMITH, C. & TANI, M. 2021. Flexibility in individual funding schemes: How well did Australia's National Disability Insurance Scheme support remote learning for students with disability during COVID-19? *Social policy & administration*, 55, 906-920, ENDERS, A. Personal Assistance Services and Assistive technology: Allies or Adversaries. RESNA, 1995 Arlington, VA. RESNA, 584-586, LITVAK, S. & ENDERS, A. 2001. Support Systems: The Interface between Individuals and Environments. In: GARY, A., KATHERINE, S. & MICHAEL, B. (eds.) *Handbook of Disability Studies*. Thousand Oaks: SAGE Publications, Incorporated.

dynamic support model, which can change over time and in different contexts depending on changing personal funding and choices.

The style of service or the model of support is based on a range of factors: approach, kind of assistance, forms of support and available network. A combination of different factors creates a support model offered by service providers. Depending on the person's choice, focus can change in between these factors. This dynamic also results in interdependence and interactions in between the factors.

Interestingly, the ambitions of the EC's Care Strategy<sup>118</sup> focusing on the whole spectrum of care and support services<sup>119</sup> can be monitored by the framework. Care should be available, affordable, accessible and of high quality for all.<sup>120</sup> Availability is foreseen by the factors determining the Style of service or support model. Affordability is linked with the variable of funding, whereas accessibility is covered by time and context. The Quality for all deviates from the QoL framework in which this study argues to look at the capabilities approach of Martha Nussbaum as this holistic approach not only incorporates people's personal needs or capabilities but also underlines the interaction and value of other living species on earth, a very sustainable and future oriented approach.

Whereas many QoL-frameworks direct towards a personal assessment evaluation, this framework shows potentials in an outcome measure of common language in between disciplines intending a sustainable holistic approach. It avoids stigma as it starts from the capabilities of people. For example, someone can be born with a disability but not experience it as such and consequently has few or no specific needs.<sup>121</sup> Consequently, this study argues to avoid explicit references to people's multiple impairments because inclusion does not start from defining what people 'have' (disabilities) but from what people 'want' (capabilities, needs). This conceptual framework aims to clarify and visualize the complex interactions and actors within the state of independent life and served as a basis for determining the theoretical indicators for the selection of promising practices.

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<sup>118</sup> EUROPEANCOMMISSION. EU Care Strategy. In: EASPD, ed. Webinar on Stakeholders' Initial reactions, 2022 online webinar, September 9th 2022.

<sup>119</sup> VON DER LEYEN, U. 2021. State of the Union Address 2021: Strengthening the soul of our Union. In: COMMISSION, E. (ed.). Brussels: European Commission.

<sup>120</sup> EUROPEANCOMMISSION. EU Care Strategy. In: EASPD, ed. Webinar on Stakeholders' Initial reactions, 2022 online webinar, September 9th 2022.

<sup>121</sup> For example, Buntinx e.a. (2010) show that there is no linear link between someone's needs and this person's level of intellectual functioning.

## 7. Case study: promising practices.

Parallel to the theoretical research, an empirical track has been set up as explained in the methodology above.<sup>122</sup> Out of 102 examples, a selection of 18 examples was made based on the first findings of the theoretical track. More precisely, the examples were all listed in an excel-file outlined information based on a cross analysis of the information included in their websites and retrieved documents.

A first classification and selection were based on the following criteria:

- guaranteeing people's choice;
- exemplifying a human centred form of support;
- demonstrating a human centred form of assistance;
- supporting people with significant support needs;
- representing a high level of quality;
- covering a diversity of approaches
- being present in one of the five different welfare states in Europe

These 18 examples were analysed in depth and based on the theoretical conceptual framework a selection of five different models in five different welfare states was made that showed a diversity of forms, assistance, and approaches. Guaranteeing personal choice and representing a high level of quality were the main requirements for the final selection. There resulted to the following promising models: JAG (Sweden), Inclusie Invest (Belgium), Fekoor (Spain), Jamba (Bulgaria), PA model Enable Cares (Scotland).

The directors of the models were contacted by email with an invitation letter and overview of the research. Recorded interviews were conducted with the director(s) or staff member(s). In addition, the organisations were invited to make video testimonials of three people using their services based on specific questions. A triangulation and analysis of the interviews, the information retrieved and collected (internet, documents, e-mails, etc.) as well as the video testimonials provided

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<sup>122</sup> For a detailed methodology we refer to Annex 2 in this report

input for the summaries of the five selected examples described below. A similar structure was used for each model based on questions and topics as put forward by EASPD.

Selection of promising good models							
research number	country	welfare state	example: name	originated	approach	form of support	kind of assistance
SCAN003	Sweden	Scandinavian	<b>JAG's assistance cooperative and advocacy work</b>	1984	immaterial	cooperation	personal assistance
BISM013	Belgium	Bismarckian	<b>Inclusie Invest</b>	2011	material & immaterial	housing cooperation & social rental office	architecture & real estate
SOU002	Spain	Southern	<b>Fekoor</b>	1979	immaterial	independent living model	model + assistive strategy
EAS006	Bulgaria	Eastern	<b>Jamba</b>	2018	material & immaterial	educational platform , internship, career planning	assistive technology + assistive strategy + tools
ANG006	Schotland	Anglo Saxon	<b>PA model Enable Cares</b>	2013	immaterial	care model for personal assistance	model + assistive strategy



- JAG

**Example | Name:** JAG personal assistance program via the Personal Assistance Budget

**Country:** Sweden

**Founded:** 1984



**Welfare state:** Scandinavian

**Kind of practice:** cooperation and personal assistance organisation

### Description of the Practice:

JAG (*Jämlikhet Assistans Gemenskap* | Equality, Assistance, Community) is a non-profit assistance cooperative and advocacy organization that facilitates personal assistance. JAG is the Swedish word for “I” or “me” (JAG, 2021) and it focuses at the abilities of people first (JAG, 2013). The organisation has been divided in JAG’s assistance (personal assistance) and JAG’s national association (advocacy work). Its program has been founded on balancing the basic interaction between the person receiving support, the assistant, and legal counsellor. Currently, JAG supports about 400 people using personal assistance. Their head office is based in Sweden, but they are also based in Finland and Norway.

### Description of support needs:

JAG supports personal assistance for people with intellectual disabilities in a human centred way. It is an organisation that gives administrative and practical support in personal assistance. Depending on the needs of each individual, the approach can change, for example, some individuals are non-verbal and need communicative support. To be a full member of JAG you must have several disabilities of which an intellectual disability is the main requirement.

## Funding system:

Funding is based on Sweden's LSS act [*Lagen om stöd och service till vissa funktionshindrade*]<sup>123</sup>, an entitlement law that guarantees good living conditions for people with extensive and permanent functional impairment<sup>124</sup> and underlines the UN CRPD because it guarantees the daily help by choice. Each municipality has its proper LSS administrator and an obligation to provide houses for people with disabilities. A minimum of 20 hours of support per week are required to retrieve a governmental personal budget covering basic needs: eat, sleep, dressing, sanitary duties, medical care. Recent changes in the law may afford an extra salary for additional needs<sup>125</sup> at national level. The total amount of funding is based on the counted hours (counted by a social worker) required for the needs and aspirations of the person.<sup>126</sup> The funding is approximately 30€ per hour so depending on the approved minutes / hours of Personal Assistance individuals receive a total sum.

## Description of the support model:

### **Support available:**

JAG offers administrative support as well as practical support for personal assistance (PA) in the context of Independent Living. JAG's model of personal assistance has been built around the people/members themselves. Defining the required support is at the very start of the personal support system and based on questions and experiences of each person they build a framework of personal assistants around each person's needs and choices (with an average range of two to 18 assistants per person). Personal assistants support the people who draw on support in daily life to cover their essential needs to live as independent as possible. There is a different range of set-up

<sup>123</sup> The act focuses on specific groups, for example people who have intellectual disabilities or autism, who have a considerable and permanent mental impairment following brain damage sustained as an adult or people who have a physical or mental impairment that is not due to normal ageing. The act entitles: 1. Advice and personal support, 2. Personal assistance, 3. Companion Service, 4. Contact person, 5. Relief service in the home, 6. Short stay away from home, 7. Short period of supervision for school children over the age of 12, 8. Living arrangements in family home or in a residence with special services for children and adolescents, 9. Residence with special services for adults or other specially adapted housing, 10. Daily activities.

<sup>124</sup> It is a Swedish act that concerns "Support and Service for Persons with Certain Functional Impairments KÖNBERG, B. & WESTERBERG, B. 1993. [*Lagen om stöd och service till vissa funktionshindrade (LSS) [Act concerning Support and Service for Persons with Certain Functional Impairments]*. In: AFFAIRS, M. O. H. A. S. (ed.). Sweden: Swedish Parliament.. Thus, the personal assistance service is covered by the National social insurance agency, and this is an achievement thanks to JAG, that lobbied for this.

<sup>125</sup> e.g. preventive support to avoid people harming themselves, extra support during "attacks" when you can be a danger for yourself, or your family members, support for medical needs as well as activation and motivation needs, practical help without reducing the parent's responsibility

<sup>126</sup> To receive a personal funding, people must fill in an extensive and comprehensive administrative file and most people need support in this.

depending on each individual, network and the context. For example, a child might need less hours compared to an adult, if family members cover certain activities. Furthermore, the aspect of time in relation to people's needs can influence the model. For example, some people work two hours a day whereas others 8 hours.

**Approach:**

The whole service is founded on an immaterial approach, representing a conceptual model of needs and aspirations of the people using the service themselves covered by the personal assistants. For JAG, "communication" is key for independent living. Therefore, the level of interaction and communication in between the personal assistant and the individual through personal support in soft skills, medical, technical aids will determine its success rate.

**Community integration:**

JAG's program and mission is built around independent living within the community. Personal assistants bridge the gap in between people who draw on support and their community. Apart from the personal preferences of each person (hobbies, job, family visits, etc.), JAG invests in a day care centre in which they explore how art can form a mediator in between the people they support and the community. More precisely, these interactive cultural activities contribute to the communication and language that connects the people and the community.<sup>127</sup>

**Rights enjoyment article 19 of the UNCRPD:**

JAG's core vision is that every member has the right to use their voice for independent living. Members can choose where, how they live and choose their personal assistants as well as their daily habits and activities.

**Support Staff:**

The cooperative's board is only managed by the JAG members themselves with support from their legal counsellors or spokesman. JAG is one of the few organisations in Europe led by people with disabilities. In a recruitment process for personal assistants, diploma or education are not considered

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<sup>127</sup> For example, currently, a play about the human rights of independent living tours around Sweden. This way players who are members/users of JAG communicate to society in their language about human rights. This contributes to a general awareness raising in society.

as the main selection criterium. Instead, potential for communicative skills and learning is set forward as the most important skill. Each assistance support team has a program manager who collaborates with a legal counsellor. All employees receive regular trainings from JAG to keep everyone updated and aware of the central vision, mission, communication objectives and required knowledge. An average of 18 people for each member is foreseen and approximately 4000 people are employed at JAG.<sup>128</sup>

### **Sustainability of the practice:**

Like many non-profits, JAG maintains their focus on a healthy strategy to manage budget and sustain future growth. JAG keeps track of all their processes and practices and conducts constant evaluations. During the Covid-19 Pandemic, JAG noticed their personal assistance model to be effective in terms of health and safety, as well as efficiency compared to alternatives.

### **Strengths – Weaknesses (SWOT-analysis)**

JAG stands out for its huge focus on communication as driver for their vision and mission. A human approach that constantly monitors the right balance in between assistant, team, people using the service, and the legal counsellor provides insights in the quality of the support model and ensures the choices of the members. Members' needs are at the heart of this personal assistancemodel. Each support model is personal and starts from the members themselves who direct their style of service. Remarkably JAG also encompasses a strategy to overview all the other variables such as time, context, and funding. For the latter they support in administration and when needed provide pioneering advocacy work.<sup>129</sup>

JAG constantly demands extraresources (human and organisational) to keep up with new accelerations or innovations.

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<sup>128</sup> An average of 60 people for administration.

<sup>129</sup> This organisation makes the unseen visible, because they start from an inclusive mission that everyone counts JAG 2011. Strasbourg Freedom Drive. JAG.. For example, as a result of a JAG-meeting of Swedish EU parliamentarians, 12 Swedish MEP's wrote an opinion in the newspaper, a call for Europe to act and accelerate deinstitutionalisation. Another strength is that they can shift very quick to involve in upcoming policies and their beliefs and motivation are very high. In their culture of demonstrations and activism, they are respected and considered as one of the first Swedish pioneers and one of the biggest organisations.

Approximately 90% of a member’s personal budget goes to salaries, which can be problematic in times of inflation. Another threat is a current governmental investigation on political responsibilities for personal assistance: national government or municipalities.<sup>130</sup> JAG considers themselves “resilient”. Their organisational attitude is a huge strength because of their pioneering work. It is noticed that JAG has a good overview on all the actors and factors that impact a support model because their organisational iterative processes involve constant evaluation and improvement (services, staffing, recruitment digitalisation).<sup>131</sup>

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<sup>130</sup> The outcome can be a threat and depends on the decisions made. If it is a local responsibility, people depend on local politics.

<sup>131</sup> If necessary, they will innovate and anticipate at political level to reassure quality and effectiveness of the PAS-model. For example, in their plea to revise the system of counting minutes and hours in terms of funding. This topic is quite controversial because the social department investigates it in detail, which can be an invasion of privacy. JAG wants to advocate for a change in this system.

## ▪ Inclusie Invest

**Example | Name:** Inclusie Invest cvso

**Country:** Belgium

**Welfare state:** Bismarckian

**Kind of practice:** social real estate company



### Description of the Practice

To make independent living affordable, available, and accessible, Inclusie Invest originated in 2011 as a non-profit housing organisation for qualitative housing in Flanders, Belgium. It can be considered as the first legal social real estate company in Belgium, that builds, maintains, and rents buildings for people with support needs. They invented a financial model that makes independent living possible for people with significant support needs. In collaboration with partners (a service provider to guarantee and cover a high quality of support, and non-profit organisations) their main vision is built upon three pillars: 1) Avoid poverty due to care and support related expenses, 2) Create a more inclusive society, 3) Guarantee (Financial) independence of people with support needs. Different houses in different regions in Flanders are renovated and built and each house has its own typology and story.

### Description of support needs

Focus is on supporting the search process for an actual physical place to live in. Inclusie Invest serves people with multiple disabilities (ASS, visual impairments...) as well as people without disabilities. Support involves the implementation of governmental criteria in the available buildings as well as the facilitation of the process towards independent living itself (needs and choices of the people residing

in these properties). In addition, they follow up all the administrative and legal management for all partners.

### **Funding system**

At this moment, the government covers only part of the funding for independent living of people with significant support needs in Belgium. Social building companies solve part of the problem but deal with a shortage of housing. Inclusie Invest wants to bridge this gap by a financial model in which a project carer (a care institute or a non-profit organisation) and Inclusie Invest, raise the building budget through a cooperation agreement with investors. Currently, all buildings are built after an explicit question of a -by the government- recognised care institution, or a non-profit organisation (mostly organised by parents). Residents rent a house with a maximum of 1/3 of their income. Other costs are covered by partners and governmental fundings. Investors receive a dividend in return for their investment<sup>132</sup> and might also donate properties in ground lease. By starting up a project, all partners are invited to find new investors. A caregiver must find at least 50% of the total budget. VIPA (*Vlaams Infrastructuurfonds voor Persoonsgebonden Aangelegenheden*)<sup>133</sup> funding is always applied for and received when the house meets sustainability and inclusive design criteria.

### **Description of support model**

**Support available:** Inclusie Invest supports people with significant support needs, investors, NGOs and care institutions in building and renovating affordable, accessible, available housing for everyone. They facilitate project management of each project (planning, administration, architectural follow up,...) and also own the project for a certain amount of time as agreed upon. The service provider can deliver care and support and rents the housing environment to people. People can choose and rent their house or apartment and live together with a mix of residents. Investors are for example: banks, companies, funds, ... that want to invest in stocks of Inclusie Invest and support financially.

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<sup>132</sup> It can be a moveable or immovable property

<sup>133</sup> Flemish Infrastructure Fund for Personal Affairs: funding Flemish government

**Approach:** For each case the following required parameters are set up as a requirement: 1) small scale<sup>134</sup>, 2) qualitative<sup>135</sup> and 3) affordable housing<sup>136</sup> for everyone. Every person has a proper house or housing unit.

**Community integration:** Each location of a housing project and all buildings are always considered as a key determinant for community integration.<sup>137</sup> Commitments from small entrepreneurs nearby the building's location, contribute to interaction at both social and economic level. Employees who work at the public restaurant or café, located in the building, are often residents. A caregiver can sometimes offer workshops for residents as well as externals. A multi-disciplinary mix of users of these buildings and an inclusive architecture support community integration at all levels. Partners are always invited to search for investments, which encourages a sense of responsibility for each project and strengthens the sense of community.

### **Rights enjoyment article 19 UNCRPD**

The mission to create accessible, affordable, available, qualitative housing for independent living so people can choose their proper living environment and who they live with is at the core of this model. Moreover, people can use their own budget to rent a house contributing to their autonomy and self-determination.

### **Support Staff**

Inclusie Invest always collaborates in partnership with an organisation offering care and support (*projectdrager*, project carrier), residents and investors as described above.

**Sustainability of the practice:** Their mission and vision put focus on the SDGs, caring for carers and an inclusive society. Inclusie invest uses a transparent communication and considers this as part of their inclusive model. Their business model is published online and public for everyone. Several other organisations already copied the financial model of Inclusie Invest and this proves its success.

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<sup>134</sup> Small scale refers to the human scale, so it doesn't relate to the physical environment but more towards the sense of experience of the project.

<sup>135</sup> With a qualitative approach they aim for the integration of the needs of caregivers and people.

<sup>136</sup> Each project must be affordable for everyone, and this is the main priority. This includes both the aspect of care as well as the living environment. They only use a maximum of 1/3 of the income for the renting regardless of the amount.

<sup>137</sup> For example, at urban level, the projects are often located at a small distance from the centre of the village, and the garden is often an attractive communal garden, open for everyone. At an interior level there is for example the design of a flexible wall in between two living rooms that can be removed so the two living rooms serve as a party room for residents as well as people outside the house. The multidisciplinary approach of the project also contributes to the community integration.



Shareholders receive social as well as financial value (safe investment with an interest rate like the banks).<sup>138</sup>

### **Strengths – Weaknesses (SWOT-analysis)**

This financial model creates an option for people to live independently, with respect to proper choices and income. In Belgium, real estate is often unaffordable for people with significant support needs and does not cover accessible and available housing. Inclusie invest wants to meet this huge practical and financial support need. Its business model is built around an inclusive design process and logically it starts and ends with the needs and wishes of people.<sup>139</sup> This inclusive mindset is at core of their communication and business model. As a facilitator they not only support residents but all employees through the administrative and project management of a building process. This approach serves the quality and experiences of all partners involved. Moreover, their inclusive attitude contributes to an acceleration of organisations that copy their model. Community integration is stimulated by means of the interaction of different actors as well as the physical building and location itself.

The requirements for each healthcare provider (partner) to raise 50% of the investment for the project, remains a huge challenge and Inclusion invest is currently reviewing their business model to overcome this. Although enough staff expertise is present, there are no user representatives in the board yet. Furthermore, each building represents a different cooperation and consequently every housing has different employees linked to different organisations which makes the board and staff of Inclusion Invest the only personal connectors in between the different housing projects. With their future growing ambitions, it is recommended to start monitor the different projects. Regarding the external investors, it remains advisable to always stress their social commitment to avoid investors are merely interested in profit. Governmental housing criteria change regularly, and flexibility on the

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<sup>138</sup> Focus is put on small investors with a link to the participants, the organisation Inclusion Invest or the physical environment of the planned building. However, they are currently evaluating their business model for future, middle and long-term planning, and they will move towards a new organisation in which 33% will be of institutional shareholders or externals. This way they want to decrease the pressure on care institutions and non-profit organisations.

<sup>139</sup> They also conduct POEs (Post Occupancy Evaluation), research with the residents of projects for the evaluation of existing housing before they start planning the renovation.

implementation of guidelines is required. Because the model is so new, communication is key in enabling people to understand it properly. With their new legal statute<sup>140</sup>, this model can be upgraded to any group in need and consequently they can expand their tasks.<sup>141</sup>

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<sup>140</sup> A new statute in Belgium in which Inclusie Invest is pioneering: the SGVV (*Sociale Gereguleerde Vastgoedvennootschap*, A social and legal real estate company).

<sup>141</sup> Expanding tasks with a 1) knowledge centre, 2) investing partner, 3) building manager and intend to become a knowledge centre on inclusive housing that strengthens the link between care and real estate.

- Fekoor

**Example | Name:** Independent Living Programme by Fekoor

**Country:** Spain

**Welfare state:** Southern

**Founded:** 1979

The logo for Fekoor consists of the word 'fekoor' in a lowercase, grey, sans-serif font. The letter 'o' is replaced by a blue circle with white diagonal lines.

**Kind of practice:** a non-profit model for Independent Living that serves as a strategy

### Description of the Practice

The independent living model of Fekoor, a coordinating organisation that supports people with disabilities, aims to create a personal symbiosis between all different activities regarding IL within a person's life. Fekoor's main objective is to advise and support everyone during their transition processes to IL and to promote innovation, learning and activism for IL and universal accessibility. Fekoor originated out of 18 associations of people with physical and/or organic disabilities and represents more than 8700 members, linked to different partner organisations.

### Description of support needs

Interestingly, Fekoor considers Independent Living as a state of being connected to all different aspects in life. Hence, they intend to support people in all the choices and needs that relate to these aspects in life.

## Funding system

As a non-profit private organisation, declared as public utility by the Basque Government,<sup>142</sup> Fekoor's main budget is funded through grants of public administrations (Basque government, province, and municipalities) and private companies (e.g. Eleven, Once). The pension and personal service budgets are based on the evaluation of social workers appointed by the government, but only covers for two support services, whereas the IL-model offers a range of services.

## Description of support model

Fekoor's Independent Living model<sup>143</sup> is their key project that encompasses a main strategy to support everyone on IL. The model is built around three pillars: 1) environments (universal design, activism and awareness creation), 2) people (for everyone with all abilities) and 3) support (administration of partners must give an overview of economic resources and portfolio), it mainly focuses on people with physical and/or organic disabilities.

### **Support available:**

The whole model aims to support social work, legal advice, psychological support, employment, personal assistance, technical aid. There are trainings available on cognitive, emotional, household, use and enjoyment of personal leisure, economic life, community life, personal care training. Their main vision and mission states that IL goes beyond personal assistance and subsequently it expands towards four kinds of assistance:

1. Counselling, self-determination, and self-management for independent living (day centre, personal assistance program)
2. Innovation for independent living
3. Learning platform (leisure, employment, and independent living mentoring program)
4. Collaborative base for responsible citizenship

**Approach:** Fekoor follows a holistic approach for its IL-model based on three theoretical pillars: 1) WHO International Classification of functioning, Disability and Health (ICF), 2) Fekoor Independent

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<sup>142</sup> (Decree 239/1995 of April 11)

<sup>143</sup> In 2003 Fekoor organised a European congress in which external members valued the IL model and insisted to write it out. This was conducted by a committee of people with disabilities assisted by a secretary.

Living Model, 3) Person Centred planning (PCP) methodology (participation, co-creation, responsibility, freedom of choice).

**Community integration:** In the IL model everyone has the right to live independently in the community which is as enriching and supportive for a more sustainable, smarter, and inclusive society. Fekoor promotes active citizenship committed to Universal Accessibility, full equality of opportunities and a profound social transformation. By their IL-model they empower people and beneficiaries to engage in the community and to give back to the community as active agents (for example by the use of public transport, employment, information, etc.).

**Rights enjoyment article 19 of the UNCRPD:** Implementing the IL model contributes to a cultural spirit and paradigm shift in our society, considering IL as a human right, strengthening complete freedom and equality, and promoting equal opportunity in an advanced social welfare state and everyone's own community environment. The model is scientifically built upon the UN CRPD and supports people in their right to live freely and to decide on what to do and how to live.

**Support Staff:** Support staff consists out of people with and without disabilities, an inclusive mix of employees. The board of directors also consists out of members with a disability. An inclusive HR-approach is appreciated and therefore Fekoor holds an active recruitment on people with disabilities. Currently, new projects start to empower people with significant support needs with the help of peers with significant support needs.

**Sustainability of the practice:** At economic level it remains difficult to find enough grants and budget to cover all costs. However, by means of constant monitoring, they keep track of the IL model's evolution and impact, and its socio-cultural impact is very clear. For example, the findings of the IL model are also used for improvement on the technical and scientific innovation of home environments. To ensure governmental funding and grants, Fekoor engages in advocacy and awareness creation which makes their voices heard by policy makers.

### **Strengths – Weaknesses (SWOT-analysis)**

Whereas it was initially designed for people with disabilities, the Independent Living model proves to be transferrable to any other context because of its inclusive approach. Human centredness

is at core of Fekoor’s DNA and relates to its members as well as everyone involved: for all. Members as well as employees and partners, have a voice and everyone contributes to set future objectives.

Their financial model is challenging as they completely rely on the government for their main funding. The current economic situation influences the salary raise of employees, without increasing governmental funding. On top, Fekoor loses many volunteers because of ageing society and a vulnerable economic situation. The Covid-19 pandemic revealed the limitations of a residential model and proved the valuable impact of Fekoor’s IL model-support at home.



Figure 8 scheme of the model of independent living in the vision and mission of FEKOOR

## ▪ Jamba

**Example | Name:** JAMBA

**Country:** Bulgaria

**Welfare state:** Eastern

**Founded:** 2017



**Kind of practice:** career planning, education, internship

### Description of the Practice

JAMBA is an organisation that offers a physical and online platform for education, internship, and career for people with diverse abilities.

### Description of support needs

Independent Living requires financial resources and unfortunately many people with significant support needs are unemployed and rely on a small pension or allowance. However, many are willing and eager to work. JAMBA wants to bridge the gap between employers and 'people with diverse abilities'. Supporting people in their career, not only contributes to a possible employment but also to their social (self-esteem, self-determination, community integration), cultural (network), cognitive (education) and financial capital. During their early start-up they discovered that many users lacked essential skills to apply for a job or to potentially doing the job, because only limited people have access to education. That's why they extended their scope from employment to training and education as well. Consequently, they started with a parallel track for trainings. Their target group for employment are people with physical disabilities, hearing impairments, visual impairments, and chronic illnesses and a minority has intellectual and cognitive disabilities (like Down syndrome or autism).

## Funding system

In Bulgaria, people with a disability, receive a very low monthly salary: an average of 150€ per month. In addition, depending on their personal context, they can receive an average of 350€ for a personal assistant. Consequently, if possible, it is reasonable to work so that they can raise their monthly income. To make their support service inclusive for their target group, JAMBA covers the costs of the whole employment process: from onboarding of users, over training to actual execution on the job. JAMBA's business model is built on free services in the first stages and paid services for companies (on recruitment, onboarding skills and team buildings). Partner companies who deliver trainers for free (without any expectations), may receive free advice on inclusive workplaces (sign language, interpretation, captions, hearing aids, ...). The recruitment, specific training and consulting for companies and other more specialised support must always be paid by the companies. Extra budget comes from donations and investments of organisations, companies, and entrepreneurs.

## Description of support model

People receive help in their search for the right job and are empowered and supported during the whole process from the early start of insight on self-knowledge to the actual onboarding and follow-up of the employment.

### **Support available.**

JAMBA supports in personal career planning and career search as well as in educational training. Four main tracks determine their process:

1. Capacity building through three different pillars: 1) Soft skills (cv, motivation letter, negotiation skills, presentations skills, ...); 2) English language skills; 3) Professional skills (diverse portfolio of professional skills: marketing, digital skills, software development, assurance, and different professional skills like cooking, bartending, ...)
2. Application process support: Intake and assessment of the profile; training; application process, physical Career centre
3. Contract and onboarding process with the employer: Intake of companies in terms of inclusion, Intake and assessment of the company, Advice and trainings for the company,



Workshops (practical trainings, understand the daily life of people...), HR-screening (jobs, people, etc.), Advice in specific talents for specific jobs, Theoretical trainings (awareness raising)

4. Consulting (diversity and inclusion strategies for companies)
5. Awareness campaigns (organisation): Career fairs for people with disabilities, big running event (“Run together”: biggest event in Bulgaria with social cause), Entrepreneurship academy for women with disabilities.

After the pandemic they set up an inclusive digital platform for trainings. With the help of the labour agency of the national government, they support organisations and companies in their transformation toward inclusive employment. Hence, they are recognised as official recruitment agency by the government. As member of the governmental NGO commission, they represent NGOs working on disability issues.

**Approach:** JAMBA engages in inclusion at all stages of the career process and within all decisions for their business. Their approach is very inclusive and flexible. Moreover, their awareness raising, and advocacy creates insights for policy makers to enable companies to hire people without fear.<sup>144</sup>

### **Community integration**

Apart from, the active integration of people in a community by means of career planning and employment process, JAMBA also actively contributes to awareness raising in Bulgaria. The disappearance of cultural stigma towards hiring people with disabilities, is JAMBA’s merit. Awareness campaigns, supported and under the patronage of the Sofia Municipality and the president of Bulgaria, are set up as active events, encouraging community integration. JAMBA organises social activities (Running together, etc.) as well as yearly award ceremony for the rewarding of inclusive achievements of different sectors (individuals, NGOs, institutions, companies, etc.) This ceremony is also a social event that connects different people and broadens their network.

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<sup>144</sup> JAMBA states that there needs to be protection for the employee, but also for the employer who must overcome the anxiety of the unknown. For example, in Israel people with disabilities can start to work without immediately losing their funding. For two years they can try if the job fits their needs. This aspect and the recognition of the flexibility in hours of work is an advocacy opportunity that JAMBA would like to tackle.

Recently, they also opened a career centre, linked with a ground floor café that is open for everyone. JAMBA proves to contribute to community integration at all levels and is a respected and well-known organisation contributing to the Bulgarian shift towards inclusion.

### **Rights enjoyment article 19 of the UNCRPD**

Personal choices and talents are core in their work and it is always a personal choice of people to engage in a career process. JAMBA holds a very inclusive vision and starts out of the idea and need for more support for employment for people with disabilities enabling them to live independently.

### **Support Staff**

People with disabilities are on the board of directors of JAMBA. Most of the employees are people with disabilities. (For example, the whole career centre is run by people with disabilities.) Both founders have disabilities, and this contributes to the general awareness at work. Within their work culture they create a huge sense of belonging. Until now, more than 700 people are trained by JAMBA and 400 people have been employed. Their regular training sessions are also open for the employees.

### **Sustainability of the practice**

JAMBA holds a solid and sustainable vision and mission. In every step and decision, JAMBA questions the level of inclusion. Their awareness in their daily operational organisation makes sustainability a realistic fact and creates a sustainable and inclusive business strategy. They constantly revise their business model.

### **Strengths – Weaknesses (SWOT-analysis)**

JAMBA provides high quality and inclusive training programs and support for people with disabilities. Peoples' talents and skills, or their capabilities, are at the core of their work through their fast efficient process for job employment. As the first and only professional provider for this kind of services in Bulgaria, they are known for their inclusive vision and mission and receive financial as well as practical support. This creates a win-win for everyone and first and foremost for society. Their

dream to have a career centre to work on a daily base with people with disabilities opened in October 2022 and offers a physical meeting point. Their digital inclusive platform connects a huge range of participants.

As a self-made, and a relatively small organisation, their demands are already more than manageable but they still rely on external funding to make the business a reality. Resources, trainings, materials, and logistics are paid by JAMBA and the state owns the location for their administrative centre what makes its existence vulnerable.<sup>145</sup> However, the faster they grow, the more people with disabilities can be trained, hired, and connected to a broader network. At the start they had to search for companies, today companies approach them.

JAMBA's model can easily upscale and already started in Austria and Hungary.

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<sup>145</sup> The political situation in Bulgaria is very unstable at this point and this puts questions behind their advocacy practices.

- Enable Cares

**Example | Name:** PA model of ENABLE Cares

**Country:** SCOTLAND

**Welfare state:** Anglo Saxon

**Founded:** 2013



**Kind of practice:** new care model for Personal Assistance

### Description of the Practice

Enable delivers human rights-driven self-directed care and supports for all -regardless of commissioning arrangements to support citizens across Scotland in independent lives within their local communities. The PA model is part of Enable cares, one of the 3 charities besides Enable Scotland (activism and campaigning) and Enable work (employment training). People can direct every element of their support (hours, staff, things they enjoy in the communities, where they choose to live in, with people they like to spend time with, across 27 of Scotland's 32 authority areas). The PA model was intentionally built and designed by ENABLE Scotland in response to the Social Care (Self-directed support, SDS) Scotland Act 2013 as a mechanism to deliver both the spirit and the objectives



of the legislation for everyone supported by the charity. The choice of people is at the centre of this model. This is quite rewarding as the service provider themselves took the initiative to set up a

promising inclusive oriented model built around the policy and executed following the principles of inclusive design, an iterative process focussing on an inclusive culture, vision, and mission.

## **Description of support needs**

The four pillars that cover the support by the PA ENABLE model are:

1. Service design: this how and what everyone chooses to live the life they want.
2. Support strategies: describes how an individual should be supported to achieve their identified aspirations and outcomes.
3. A team of personal assistants
4. Individual service funds (ISF): details and itemises everyone's available budget. Each ISF is bespoke to an individual, with full transparency of budget spent and funding availability.

The model supports individuals and their families to make the right decisions for their needs, regardless of their care (whether it be a learning disability, physical disability, acquired brain injury, mental health conditions or autism).

## **Funding system**

The funding is connected to the SDS legislation. 32 local authorities across Scotland follow this SDS (Self Directed Support Act) but have the flexibility to interpret and apply it in different ways. The assessment is conducted by social workers who have access to all the medical and personal proof required for the assessment. There is a statutory income foreseen for health and social care in the welfare state. In addition, Enable receives grants and funds, trusts and government funding for Enable work and Enable Scotland and as explained, these three pillars are interconnected. The interventions made to democratise the ability to access a PA model make this funding system inclusive for all.

## **Description of support model**

### **Support available.**

ENABLE is built on the support of people with learning disabilities but goes wider than that and aims to be inclusive for all care in the future. Currently, support is delivered to over 1000 people through this model. They have a very focussed way of working on processes with and for people. When other

providers cut back delivery of hours, ENABLE has delivered 98% of commissioned hours with the people they support.

### **Approach**

The model is built around a tailored service for the person and their needs, not the organisation or commissioning body. The PA model actively nurtures the relational elements of social care; meaning relationships and trust development between the person ENABLE works for and their PA and team. Individuals direct their own support and building supportive networks within their local communities. In this context, the PA model aims for a culture of self-directedness and a long-term vision instead of solving short term care problems in a state of dependence. Besides the actual PA model, they also have the two other pillars in which employment and activism cover the plea for new and future oriented visions and for instance the campaign: *“Be the change”* is one of the examples of activism that contributes to a mental shift. The process itself has shown that it evolved from 30 years of social policy going from hospital institutional living to scaled houses to individual homes.<sup>146</sup>

### **Community integration**

ENABLE encourages people to appeal and apply their talents in the community. The whole model is based on being in the community and being supported in the community. People can access community assets and data. It moves away from a hospital type of environment towards a life enhancing environment.

### **Rights enjoyment article 19 of the UNCRPD**

ENABLE’s work is human rights driven and this is represented in their value driven mission for people: freedom, flexibility, choice, and control. For ENABLE, the PA model is the embodiment of the UNCRPD and puts on the rights enjoyment of article 19 of the UNCRPD and far beyond. Human Rights are central and core to their business in the whole flow of their practice, from the first meeting until the very last collaboration. The service design is self-directed by the individual, they choose their proper outcomes. Each person interviews and chooses their own PA and is also directly contracted by them,

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<sup>146</sup> The huge opportunity according to the chief executive of ENABLE, Theresa Shearer, is not the copying of the model to other countries but more the expertise of 30 years of historical change in social policy going from hospital-oriented models towards the ENABLE model. The advice she gives to other countries is to learn from this evolution and to apply it to their own political system according to geography, politics, culture, and demography.

with ENABLE becoming the employer on their behalf. Every person chooses to utilise their ISF in a way that meets their own chosen outcomes. Needs can change over time, so the PA model is designed to be flexible, to allow for changes to be made easily. The PA model is, for ENABLE, the embodiment of the UN CRPD and self-directedness.

### **Support Staff**

ENABLE Care offers 2200 employees a job and supports over 1000 people. The PA model delivers small, bespoke teams, chosen by the individual and contracted directly to them. People are always in charge of their own PA, but they don't act as an employer. The service design involves key stakeholders and multidisciplinary professionals. Support strategies act as a guide for the team and demonstrate how best to support the person in a way that works for them. ENABLE is one of Scotland's 40 largest employers outside the public sector. Individuals are recruited for their values and experiences but not necessarily for their care expertise.

For example, if you left as a care worker and you return, you receive 1000£ onboarding payment. Focus is put on getting the right qualities of caregivers and rewarding them properly. The chief executive refers to Maslow's hierarchy of needs, for caregivers: *"If you cannot pay your rent or pay your mortgage or pay your bills, then how on earth can you be giving your 100% to support precarious people? And often in social care we have people who are financially precarious, supporting those who are physically precarious or precarious in terms of their situation."* ENABLE honours their employees not only by words but also by salary. ENABLE made a successful plea at the government to raise the salary and to cover nightshifts in a reasonable way.

ENABLE has also elected members with disabilities in their board. They are currently working with their members towards a next generation that can be employed in the organisation.

### **Sustainability of the practice:**

The sustainability of the model can be explored at several levels: system, people, carers and socio-economic.

SYSTEM: ENABLE's PA Model is a scalable, transferable, and tested model of human rights-driven, self-directed social care, delivered through a valued, skilled, well represented and well remunerated workforce, contracted directly to the person supported.

**PEOPLE:** Small teams and strong relationships meant that the PA model stood the test of Covid-19. The model has proven to be highly beneficial in controlling risk of infection and enabling consistent hours of support to continue. The service design is continuously updated to make sure they cover and meet the changing circumstances and aspirations of the individual; it is the individual's choice. They make ENABLE the most sustainable, thanks to their choices and belief.

**CARERS/ PERSONEL:** The service design involves key stakeholders and multidisciplinary professionals.

**ECONOMIC:** It is a tight labour market, but still the choice of people is central.

The ENABLE PA's model meets the Scottish Government's key objectives for the National Care Service by delivering care and support that is: consistent, fair, high quality and for everyone.

The model's financial business plan grows every year thanks to the increase of members and the acquisition of less successful providers. They doubled revenue levels from 2016 to 2022.

### **Strengths – Weaknesses (SWOT-analysis)**

ENABLE has set the agenda for the PA model and its connection with SDS. The management and staff pioneered in Scotland and consider the different options within the SDS<sup>147</sup> legislation as forms of human culture, so it offers a more flexible way of supporting people. Wherever you live in Scotland you can access the model and design it according to proper wishes.

Moreover, the model evolves towards a "network-oriented situation" and considers not only the person themselves, but everyone connected with each other in terms of support needs.

The management has a very strong vision and mission and an inclusive leadership and approach themselves. They don't fear to take risks in terms of new procedures and solutions and phrase it themselves as: "*Demonstrate by doing*". Inclusion is at the heart of everything they do.

ENABLE is high quality: 88% of ENABLE services have wellbeing grades of "very good" or "excellent" from the Care Inspectorate, compared to a national average of 63%. Whereas they are a big organisation, focus is put on the family experience and this way the sense of belonging has been met at several levels. There is a huge confidence of most people in ENABLE because of their engagements.

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<sup>147</sup> The full benefits of SDS are available to everyone, regardless of their own or family members' level of education and social capital.



Their model includes “time” as a parameter and influencing factor. Context and needs may change over time and the model can adapt to that. Their whole business model has been founded on a respectful and decent collaboration between employers, clients, and organisations. Over the years they have become the prior social organisation in the country.

The PA model serves the mission that people choose their own PA based on preferences.<sup>148</sup> Whilst the principles of self-directed support (SDS) are so well enshrined in enabling legislation, far too many individuals and families are not yet able to access it because they don’t have funding.<sup>149</sup> ENABLE works on very low margins, because they rely on funding, and put it to the frontline. This makes the organisation politically vulnerable, and they realise that they must be mindful of this context. This approach has so many advantages in terms of care but often invaluable moneywise. Compared to other systems, this approach is still more expensive.

The choice of people for their personal assistants is a very valuable way of working because ENABLE acts as the employer. However, from a legal point of view it is a new approach and beforehand lawyers warned them about the threat of an employment tribunal. Again, ENABLE countered this by their progressive way of thinking, more precisely by means of setting what they define as a psychological contract between the PA and the people.

Time can sometimes be a threat in terms of political decisions and funding as well, but the organisation is very organised and well managed to anticipate on this.<sup>150</sup>

The model can flex to the entire environment and family because context and time are taken into consideration. The model can be upgraded or decreased depending on the family situation even on a temporarily basis. This proves the high level of inclusion of this model. Every person has significant and specific requirements. The ENABLE model makes progress by means of “demonstration by doing”.

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<sup>148</sup> This fact is something the trade unions were aware for. It is ironic that they must defend themselves not excluding anyone because of their HR model. ENABLE firmly states that it is a personal and psychological choice of the client and no employer-based decision, so they always follow the employment legislation.

<sup>149</sup> ENABLE is currently working with the Group’s ENABLE Scotland charity to campaign for people with support needs and their families, to ensure they have the same rights to access support to independent living, and that they can get the flexibility and person-centred focus that SDS promises.

<sup>150</sup> They often need to negotiate with commissioners about specific cases in terms of uncovered care for people and this requires a lot of negotiation work and administration, hours that cannot be put into care. The financial funding is linked to the welfare state, and this is an external objective that needs to be covered. 44% of the budget has been spent on care and health costs and most of their money comes from public funding.

## ▪ Voice of the clients: video testimonials

As explained before, this research starts from an inclusive approach in which experiences of users are put at core of this study. Consequently, users are invited to speak for themselves during short video testimonials.<sup>151</sup> Each organisation delivered at two or three testimonials and, depending on people's abilities, the interviewees spoke for themselves or were guided by their legal representatives and personal assistants.

In general, these testimonials confirm the importance of personal choice. Residents refer to their autonomy and self-determination. One user clearly states: *"I like my independence"*.<sup>152</sup>

All organisations position themselves as facilitator and share a huge awareness for this role, because every decision is made with respect to the voice of their clients. One interviewee explains: *"I would recommend this organisation to anyone who can use support, because the staff asks good questions and, in this sense, they can support you better. (...) I feel comfortable"*<sup>153</sup> All interviewees confirm that the approach enables them in their transformation towards an independent life. All interviewees confirm that each organisation invests in trainings to empower them. For example, JAMBA's cognitive training sessions contribute to education, whereas Inclusie Invest creates training sessions on daily habits to manage daily household. One interviewee shows how he printed, and plasticised his daily habits and respectively hung them at different the locations.<sup>154</sup>

Another important aspect for all interviewees is the feeling of belonging, being part of the community. One interviewee explains that for him his job is synonym for "meeting other people"<sup>155</sup> and he refers to his neighbours as "one big family".<sup>156</sup> The availability of a network is also referred to as very important in a context of IL, because it expands and strengthens the style of service. When asking what could have been better, possible improvements are rather practical aspects (such as the invitations of new service users, the need for more staff to support, a faster shift of staff when they are not satisfied with their assistant, etc.).

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<sup>151</sup> Details on the data collection and methodology in annex 2.

<sup>152</sup> Respondent ENAVI02

<sup>153</sup> Respondent ENAVI02

<sup>154</sup> Respondent INVI01

<sup>155</sup> Respondent INVI01

<sup>156</sup> Respondent INVI01

## 8. Findings Promising Practices

All the selected Promising practices of independent living share similar characteristics within their support models that demonstrate scalability towards other support domains.

The core vision of all models is embedded in people's capabilities or abilities and choices, and interestingly all these models are designed according to the principles of an inclusive dynamic process. All models recognise the dynamic interrelatedness between the choice, context, time and funding in which the support model is embedded. It is crucial to state that independent living cannot be ticked off but that it constantly relates to a dynamic process.

Moreover, all models prove to be frontrunners and pioneers, always in search of new solutions and opportunities and keeping up with innovations. This attitude is required in an inclusive approach on independent living since it acknowledges the complexity of life. More precisely, all conditions for Independent Living are connected, like in an ecosystem, and consequently organisations have to keep an overview on all the actors in the system. Shifts may impact the style and quality of their services. A "demonstrate by doing" attitude characterises the approaches. Furthermore, since an inclusive support model is part of society's transformation, all organisations feel obliged to engage in advocacy work. Although this asks for a huge investment in hours, which could be spent on support, they all underline the necessity.

All models commit towards a very inclusive and transparent work ethic, enabled by transparent communication towards all stakeholders and the public. For example, Inclusie Invest shares its business model online and invites other organisations to copy their model, with success. Moreover, all organisations aim towards an inclusive culture offering meaningful jobs and including a diversity of employees within all ranks of the organisation.

Conscious material as well as immaterial actions of the organisations are set-up to enable community integration. Whereas the physical location and architecture contributes to a community's performance, immaterial actions, like

Nevertheless, the biggest challenge for all organisations is their budget. A support model is a process and requires many hours of support. Enable rightly states that paying employees well is a

return on investment by means of the quality of the service, because happy employees will also offer better services. Funding systems are often linked to political decisions and this way the financial model of Inclusie Invest and Jamba working with social investors might offer opportunities. Another challenge for all models is the huge amount of administration that comes with their daily practice. Apart from the organisational administration, they offer support for their clients' administrative work.

To reduce costs, all organisations stress the importance of an available network. Most of them rely on a social network (formal as well as informal) to overcome lack of resources but at present they experience a decrease of volunteers.

Because these promising practices perform in excellence, they grow exponentially, and this brings new challenges in terms of resources and operational planning.

Their common added value lies in the fact that all promising models aim to serve all needs of all stakeholders involved in the support model for independent living: users, support givers, network, collaborators, government,... society at large.

## 9. Conclusions

This research investigated how people with significant support needs can be empowered in the context of independent living. Besides a theoretical outlining of definitions and a conceptual framework, five promising models for independent living in five different welfare states were selected and analysed.

By means of defining “people with significant support needs” in the context of independent living, the concepts and frameworks are clarified and can be used as generators and gatekeepers for policy makers to encourage more inclusion. Independent living as intended by the UN CRPD is an inclusive state of being created by a support system that links all aspects of life. A support model can be successful when all aspects of quality of life are met and balanced with choice, time, context, and funding. Currently, there is a lack of inclusion in the context of Independent Living due to a lack of common knowledge and language. Based on the theoretical study we argue for more research on the inclusive processes that generate support models. Indeed, research shows that support models and services are dynamic iterative processes that involve inclusive decisions at every stage.

The empirical study exemplified different promising models of independent living that support inclusion and community integration by means of personal assistance, inclusive employment, education, leisure, sense of belonging, affordable housing, assistive strategies, and assistive technology. Although all models intentionally started from the support of people with cognitive, mental, physical, social disabilities, they prove to serve for different forms of support needs (e.g. child care, ageing centres, etc.) which confirms its inclusive outcome. Apart from the support in basic needs all models enable a holistic approach to meet all Qualities of Life.

Both theoretical and empirical track reveal the importance of awareness raising and common knowledge on the complexity of a support model for independent living. It is recommended that besides policy making, stakeholders are trained on inclusive processes and concepts and to not specifically link people with significant support needs to people with disabilities but to invest in inclusive support models built upon human capabilities.

## 10. Epilogue author

This study called upon to focus on promising models of independent living for people with significant support needs. It feels right to clarify some sensitive and scientific issues regarding the position of the researcher and research decisions during the study. In this study, an objective and scientific, but humble and open mindset was adopted. Research has been approached from a bottom-up and human-centred perspective. The main expertise and training of the researcher is situated in design, inclusive design, and disability studies and less in policy and social sciences. As a designer, one has been trained as a problem solver, connector, creator, and creative thinker to link different areas of specialty. A designer must unravel diversity and find answers in innovation. The researcher feels very grateful to the staff of EASPD in recognising this perspective as we believe that cognitive diversity holds innovative solutions for inclusion.<sup>157</sup>

An interdisciplinary approach can expose the complexity of the research question as well as the layered complexity of life in which this topic is grounded. Hence, the diversity of approaches and perspectives has been the driver of this research and the reader is included in these, as we consider this study as a contribution to an ongoing process of transformation towards more inclusion.

In both theoretical and empirical track, a very high sensitivity towards terminology and definitions on this topic has been acknowledged. However, since language is part of a social transformation, it is recognised that certain terms might change in the future or other words had been more appropriate. However, this report is written with the highest awareness for terminology. This was a very short four-month study and although research has been intensively conducted during these months, this time restriction does not allow in-depth research and urges to consider the outcome not as a measure, but as an exploratory pilot research that can develop further into in-depth research.

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<sup>157</sup> SYED, M. 2019. *Denk als een rebel*, Amsterdam, Uitgeverij Luitingh-Sijthoff B.V.

## 11. Annex

### ▪ Annex 1

#### Research methodology of the theoretical track

##### Scoping

Before we started to search for literature, several key issues were considered as a first step in conducting this literature review. The first key terms listed, were based on the main research question:

- Significant support needs
- Independent living

These terms were used for a first search and familiarising with the topic. A thorough search has been conducted to discover whether a systematic review of the research questions has been conducted in the past.

It was clear that there was no systematic review done on this topic. This first search and reading contributed to a familiarisation of the topic.

The next step was to break down the concepts and look for independent words or similar terminology:

- Systems
- Support
- Needs
- Disabilities
- Housing for people with disabilities
- Different databases were searched, and a first list of literature came out.

##### Inclusion criteria for research

Different inclusion and exclusion criteria were formulated to select.

Since it is difficult to determine one objective definition, we focus on the following inclusion criteria. For these, decisions were taken based on the focus of research domains and topic.

- **Disability studies**

We decided to mainly focus on studies in disability research and skip articles focusing on medical care or psychology because the focus is put on the aspect of independent living and less on the medical approach. However, considering the history in the approach and definition of people with disabilities in general, we also felt that it was interesting to include general theoretical frameworks to clarify the evolution and current perspectives.

- **Independent living**

The main objective of the study is to find insights regarding independent living so this was the second criterium that has been look at during the search.

- **Participants**

Since this research's main objective is to analyse the implementation of the UN CRPD, main focus was put on articles focusing on people with disabilities.

- **Types of study**

Preference was put on theoretical studies but not limited to literature reviews.

## Search strategy

The search strategy aimed to find published and unpublished studies in English and Dutch. No date limit was defined for this search. However, in the first searches, a limit of articles no older than five years was installed as search function. A five-step search strategy was utilized in this review and started on July 26<sup>th</sup>, 2022, by a main search in the Hasselt University Library (a database that covers a huge amount of databases ISI Web of Knowledge, Pubmed, EBSCO, ...) and the city of Hasselt's library in Belgium.

We started this search by a robust and main digital search on Google search, a digital search in the UHasselt discovery service and a digital and physical search in the city of Hasselt's library. This search aimed at creating insight into the frequency of definitions on "people with significant support needs" and "independent living" and to familiarise with the topic.



An initial search (Hasselt Directory, Google scholar) using the following keywords: “significantsupport need”, “independent living AND support need”, “persons with significant support need”, “support needs”. This search was followed by an analysis of titles and abstracts and the index terms of each search.

A second search using all identified keywords and index terms was undertaken across the following databases:

Thirdly, the reference list of all the included studies was screened to find further studies that fit inclusion criteria.

Finally, a search was conducted on the databases of gray literature to make sure that we also covered the unpublished materials. The following databases were consulted: Google and Google Scholar, Research Gate. In addition, some contacts of the empirical track also sent articles of their own or articles and book chapters they recommended. Most of these articles were in English, apart from five articles from Japan that have been translated by the author herself through a translation program.

### **Information sources**

Following databases were consulted:

- EBSCO
- PROQUEST
- PubMed
- Researchgate
- UHasselt discovery service
- Google and Google Scholar

### **Study Selection review**

The searches were put on five years old articles, full publication available, journal article or book, discipline: environmental sciences, social welfare & social work. After the database search, the search records were collated and managed using citation management software: Endnote V 20 (Clarivate

Analytics, PA, USA). Duplicates were removed and articles were assessed for relevance based on information provided in the keywords, abstract and title.

The eligible studies were critically appraised for quality and relevance in the context of this research. By means of focusing on key terminology and a quotation system the most relevant studies were selected. Studies were selected based on the actual relevance and links with the main topic.

The articles were categorized as follows:

INCLUDED STUDIES		CHARACTERISTICS			
STUDY REFERENCE	COUNTRY	WELFARE STATE	KEY INTERESTS AND GOALS	DEFINITIONS OR CONCEPTUAL FRAMEWORK	DESCRIPTION OF MAIN RESULTS

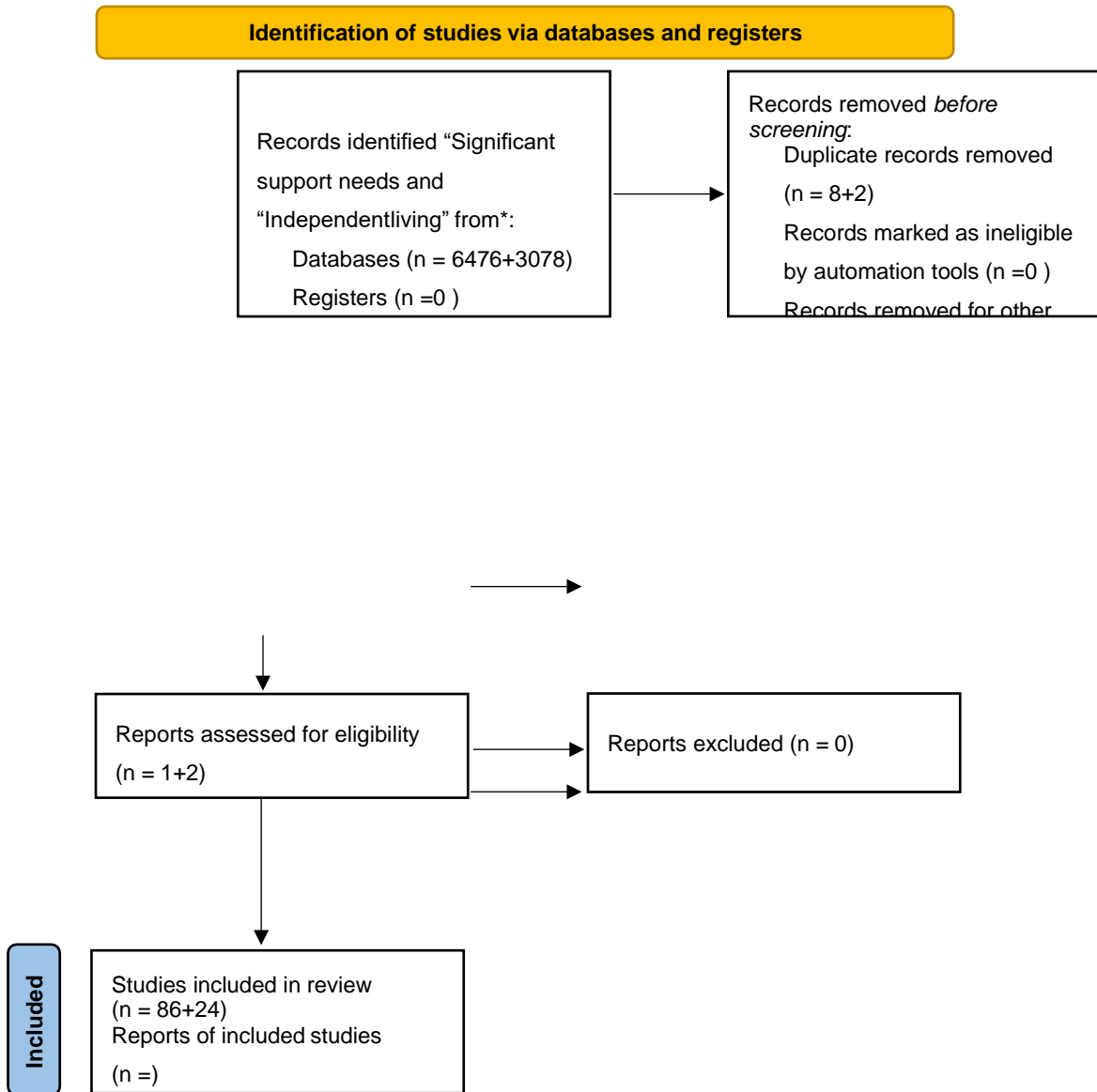
### Data extraction

The author made a first analysis based on the title and then the abstract. She compared the different descriptions, concepts, and definitions from the different studies. The data extracted included specific descriptions of the definitions, geographical locations of the studies and the researchers, culture, description of the main results and the key interests and goals, relevant to review the main objective of the study. The findings were assigned a level of credibility in the synthesised findings by means of highlighting the main links that contributed to definitions or conceptual frameworks.

### Data synthesis

Findings were aggregated and generated a set of statements that represent evidence and categorized according to the definition of “people with significant support needs” and “independent living”.

A flow chart: for these results the numbers of different searches were combined.



\*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

\*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).

\*\*If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

## **Study inclusion**

As exposed in the PRISMA flow chart, in total 9554 records were identified through systematic research. After duplicates removal, the titles, and abstracts of 1463 were reviewed and screened for eligibility. Based on eligibility criteria, 1353 articles were excluded. 110 articles selected for full-text screening. No date limit was defined in this review and all studies were published from 1995 to 2022.

For more detailed information, please contact the researchers in person.

## ▪ Annex 2

### Empirical track methodology

Several people in the network have been contacted through telephone calls, video calls, webinars, seminars and during information sessions or attended conference on the topic. Over 300 emails were sent in search for promising models of independent living for people with significant support needs.

### Phase 1

In the first phase, we started to contact our personal network at the beginning of September 2022. 4 people (in Belgium, Italy, Portugal, Spain), were contacted by phone and a total of 80 emails were sent to the personal international network of the researcher in countries over the world, because this research aims at making a geographical balance including practices of the 5 different welfare regimes. Each email was personally written and addressed with additional context and information. We received an immediate response from 29 contacts of which 11 referred or delegated to useful contacts and 12 introduced us to useful examples, models or information. We received three “out of office-replies” of which one replied two weeks later. We received two “no deliverable messages” of people who didn’t use this email address any longer. Two contact persons preferred to write and address personal contacts themselves and kept us informed of feedback and outcome.

Six people have sent us an immediate answer but postponed the actual answer to our question for later. Some people sent us names of people as a reference and didn’t have their email addresses: five people were contacted through linked in and 2 responded to this message.

Appendix 1 shows a draft template of the letters and emails that have been sent to the network. (For the integrity of the research the standard email and letter is enclosed in the appendix with the focus on America to avoid speculation of readers and guarantee GDPR). In every email we addressed everyone personally and enclosed a letter that explained the focus of the research and the focus of the examples. Depending on the country, a letter in Dutch, Spanish, Italian and Portuguese was added with the help of translation conducted by people in the network.

## Phase 2

On October 3rd, 2022, the researcher evaluated the actual responses. Following up on the emails, we concluded that there were different kind of postponed responses: 1) people who did promise to come back with information but hadn't responded yet 2) people who promised to send us further contacts 3) people who didn't respond at all. A personal text message has been sent to the group who did respond immediately and promised information but hadn't sent any information yet: six people. The researcher decided to send a gentle reminder to those who hadn't respond (51 people). In addition, two phone calls and two meetings were planned to explain the focus of the research in more detail.

## Phase 3

In a third phase we evaluated the responses based on the represented welfare states and countries and we decided to send out a second series of emails to the main contact points of countries: centres for independent living, accessibility centres, Universal Design centres, Disability organisations, ... A total of 40 new emails were sent to all the new contacts. It was double checked that all the EU-member states were contacted. However, it was not restricted to the European countries, letters were also sent to Africa, America, India, Japan, China, Mexico, Brasil, Australia and Canada. This way we guaranteed that we covered an international point of view and all the European countries and welfare states at the start.

In the second and the third phase we received a total of 39 replies of which seven gave us new examples, five delegated the work to new contacts and six postponed the questions for later. Three contacts asked for a meeting and two contacts spoke on behalf of their country in stating that there are no good models in their country. Two respondents didn't want to answer the question because they are working on a report themselves for the European Commission.

In total, during the three phases: 275 emails have been sent. In total we received responses from 73 different people.

## **Phase 4**

In the last phase, a selection of examples has been made, and we investigated these examples with the help of residents. In general, for research on people with disabilities, many researchers often rely on the information of the social network of the participant. Those are people who know the participant very well. However, research has proven that this data is not always so reliable, especially when it relies to experiences (Moonen, 2006; Moonen & Verstegen, 2006; Schuurman, Speet, & Kersten, 2004). Often there is too much focus of professionals on care, whereas negotiating and independence is as important (de Bruijn, 2014).

Therefore, we argue that it is important in Phase 4 to check and evaluate the good models with users themselves who live on site. Besides the authors own experience, this advice has been given by several experts. Two respondents in the second and third phase denounced former reports on good models, stating that they might seem good at first sight but aren't in practice.

These arguments, motivate the researcher to change the strategy in order of the quality of the research.

## **Phase 5**

Out of 102 examples, we selected 18 examples based on the input given by respondents as well as the information collected and the links with the goals and objectives of the research. These 18 examples were proposed to EASPD and for the final selection we chose 5 examples, one for each welfare state in Europe.

The directors and staff were contacted by a letter in which the research was summarised and with a call for participation. All five examples agreed for participation and meetings were planned for the recording of an interview with the directors or staff members. Meantime we also invited them to ask residents for a video recording of themselves while answering the proposed 5 questions as defined by us.

The interviews with the staff members all took place online through a zoom or teams video call. All the interviews were recorded with a consent of all the participants. The common interview language was English apart from the Spanish interview that took place in Spanish and English with the help of

google translator. The video calls were transcribed and analysed and a summary of all the cases was made based on the interview and the collected information. Four out of five cases sent video testimonials of clients. All video testimonials were personal and recordings of one person answering the questions. For one case, the videos were made with two or four residents together. This is a different dynamic, but it did show the relevance of the selected model.

For each selected promising good model we made a summary of 2-3 pages and before we included it in the report we sent it to the staff to confirm the analysis and evaluation. Apart from some typo's and small interpretations, all staff members had no comments or additional information. Two models did not send any feedback at all.

### **Data collection**

All data has been sent through email. When emails came in, they were analysed, and examples were immediately listed in an excel table with an overview on the countries and respective contacts and type of support.

Respondents sent documents, and these were immediately stored in folders by country and case and destination folder.



## ■ Annex 3

### Data collection and methodology of video testimonials

The **video testimonials** were additional data collected from all the five selected good models.

Together with the invitation letter to the directors of all the organisations, we also sent the invitation to record three testimonials of residents or clients. Attached to the letter, the staff could find the five focus questions as well as templates for the consent forms of the participants.

All the organisations sent video testimonials, and the diversity of their support model was also represented in the approach of data collection.

Depending on the resident's self-reliance, testimonials were made in live presence or by zoom calls.

Some interviewees were able to speak others weren't and relied on their legal assistants or personal assistants. In case of a non-verbal interview, the personal or legal assistants read the questions and formulated answers based on body reactions, body language and sounds (laughing, moaning,...) that could be identified as affirmative or non-affirmative.

We collected a total of 24 videos with a time span in between 57 seconds and 17:19 minutes. We had a total of 64 minutes and 37 seconds. 18 people were interviewed. All of them gave a personal interview apart from 6 people: one duo interview and one focus interview with four participants. Two people relied on their legal assistant for their answers. One person was supported by her personal assistant as well as her legal assistant and interviewed by a staff member.

Some were interviewed by a staff member or personal assistant, whereas other people made a video themselves based on the questions. Some wrote their answers on a paper and have read the answers in front of the camera whereas others answered the posed questions. When residents couldn't speak, their legal assistant did. One organisation asked to make a home tour through the whole building, while answering different questions but most of the interviews took place at the resident's home.

Some videos were recorded by a camera, while others were recorded through an internet call.

All the videos were sent to the researcher by staff members and all the participants signed an informed consent. The interviews were analysed based on the focus questions as referred to before.

European Association of Service providers  
for Persons with Disabilities

JAG		FEKOOR	
datacode	video time	datacode	video time
JAGVI01	04:00	FEKVI01	03:04
JAGVI02	05:15	FEKVI02	04:24
JAGVI03	03:47	FEKVI03	02:06
	13:02		09:34
INCLUSIE INVEST		JAMBA	
datacode	video time	datacode	video time
VI01 & INVI	15:04	JAMVI01	00:57
INVI03	01:53	JAMVI02	01:50
		JAMVI03	02:28
	16:57		05:15
ENABLE CARES			
datacode	video time		
ENAVI01	01:10		
ENAVI02	17:19		
ENAVI03	01:20		
	19:49		

Figure 9 Overview of the collected data for each model: for reasons of confidentiality and GDPR, names are left out

**EASPD is the European Association of Service providers for Persons with Disabilities. We are a European not-for-profit organisation representing over 20,000 social services and disability organisations across Europe. The main objective of EASPD is to promote equal opportunities for people with disabilities**

## 12. Bibliography

- ANDERSEN, R. & NEWMAN, J. F. 1973. Societal and individual determinants of medical care utilization in the United States. *The Milbank Memorial Fund Quarterly. Health and Society*, 51, 95-124.
- AZUMI, J., MASYUKI, O., FUMIYA, O. & SHINAYA, T. 2012. Raw Techniques. 3, 9.
- BEADLE-BROWN, J., MANSELL, J. & KOZMA, A. 2007. Deinstitutionalisation in intellectual disabilities. *Current opinion in Psychiatry*, 20, 437-442.
- BECKER, L. C. 2005. Reciprocity, justice, and disability. *Ethics*, 116, 9-39.
- BIGNAL, T., BERTRANA, I. & LEVENTI, K. 2021. EASPD position paper on EU Care strategy. In: EASPD (ed.). Brussels.
- BREDEWOLD, F., TONKENS, E., TRAPPENBURG, M. J., GOVERNANCE, U. L. R. U. P. M. P., MANAGEMENT, GOVERNANCE, P. & MATTERS, U. L. R. U. P. 2016. Urban encounters limited: The importance of built-in boundaries in contacts between people with intellectual or psychiatric disabilities and their neighbours. *Urban studies (Edinburgh, Scotland)*, 53, 3371-3387.
- BRILL, M. & KRAUSS, R. Planning for Community Mental Health Centers. In: SANOFF, H. & COHN, S., eds., 1970 Edmonton. EDRA.
- BULIC, I., ANGUELOVA-MLADENOVA, L., GYLLENSTEN, L. & MULHEIR, G. 2012. Common European Guidelines on the Transition from Institutional to Community-based Care. In: CARE, E. E. G. O. T. T. F. I. T. C.-B. (ed.). Brussels: European Expert Group on the Transition from Institutional to Community-based Care.
- BUNTINX, W. H. & SCHALOCK, R. L. 2010. Models of Disability, Quality of Life and Individualized Supports: Implications for Professionals Practice in Intellectual Disability. *Journal of policy and practice in intellectual disabilities*, 7, 283-294.
- CAMBRIDGEDICTIONARY. 2022a. *Cambridge Dictionary* [Online]. Cambridge: Cambridge University Press. Available: <https://dictionary.cambridge.org/dictionary/english/need> [Accessed].
- CAMBRIDGEDICTIONARY 2022b. Support. Cambridge: Cambridge University Press.
- CAMPBELL, F. K. 2009. *Contours of Ableism: The production of Disability and Aabledness*, New York, Palgrave MacMillan.
- CASALEIRO, T., CALDEIRA, S., CARDOSO, D. & APÓSTOLO, J. 2022. Spiritual aspects of the family caregivers' experiences when caring for a community-dwelling adult with severe mental illness: A systematic review of qualitative evidence. *Journal of psychiatric and mental health nursing*, 29, 240-273.
- CLAES, C., VAN HOVE, G., LOON, J., VANDEVELDE, S. & SCHALOCK, R. L. 2010a. Eight principles for assessing quality of life-related personal outcomes. *Social Indicators Research*, 98, 61-72.
- CLAES, C., VAN HOVE, G., VAN LOON, J., VANDEVELDE, S. & SCHALOCK, R. L. 2010b. Quality of Life Measurement in the Field of Intellectual Disabilities: Eight Principles for Assessing Quality of Life-Related Personal Outcomes. *Social indicators research*, 98, 61-72.
- CLAES, L., DE SCHAUWER, E. & VAN HOVE, G. 2013. Disability studies and social geography make a good marriage: Research on life trajectories of people with intellectual disabilities and additional mental health problems. In: WAPPET, M. & ARNDT, K. (eds.) *Emerging perspectives on disability studies*. London: Palgrave Macmillan.
- COTE, A. 2021. Social protection and access to assistive technology in low- and middle-income countries. *Assistive technology*, 33, S102-S108.
- CRPD, U. 2022. Convention on the Rights of Persons with Disabilities: Guidelines on deinstitutionalisation, including in emergencies. UN.

- DE BRUIJN, J., BUNTINX, WIL, TWINT, BRIAN 2014. *Verstandelijke beperking: definitie en context*, Amsterdam, Uitgeverij SWP Amsterdam.
- DE MAEYER, J., VANDERPLASSCHEN, W. & BROEKAERT, E. 2010. Quality of life among opiate-dependent individuals: A review of the literature. *The International journal of drug policy*, 21, 364-380.
- DE WAELE, I., VAN LOON, J., VAN HOVE, G. & SCHALOCK, R. L. 2005. Quality of Life versus quality of care: implications for people and programs. *Journal of policy and practice in intellectual disabilities*, 2, 229-239.
- DE WISPELAERE, J. & CASASSAS, D. 2012. Handicap, vrijheid en overheersing. Een republikeins perspectief op het gehandicaptenbeleid. *Ethiek en maatschappij*, 13, 53-78.
- DESROCHES, M. L., FISHER, K., AILEY, S., STYCH, J., MCMILLAN, S., HORAN, P., MARSDEN, D., TRIP, H. & WILSON, N. 2022. Supporting the needs of people with intellectual and developmental disabilities 1 year into the COVID-19 pandemic: An international, mixed methods study of nurses' perspectives. *Journal of policy and practice in intellectual disabilities*, 19, 48-63.
- DEVLIEGER, P. 2016. *Rethinking disability : world perspectives in culture and society*, Antwerp, Garant.
- DRAAK, M. D., MARANGOS, A. M., PLAISIER, I. & KLERK, M. D. 2016. *Wel thuis? Literatuurstudie naar factoren die zelfstandig wonen van mensen met beperkingen beïnvloeden*, Den Haag, Sociaal en Cultureel Planbureau.
- EEGTICC, E. E. G. O. T. T. F. I. T. C.-B. C. 2019. Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community based service. Brussels: European Commission.
- ENDERS, A. Personal Assistance Services and Assistive technology: Allies or Adversaries. RESNA, 1995 Arlington, VA. RESNA, 584-586.
- EUROPE, C. O. 2016. The Council of Europe Disability Strategy 2017-2023. Council of Europe.
- EUROPEANCOMMISSION. EU Care Strategy. In: EASPD, ed. Webinar on Stakeholders' Initial reactions, 2022 online webinar, September 9th 2022.
- FAKHOURY, W. & PRIEBE, S. 2007. Deinstitutionalization and reinstitutionalization: major changes in the provision of mental healthcare. *Psychiatry (Abingdon, England)*, 6, 313-316.
- GOLSE, B. 2022. Primary Need. *International Dictionary of Psychoanalysis*. Cengage.
- GRABOWSKA, I., ANTCZAK, R., ZWIERZCHOWSKI, J. & PANEK, T. 2021. Individual quality of life and the environment - towards a concept of livable areas for persons with disabilities in Poland. *BMC public health*, 21, 740-15.
- HALL, E. 2005. The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health & place*, 11, 107-115.
- HAMBLETON, P., KEELING, S. & MCKENZIE, M. 2009. The jungle of quality of life: Mapping measures and meanings for elders. *Australasian journal on ageing*, 28, 3-6.
- HARPUR, P. 2012. From disability to ability: changing the phraseing of the debate. *Disability & society*, 27, 325-337.
- HÖGSTRÖM, E. 2018. It used to be here but moved somewhere else: Post-asylum spatialisations- A new urban frontier? *Social and Cultural Geography*, 19, 314-355.
- IRIARTE, E. G., MCCONKEY, R. & VILDA, D. 2021. Family experiences of personalised accommodation and support for people with intellectual disability. *Journal of intellectual disabilities*, 25, 476-489.
- JAG 2011. Strasbourg Freedom Drive. JAG.
- JAG 2013. JAG a civil rights movement. In: JAG (ed.). Youtube
- JAG. Does the view of people with disabilities differ in Sweden, Norway and Finland?

- . Riksföringen JAG deltar i Almedalsveckan digital, 4-7/07/2021 2021 Youtube.
- JASKULSKI, T. M., LAKIN, K. C. & ZIERMAN, S. A. 1995. The journey to inclusion. A resource guide for state policymakers. Washington: President's Committee on Mental Retardation.
- KAPEDANI, E. 2021. *Indoor Environmental Comfort - Integrating Universal Design & Energy Efficiency in Home Renovations*.
- KAPEDANI, E., HERSSSENS, J. & VERBEECK, G. 2017. Comfort in the Indoor Environment: A Theoretical Framework Linking Energy Efficiency and Universal Design. *Advances in Design for Inclusion*. Cham: Springer International Publishing.
- KÖNBERG, B. & WESTERBERG, B. 1993. [Lagen om stöd och service till vissa funktionshindrade (LSS) [Act concerning Support and Service for Persons with Certain Functional Impairments]. In: AFFAIRS, M. O. H. A. S. (ed.). Sweden: Swedish Parliament.
- KOSTER, M. 2014. Bridging the gap in the Dutch participation society: New spaces of governance, brokers and informal politics. *Etnofoor*, 26.
- KROMTHOUT, M., FEIJTEN, P., VONK, F., DE KLERK, M., MARANGOS, A. M., MENSINK, W., DEN DRAAK, M. & DE BOER, A. 2014. De Wmo in beweging. Evaluatie Wet maatschappelijke ondersteuning 2010-2012. Den Haag: Sociaal en Cultureel planbureau.
- LITVAK, S. & ENDERS, A. 2001. Support Systems: The Interface between Individuals and Environments. In: GARY, A., KATHERINE, S. & MICHAEL, B. (eds.) *Handbook of Disability Studies*. Thousand Oaks: SAGE Publications, Incorporated.
- MANSELL, J. 2006. Deinstitutionalisation and community living: Progress, problems and priorities. *Journal of Intellectual and developmental disability*, 31, 64-76.
- MARSHALL, G. 2022. Need. In: MARSHALL, G. (ed.) *A Dictionary of Sociology*. Oxford: Oxford University Press.
- MASLOW, A. 1943. A theory of human motivation. *Psychological Review*, 50, 370-396.
- MASLOW, A. 1954. *Motivation and personality*, New York, Harper.
- MASLOW, A. 1970. *Motivation and personality*, New York, Harper & Row
- MCCARTHY, M., FRAWLIE, P., OLOIDI, E. O., NORTHWAY, R. & PRINCE, J. 2022. 'People with intellectual disabilities living in the communities is bad enough let alone having sex': Exploring societal influence on social care workers' attitudes, beliefs and behaviours towards support for personal and sexual relationship needs. *Journal of applied research in intellectual disabilities*, 35, 1037.
- MCCONKEY, R. 2007. Variations in the social inclusion of people with intellectual disabilities in supported living schemes and residential settings. *Journal of intellectual disability research*, 51, 207-217.
- MCCONKEY, R. & COLLINS, S. 2010. The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of intellectual disability research*, 54, 691-700.
- MLADENOV, T. 2012. Personal assistance for disabled people and the understanding of human being. *Critical social policy*, 32, 242-261.
- MLADENOV, T. 2020. What is good personal assistance made of? Results of a European survey. *Disability & society*, 35, 1-24.
- MOONEN, X. 2014. Visie op ondersteuning. In: DE BRUIJN, J., BUNTINX, WIL, TWINT, BRIAN (ed.) *Verstandelijke beperking: definitie en context*. Amsterdam: Uitgeverij SWP Amsterdam.
- MOREL, N. 2007. From subsidiarity to "free choice": Child and elder-care policy reforms in France, Belgium, Germany and the Netherlands. *Social policy & administration*, 41, 618-637.
- MURPHY, K. & BANTRY-WHITE, E. 2021. Behind closed doors: Human rights in residential care for people with an intellectual disability in Ireland. *Disability & society*, 36, 750-771.
- NCIL. 2022. *The National Council of Independent Living* [Online]. Available: <https://ncil.org/> [Accessed 10/9/2022 2022].

- NORDENFELT, L. 2007. The concepts of health and illness revisited. *Medicine, health care, and philosophy*, 10, 5-10.
- NUSSBAUM, M. C. 2006. *Frontiers of justice: disability, nationality, species membership*, Cambridge, Mass, Belknap Press.
- NUSSBAUM, M. C. 2011. *Creating Capabilities: The Human Development Approach*, Cambridge, Harvard University Press.
- OHCHR 2022. Draft Guidelines on Deinstitutionalization, including in emergencies Committee on the Rights of Persons with Disabilities. In: NATIONS, U. (ed.). Geneva, Switzerland: United Nations
- OXFORDDICTIONARY. 2022a. *Oxford Dictionary* [Online]. Oxford: Oxford University Press. Available: [https://www.oxfordlearnersdictionaries.com/definition/english/need\\_2](https://www.oxfordlearnersdictionaries.com/definition/english/need_2) [Accessed].
- OXFORDDICTIONARY 2022b. Welfare, Sociology of Welfare. *Dictionary of Sociology*. Oxford: Oxford University Press.
- PILLA, D. & PARK-TAYLOR, J. 2022. "Halfway Independent": Experiences of formerly homeless adults living in permanent supportive housing. *Journal of community psychology*, 50, 1411-1429.
- PRIEBE, S. 2004. Institutionalization revisited - with and without walls. *Acta psychiatrica Scandinavica*, 110, 81-82.
- REMMERY, M., ROETS, G., BENOOT, T., VERVLOESEM, E., DERMAUT, V. & ROOSE, R. 2021. Ruimte voor zorg: Reflectie- en inspiratiekader de-institutionalisering. Gent: UGent.
- ROETS, G., DERMAUT, V., BENOOT, T., CLAES, C., SCHIETTECAT, T., ROOSE, R., VAN LANCKER, W. & VANDELDELDE, S. 2020. A Critical Analysis of Disability Policy and Practice in Flanders: Toward Differentiated Manifestations of Interdependency. *Journal of policy and practice in intellectual disabilities*, 17, 108-115.
- ROOS, E. & SØNDENAA, E. 2020. Improving the transition process to independent living for adolescents with profound intellectual disabilities. Experiences of parents and employees. *BMC health services research*, 20, 1133-1133.
- ROOS, J., KOPPEN, G., VOLLMER, T. C., VAN SCHIJNDEL-SPEET, M. & DIJKXHOORN, Y. 2022. Unlimited Surrounding: A Scoping Review on the Impact of the Built Environment on Health, Behavior, and Quality of Life of Individuals With Intellectual Disabilities in Long-Term Care. *HERD*, 15, 295-314.
- ROSKEN, A., CROSBY, N. & FUZESI, P. 2020. From institution to community living: collection of Models of Good practice in deinstitutionalisation for people with high support needs/multiple disabilities including practices on how assistive technology can support inclusive living. Brussels: EASPD.
- SCHALOCK, R. L., BORTHWICK-DUFFY, S. A., BRADLEY, V. J., BUNTINX, W. H. E., COULTER, D. L., CRAIG, E. M., GOMEZ, S. C., LACHAPPELLE, Y., LUCKASSON, R. & REEVE, A. E. 2010. Intellectual Disability. Definition, Classification, and Systems of Supports. . *The 11th Edition of the AAIDD Definition Manual*. . Washington DC: AAIDD.
- SCHALOCK, R. L., LUCKASSON, R. & SHOGREN, K. A. 2020. Going beyond Environment to Context: Leveraging the Power of Context to Produce Change. *International journal of environmental research and public health*, 17, 1885.
- SCHALOCK, R. L. & VERDUGO, M. A. 2002. *Handbook on quality of life for human service practitioners*, Washington, American Association on mental retardation.
- SEN, A. 2004. Capabilities, Lists, and Public Reason: Continuing the Conversation. *Feminist economics*, 10, 77-80.
- SHOGREN, K. A., BONARDI, A., COBRANCHI, C., KRAHN, G., MURRAY, A., ROBINSON, A., HAVERCAMP, S. M., THE NISONGER, R. O. H. & FUNCTION 2021. State of the Field: The Need for Self-Report Measures of

- Health and Quality of Life for People With Intellectual and Developmental Disabilities. *Journal of policy and practice in intellectual disabilities*, 18, 286-295.
- SIDDAWAY, A. P., WOOD, A. M. & HEDGES, L. V. 2019. How to Do a Systematic Review: A Best Practice Guide for Conducting and Reporting Narrative Reviews, Meta-Analyses, and Meta-Syntheses. *Annu Rev Psychol*, 70, 747-770.
- SYED, M. 2019. *Denk als een rebel*, Amsterdam, Uitgeverij Luitingh-Sijthoff B.V.
- TANAKA, E. 2009. Independent living and Life Resources for People with Disabilities. 46-70.
- TANAKA, E. 2018. Diversity of Independent Living. *Journal of disability studies*, 14, 35-53.
- THOMPSON, J. R., BRADLEY, V. J., BUNTINX, W. H., SCHALOCK, R. L., SHOGREN, K. A., SNELL, M. E., WEHMEYER, M. L., BORTHWICK-DUFFY, S., COULTER, D. L., CRAIG, E. P., GOMEZ, S. C., LACHAPPELLE, Y., LUCKASSON, R. A., REEVE, A., SPREAT, S., TASSE, M. J., VERDUGO, M. A. & YEAGER, M. H. 2009. Conceptualizing supports and the support needs of people with intellectual disability. *Intellect Dev Disabil*, 47, 135-46.
- TØSSEBRO, J., BONFILS, I. S., TEITTINEN, A., TIDEMAN, M., TRAUSTADÓTTIR, R. & VESALA, H. T. 2012. Normalization Fifty Years Beyond-Current Trends in the Nordic Countries. *Journal of policy and practice in intellectual disabilities*, 9, 134-146.
- UN 2007. Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly. In: NATIONS, U. (ed.) *A/RES/61/106*. New York: UN General Assembly.
- UN. 2015. *Sustainability Development Goals* [Online]. Available: <https://sdgs.un.org/> [Accessed].
- UNKNOWN 2022. *Significant*. Cambridge Academic Cambridge: Cambridge University Press.
- VAN GENNEP, A. T. G. 1997. *Paradigmaverschuiving in de visie op zorg voor mensen met een verstandelijke handicap*, Utrecht, NIZW.
- VAN GENNEP, A. T. G. 2000. *Emancipatie van de zwaksten in de samenleving: Over paradigma's van verstandelijke handicap*, Amsterdam, Boom.
- VAN GENNEP, A. T. G. 2009. Verstandelijke beperkingen als sociaal probleem? Kansen of bedreigingen vnan het burgerschapsparadigma. *Nederlands Tijdschrift voor de Zorg aan mensen met verstandelijke beperkingen.*, 35, 101-124.
- VAN HECKE, N., CLAES, C., VANDERPLASSCHEN, W., DE MAEYER, J., DE WITTE, N. & VANDEVELDE, S. 2018. Conceptualisation and Measurement of Quality of Life Based on Schalock and Verdugo's Model: A Cross-Disciplinary Review of the Literature. *Social indicators research*, 137, 335-351.
- VERVLIET, M., REYNAERT, D., VERELST, A., VINDEVOGEL, S. & DE MAEYER, J. 2019. "If You Can't Follow, You're Out." The Perspectives of People with Mental Health Problems on Citizenship. *Applied Research in Quality of Life*, 14, 891-908.
- VON DER LEYEN, U. 2021. State of the Union Address 2021: Strenghtening the soul of our Union. In: COMMISSION, E. (ed.). Brussels: European Commission.
- WHOQOLGROUP 1995. The World Healt Organization Quality of Life Assessment (WHOQOL): Position paper from the World Health Organisation. *Social Science and Medicine* 41, 1403-1409.
- YATES, S., DICKINSON, H., SMITH, C. & TANI, M. 2021. Flexibility in individual funding schemes: How well did Australia's National Disability Insurance Scheme support remote learning for students with disability during COVID-19? *Social policy & administration*, 55, 906-920.
- ZAAGSMA, M., VAN DE VELDE, D., KONING, M. H. M., VOLKERS, K. M., SCHIPPERS, A. P. & VAN HOVE, G. 2021. 'When I need them, I call them and they will be there for me'. Experiences of independently living people with intellectual disabilities with 24/7 available online support. *Disability & society*, ahead-of-print, 1-24.