CISCOS
- *Part 3*

CISCOS Manual

Connecting inclusive social planning,
community development and service
provision for persons with disabilities / CISCOS

Connecting Inclusive Social Planning, Community Development and Service Provision for Persons with Disabilities / CISCOS

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Curriculum Element 1: Planning Approaches on the Implementation of the UN CRPD and Consequent Implications for Service Providers

The main goal of this curriculum element of the CISCOS training course is to demonstrate how to implement the UN Convention on the Rights of Persons with Disabilities (UN CRPD) in municipalities, districts or at other local political levels using public planning. Therefore, in-depth knowledge of its contents and significance within the system of Human Rights legislation as well as planning concepts and methods, is essential for participants of the course. In part A, readers will find an overview of the UN CRPD with key information on its history, structure, definition of disability and its concept of progressive implementation. A further section of this chapter looks at preconditions for progressive UN CRPD implementation and the role of local governments. In this chapter, you will learn about:

- The UN Convention on the Rights of Persons with Disabilities (CRPD), how it marks a paradigm shift in the understanding of disability and how it sets clear obligations for all levels of government;
- The capacities and opportunities of local governments with regard to UN CRPD implementation and requirements within local planning theory and practice;
- Different dimensions of inclusive local development, including raising awareness, participation, accessibility, universal design and inclusive services.

1.1 Basic Concepts of Disability and Local Planning

The UN CRPD was accepted by the General Assembly on December 13th, 2006 and entered into force on May 3rd, 2008. As of March 2019, 177 states have ratified the UN CRPD including all EU-member countries and the European Union itself. As stated in Article 1, the purpose of the UN CRPD is "to promote, protect and ensure the full and equal enjoyment of

all human rights and fundamental freedoms of all persons with disabilities, and to promote respect for their inherent dignity"[1]. With regards to economic, social and cultural rights, for example those that refer to education or services systems, each State Party of the UN CRPD has obliged to the full realisation "to the maximum of its available resources" (UN CRPD Article 4, para 2).

The UN CRPD consists of 50 articles that follow a very substantial preamble that puts the text in the system of human rights legislation as a whole. It is expressed that the UN CRPD does not define special human rights for persons with disabilities but specifies existing human rights documents for this group. By doing so the UN CRPD is also a contribution to the further development of the human rights system.

Adopted in 2006, certain articles of the UN CRPD have been further developed in General Comments[2] adopted and published by the UN Committee on the Rights of Persons with Disabilities. Today, General Comments to seven key articles are available with the mission to assist States Parties in their implementation of all articles and fulfil their obligations under the Convention (as of March 2019). Some of the comments are also translated in easy-to-read-versions and are available in plain English. All General Comments are very relevant for local planning approaches that are the focus of this course. Two of those documents have a specific importance. General Comment No. 5 is related to Article 19 ("Living independently and being included in the community") and is explicitly relevant for local planning and development of community services[3]. This comment specifies what is meant by the right to live independently and be included in the community. General Comment No. 7 on Article 33 of the UN CRPD stresses the obligation to involve persons with disabilities and their organisations in the monitoring process.

1   United Nations 2006.

2   OHCHR n.d.

3   Committee on the Rights of Persons with Disabilities 2017.

General Comments explicate rights mentioned in a specific human rights treaty. Thereby, they fill the abstract right with meaning. Using State Reports as an outset, the General Comments are authoritative interpretations of either individual human rights or the legal nature of human rights obligations. General Comments provide orientation for the practical implementation of human rights and form a set of criteria for evaluating the progress of states in their implementation of these rights. General Comments themselves are not treaties and do not need ratification by treaty parties. Strictly speaking, they are not legally binding, but have a highly authoritative character with legal basis[4].

General Comment No. 1 - Article 12: Equal recognition before the law, including children with disabilities, in the implementation and monitoring of the Convention

General Comment No. 2 - Article 9: Accessibility

General Comment No. 3 - Article 6: Women and girls with disabilities

General Comment No. 4 - Article 24: Right to inclusive education

General comment No. 5 - Article 19: Living independently and being included in the community

General Comment No. 6 - Article 5: Equality and non-discrimination

General Comment No. 7 - Article 4.3 and 33.3: Participation with persons with disabilities in the implementation and monitoring of the Convention

1.1.1 Understanding Disability

The Convention marks yet another paradigm shift in the understanding of disability. In this context, the Convention continues previous considerations of the International Classification of Functioning, Disability and Health (ICF) and earlier discussions within the professional community. Following the Convention, disability is not to be seen as inherent to a person, but as the result of an interaction between the condition of a person (e.g. having a visual impairment) and environmental factors (e.g. negative attitudes or inaccessible

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4   Deutsches Institut für Menschenrechte n. d.

buildings). Personal conditions are multi-layered and can interrelate with each other. They can be both physical and socio-economic in nature. The possible interrelation between personal factors is complex. Overall, different personal factors can result in intensifying or reducing disability. For example, a wealthy person with a physical disability might be able to access tertiary education and find a job afterwards.

Environmental factors can relate to different factors in the individual's outside world: to the human, natural or artificial environment, to accessibility, to the legal framework, to the socio-economic conditions and to the extent to which services are inclusive. As with personal factors, there can be complex interrelations between different environmental factors. For example, a person's environment might be relatively accessible, but only segregated services are available. In total, all aspects mentioned determine the extent to which an individual can participate in society, or the extent to which disability exists

Models of Disability: From the Medical Models Towards a Human Rights Approach

History has seen very different models of disability: the sub-human model, the charity model, the medical model and the social model. It can be assumed that all of these are, at least in part, still extant and influential. How disability is understood has consequences for the way persons with disabilities are treated in society, and how services are shaped[5]. Below are the main characteristics of these various models.

The **sub-human model** treats persons with disabilities as being potentially capable of assault, generally dangerous, destructive and lacking in self-direction and constructive purpose. This is reflected in service models with restrictions in the movement and strict control of persons regarded as severely disabled. Usually, their accommodation and living environment is designed in a similar way to how animals are kept, so that it can be clea-

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5   Wolfensberger 1969, 70.

ned easily, frequently, efficiently for a large number of residents by a small number of caregivers.

The **charity model** treats persons with disabilities as passive and thankful recipients of kind acts or welfare payments. As such, they are not seen as citizens who are entitled to support by law. The charity model gives persons with disabilities no reliable basis to cope with their dependencies and hinders the ability of individuals to realise their personal potential in life. The charity approach lacks an understanding of the importance of environmental aspects related to individual disability. As a charitable society's reaction towards disability is mostly limited to care and assistance, it can inadvertently intensify individual disability[6].

The **medical model** of disability focuses on individuals' impairments or physical factors. Disability is mainly seen as a health deficit, and any problems which arise are said to stem from an individual's health condition. From this perspective, individuals are treated by medicine or rehabilitation programs with the aim of overcoming the person's disability by concentrating on their deficits. With regard to its relation to clients, the medical model is criticised for the extensive power it grants to professionals such as doctors, nurses and therapeutic and pedagogic staff.

The **social model** understands disability as a result of an individual's interactions with his disabling environment. From this perspective disability results from an environmental lack of accommodation with regard to individual differences. In terms of a general understanding, disability is a result of discrimination. As the assumption is that persons become disabled by their social environment, disability can be overcome by removing social and economic barriers.

6   OHCHR 2014, 8.

The **human rights model** of disability builds on the social approach but adds the dimension of interaction. The human rights model of disability is the core of the UN CRPD, and it codifies the acknowledgement that persons with disabilities are subjects with equal rights. The state and others are in the position of having responsibilities to respect, protect and fulfil these rights "on an equal basis with others"[7]. This perspective also changes the way barriers in society are seen. It perceives the barriers for equal participation in society as discriminatory and provides opportunities for persons with disabilities to complain effectively when they are faced with such barriers. This can be characterised as a human rights approach to disability.

A significant challenge lies in the fact that the UN CRPD focuses on the categorisation of barriers rather than the categorisation of human beings. Therefore, it does not explicitly define disability, but states that "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others"[8]. This implies a cross-disability thinking that the evolving concept of disability (Preamble, item e) also applies for example to elderly persons with long time care needs or persons with psychosocial disabilities[9].

Guiding Principles of the UN CRPD

There are eight guiding principles[10] which underlie the Convention and each one of its specific articles. They are:

i.   Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, independence of other persons;

ii.   Non-discrimination;

iii.   Full and effective participation and inclusion in society;

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7   United Nations 2006, art 7.

8   Ibid., art. 1.

9   OHCHR 2014, 18.

10   United Nations 2006, art. 3.

iv.   Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

v.   Equality of opportunity;

vi.   Accessibility;

vii.   Equality between men and women;

viii.   Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Monitoring System

The Convention contains a monitoring system based on the reporting of States Parties to the **UN Committee for the Rights of Persons with Disabilities** in Geneva. The committee is composed of 18 independent experts that review state reports and adopt concluding observations, undertake inquiries into States Parties when there is reliable information on grave and systematic violations of the Convention, and hold thematic discussions and adopt general comments. After ratifying the Convention, states have to submit an initial report on the implementation of the Convention within two years. This report is analysed and discussed by the committee, which may adopt concluding recommendations. This process takes place every four years.

Some country's national reports on the implementation of the UN CRPD were accompanied by shadow reports from civil society, most of which were very critical. In addition, sub-national regions have also developed political plans for inclusive action relating to the principles of the UN CRPD. From these efforts, it became evident that implementation of the UN CRPD needs a multi-level approach in which European, national and regional political actors have clear responsibilities for non-discrimination policies and inclusive legal frameworks, as well as strong entitlements for socially vulnerable groups, such as persons with disabilities.

Article 33 of the UN CRPD demands that state parties establish within their countries a monitoring system that consists of four elements:

i. A "focal point" that oversees and documents the process of implementation;

ii. A coordinating mechanism on implementation across government departments and statutory bodies;

iii. A "framework" to "promote, protect and monitor" the implementation of the UN CRPD;

iv. Strong involvement and participation of Disabled People's Organisations (DPOs).

General Comment No. 7 on Article 33 of the UN CRPD stresses the obligation to involve persons with disabilities and their organisations in the monitoring process, e.g. by stating with special regard to establishing inclusive service models: "persons with disabilities, including those who are currently living in institutional settings, should be involved in the planning, implementing and monitoring of deinstitutionalization strategies, and in the development of support services, with special regard to those people"[11].

The real challenges related to the UN CRPD are those regarding its implementation. National reporting by itself does not lead to more accessibility, equal participation and inclusion. It has become obvious that if the more abstract demands of the UN CRPD are acted upon during its implementation, then the importance and relevance of the local level and the municipalities comes to the fore. This is because of their proximity to the lives of citizens and the responsibility of local governments for services of public interest. It is the local level that plays a crucial role in bridging the gap between inclusion principles and respective policies, and has the practical capabilities for groups in particularly vulnerable situations, including people with disabilities, to make use of their rights. This suggests high potential for local-level approaches to better meet the requirements and objectives of higher-level development strategies and the provisions of the UN CRPD.

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11   Committee on the Rights of Persons with Disabilities 2018b, para. 83.

However, it cannot be assumed that such requirements and guidelines automatically diffuse from national to sub-national level, triggering respective change processes at the local level. On the contrary, realising the potential of local governments and local planning is a political process which requires a "push from below"[12]. Based on a socio-spatial approach, interested actors in local communities have the potential to lobby and initiate cross-sectoral planning processes towards better public well-being and the inclusion of particularly vulnerable groups, such as persons with disabilities.

The General Comment on Article 19 of the UN CRPD specifies the importance of public planning activities related to the transformation of service models.

"States parties have the immediate obligation to enter into strategic planning, with adequate time frames and resourcing, in close and respectful consultation with representative organizations of persons with disabilities, to replace any institutionalized settings with independent living support services. The margin of appreciation of States parties is related to the programmatic implementation, but not to the question of replacement. States parties should develop transitional plans in direct consultation with persons with disabilities, through their representative organizations, in order to ensure full inclusion of persons with disabilities in the community"[13].

While it is stressed that the implementation of new service models in a given region should be based on strategic planning, there are many political challenges when changing service models. Planning and managing change needs not only strong leadership and resources, but is often faced with resistance from established systems, local service traditions and certain welfare state arrangement which have not yet adopted the principles of inclusion and independent living.

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12   Romeo 2012, 2.

13   Committee on the Rights of Persons with Disabilities 2017, para. 42.

1.1.2 UN CRPD at the Local Level

What are the state's responsibilities and opportunities regarding the implementation of the UN CRPD at the local level, where the realisation of legal and policy provisions takes place as a very concrete encounter between the state, its citizens and local self-government? The local level forms the core geographic and social framework for the CISCOS approach towards UN CRPD implementation. This study text outlines the relevance of the local level for the implementation of the UN CRPD. It aims to clarify that this approach is based on multi-level responsibility and does not seek to exclude national statutory levels from their responsibility for citizens' rights. The following section will provide the reader with the understanding of the 'local level' as it is referred to in the CISCOS course.

Defining the Local Level

The term 'local level' refers to those politically defined territories and their population in a certain country that are closest to the citizens. More specifically, this includes small regions, districts, cities, towns, villages or a grouping of villages that form a sub-provincial entity with a democratically elected representative leadership, as well as a local council with budgetary powers and a local administration with the power to take administrative or policy decisions for that area within the legal and institutional framework of the state.

In European countries, the political structure of a state can be different depending on the size of a country and/or historical developments. The Classification of Territorial Units for Statistics (Nomenclature des unités territoriales statistiques (NUTS)) is a geocode standard developed and regulated by the European Union for referencing the subdivisions of EU countries. Following the NUTS Classification, the term 'local level' refers to the NUTS 3 level (small regions of 150.000 – 800.000 inhabitants) and its subdivisions, the Local Administrative Unit (LAU, formerly NUTS 4 and 5).

From a socio-spatial perspective, local level is where the sites for people's housing are, where education, employment, health care, social services, daily convenience shopping, and other

activities that sustain inhabitants physically, emotionally, socially, and psychologically take place[14]. The development and maintenance of this local infrastructure is in the common interest of all local inhabitants. Some services are privately organised, many others are part of a public infrastructure managed by local authorities charged to act in the public interest.

In all European countries there is a certain degree of right for self-government, which varies for example in the right to raise local taxes and with regard to government competences[15]. The local political level of municipalities, districts or counties comprises the direct political interface between governments and citizens.

Local-level Responsibilities and Public Planning

The constitutions, national laws and regulations of a country determine which public tasks will be performed by which level of government or administration and the way and the extent to which citizens become involved in decision-making processes. These laws and regulations build the legal and regulatory framework that shapes relations between the government and the citizens of a country. Decentralised governmental systems are based on the principle of subsidiarity, i.e. the sharing of powers between government levels. It must be ensured that certain tasks are performed by the level of government and administration that is closest to the citizens and that has the capacity to competently fulfil these tasks. Therefore, it is the local level of governments and administrations that has direct interaction with the citizens.

Whilst the European and national levels pursue a policy-oriented perspective, the local level focuses more on the needs of communities and the strategic planning of programmes and services. Different historically evolved welfare traditions and legal frameworks in European countries have an impact on the policy areas that local authorities are responsib-

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14   DeFilippis and Saegert 2012, 3.

15   For an overview see: Council of European Municipalities and Regions 2018.

le for[16]. Local governments interact on a daily basis with citizens and therefore possess first-hand knowledge of the citizens´ needs, preferences and challenges[17]. They are responsible for the good local management and administration of tasks and services of public interest, ideally in line with citizen demands. These can include the provision of administrative services such as the issuing of birth certificates, identity cards, or ballot papers, as well as services and infrastructure related to energy and water supply, sanitation and solid waste management, hospitals, social housing, public transport, education, health care, social services, cultural life, leisure and sports. These services have a direct impact on the quality of life of the local population including those inhabitants with disabilities.

The local level is inhabited by a large diversity of people and groups with different needs and interests that all have the right to use public infrastructure and social spaces. According to the British public planning theorist Patsy Healey, it is appropriate to perceive the places of community life as shared places where the co-existence of people must be managed by public agencies[18]. This requires local planning systems. The role of such local planning systems and practices can be seen as helping local entities work out how to manage their collective concerns about the qualities of shared spaces and local environments[19].

Local planning should not be considered a task of politicians and planning experts that implement desk-based solutions to local community problems. Instead, planning should be understood as a participatory and learning-oriented process based on dialogue and communication with community people ideally including representatives of all diverse groups. The concept of local governance refers to collective action that is shaped by informal norms, networks and the community and neighbourhood associations involved. Multiple and diverse power structures take effect in complex causal networks and networks of relation including local government structures. However, even in such participative proces-

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16   European Social Network 2015.

17   Ibid.

18   Healey 2006, 3.

19   Ibid., 3–4.

ses, the political leadership and coordination of local governments is crucial for successful planning processes. Due to the key tasks of local politicians, local governments should be recognised as "the principal legitimate agent of the local development process"[20] when it comes to public planning.

Local parliaments are at the centre of political power in local communities and it is there where the formal decision to start a planning project and to implement an action plan is taken and acquires binding force. For those interested in implementing the UN CRPD in a certain municipality through local planning activities, it is necessary to understand how the local system of politics and self-government politics works.

Local Implementation and Path Dependency: History Matters

Planning initiatives at the local level requires awareness of the given social and political conditions of the addressed region. This includes the local political structure, i.e. the political actors and organisations that play a key role in the various domains of public life and infrastructure relevant for the implementation of the UN CRPD. Furthermore, it is necessary to fully understand the policies of the actors involved, including their specific interests, traditions, programmes and potential. It is also helpful to gain knowledge of how certain actors usually articulate their interests and how local cooperation and coordination of disability politics work.

To understand a given local support system is challenging. The best way to gain a deeper understanding is to learn about the relevant developmental paths that have shaped the local history of care for people with disabilities. These could include:

- The traditions of local self-help organisations;
- The history of local services for people in special living conditions (e.g. people with long-term care needs, disabilities and long-term psychiatric illnesses);

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20   Romeo 2012, 10.

- The history and routines of local cooperation and coordination structures;
- The history and routines of assessment procedures and funding systems.

It is also important to note that such local developmental paths are embedded in national contexts. National frameworks in developed welfare states wherein local planning operates are complex. It is necessary for planners to know about relevant social welfare legislation, the arrangement of competences of different political levels and relevant individual entitlements of people with disabilities.

Inclusive local planning needs to be informed about:
- Social protection and social care;
- Health care;
- Education;
- Youth welfare;
- Rehabilitation;
- Disability allowances.

It is important to note that welfare state arrangements differ from country to country. They are also shaped by different developmental paths, for example with regard to tax-funded systems or social assurance systems, means-testing or out of pocket payments. It can be helpful for understanding the local situation of social services to perceive how it is framed by national welfare state traditions.

The aforementioned considerations on national and local frameworks for social planning can be summarised with the phrase "history matters"[21]. This slogan refers to theoretical approaches to path development and path dependency.

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21   Schreyögg, Sydow, and Koch 2003, 260.

Developmental paths can lead to situations where options for change become increasingly restricted. In such cases actors may find themselves in the position of being locked into the given conditions and with no other alternative in decision-making forced to follow their paths, even under critique and with the knowledge of better available options.

In the context discussed here, it is important to be aware that even under conditions of locked in mindful deviation for an organisation (e.g. a service provider organisation) there are still possibilities. Change processes can be initiated though individual or organisational decisions that start and foster learning processes and ultimately lead to the establishment of new institutional frameworks in organisations. Decisions for a change process will always be risky for organisations and their members and can be facilitated by an external momentum that provides certainty for decision-makers. In our context, increased public attention to the UN CRPD in many places has created such a momentum for inclusion. This can support change processes, even in the face of resistance.

Participation in Decision-Making in Local Development

As seen in Study Text A 2, many changes required to meet the obligations of the UN CRPD are under the responsibility of local governments and authorities. Participation is a core human rights principle, allowing individuals to play a significant role in the development of every democratic society. This particularly holds true for local-level development processes. At the local level, various opportunities exist for citizens to contribute their perspectives, ideas and interests in decision-making and planning processes. These can include the elections of local parliaments, local development and planning procedures, public hearings and citizen initiatives. The local level offers opportunities for citizens to experience democracy and citizen participation first hand. However, it is important for citizens to know and learn how decisions are made and find an environment in which they can voice their interests and effectively participate in public affairs.

Participation Restrictions

Persons with disabilities across Europe are facing significant attitudinal, physical and communication barriers to participate in public life. They are frequently not consulted or considered when decisions are made on their behalf, or about matters relating to or affecting their lives. On many occasions, their perspectives are disregarded in favour of those of disability experts representing service providers or other organisations. It is crucial for local governments to ensure that persons with disabilities are involved in policy and decision-making processes to include a disability perspective in local development and to protect, respect and fulfil basic human rights. However, persons with disabilities are frequently regarded as being unable to make independent decisions and contribute in collaborative planning processes.

Recent evidence suggests that, given the opportunity, persons with disabilities actively participate in politics. Given an accessible and enabling environment, many persons with disabilities are active citizens keen to be engaged in the political life of their communities. They make use of their voting rights and take part in political activity, including as members of political parties, attending political meetings and contacting elected officials[22]. However, significant challenges of participation, on an equal basis with others, remain across EU member states. These include legal obstacles (e.g. restrictions on the right to vote), inaccessible environments, processes and information, a lack of awareness about the right to political participation among rights holders and duty bearers, as well as limited opportunities for effective participation[23]. Existing barriers to active citizenship do not affect all persons with disabilities equally. People with more severe impairments as well as persons with particular types of impairment - for example, people with intellectual or psychosocial impairments - disproportionately face barriers to their participation in political life[24].

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22   European Agency for Fundamental Rights 2014; Düber, Rohrmann, and Windisch 2015.

23   European Agency for Fundamental Rights 2014; Düber, Rohrmann, and Windisch 2015.

24   European Agency for Fundamental Rights 2014; Düber, Rohrmann, and Windisch 2015.

Legal and Policy Framework

The active and informed participation of everyone in decision-making that affects their lives and rights is consistent with (and requires) a human rights-based approach to governance and planning processes at the local level. The principle of participation is well established in the Universal Declaration of Human Rights[25], as well as the International Covenant on Civil and Political Rights[26], which recognises and protects the right of every citizen to take part in the conduct of public affairs, the right to vote and be elected, and the right to have access to public service.

Participation is a cross-cutting theme of the UN CRPD. The preamble calls upon States Parties to consider that persons with disabilities should have the opportunity to actively participate in decision-making processes about policies and programmes including those directly concerning them at all levels[27]. The General Principles of the UN CRPD[28] call for full and effective participation and inclusion in society, followed by the provision of the General Obligations[29] to closely consult with and actively involve persons with disabilities in the development and implementation of legislation and policies and in other decision-making processes concerning issues relating to disability[30]. Article 29 of the UN CRPD obliges States Parties to ensure the participation of persons with disabilities in political and public life at all levels.

Article 33 calls upon States Parties to ensure that persons with disabilities and their representative organisations are involved and participate fully in the monitoring process of the UN CRPD. General Comment No. 7 on the UN CRPD Article 33 explicates the rights of participation and stresses the obligation of duty bearers to involve persons with disabilities and their organisations in the monitoring process[31].

26   United Nations 1966, art. 25.

27   United Nations 2006, preamble o.

28   Ibid., art. 3c.

29   Ibid., art. 4, no. 3.

30   Compare also: United Nations 1993, rule 18, which prescribes, inter alia, "States should also recognize the advisory role of organizations of persons with disabilities in decision-making on disability matters".

31   Committee on the Rights of Persons with Disabilities 2018b.

The European Disability Strategy 2010-2020 highlights participation as a key objective to eliminate barriers for persons with disabilities[32]. The European Commission has identified participation as one of the eight main areas for action. The provisions under this area of action include, inter alia, effective measures to overcome the obstacles persons with disabilities face in exercising their rights as individuals and political actors[33].

Dimensions of Local Level Participation

There are numerous definitions of the concept of political participation, that can be loosely defined as activities of citizens affecting politics at various levels. At the local level, inter alia, elections of local parliaments, local development planning procedures, public hearings and citizen initiatives are very concrete opportunities for citizens to put forward their interests in decision-making and planning processes. The UN CRPD calls upon States Parties to "promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others"[34]. This is to be understood as the responsibility of a planning task to be implemented by the various political levels. However, the implementation of the UN CRPD at the local level touches on various fields and dimensions of planning and should frequently address intersecting competencies, responsibilities and powers. Hence, local authorities as the principal legitimate agents of the local development process, have to find ways of engaging diverse local community stakeholders in decision-making and planning processes, including people with different types of impairments. The extent and scope of political participation of persons with disabilities builds a benchmark for the quality of local-level democracy and political inclusion.

As early as 1969, Sherry A. Arnstein developed a 'Ladder of Citizen Participation', ranging from information and consultation to delegated power and citizen control[35]. Considering

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32   European Commission 2010.

33   Ibid.

34   United Nations 2006, art. 29b.

35   Arnstein 1969.

the background of this ladder, consultation with Disabled People's Organisations (DPOs) can be regarded as the preliminary stage, while delegated power and co-determination builds the framework for real participation. However, the obligation of creating an environment for full and effective participation in the conduct of public affairs entails various dimensions of preconditions, as described below. The following dimensions developed by Rohrmann et. al[36] can help to assess the state of participation in a local entity. They also provide concrete starting points to raise the participation of persons with disabilities and others in local development processes.

Culture of Participation and Collaboration

A well-established culture of citizen participation provides a good basis for the systematic development of inclusive local planning structures and approaches. A culture of participation concerns the perception of different tasks of local planning and development. Citizen participation is primarily realised through the local parliament (e.g. city council or district council) and its committees. However, the parliament must represent the social groups and the different neighbourhoods in the municipality or district. A culture of participation and collaboration is based on experiences, knowledge and capacity within the local government and local authorities of various sectors with regard to citizen participation. It requires open participation procedures without preconceived expectations and the inclusion of results of participative dialogue processes in decision-making process. Finally, it is important to make sure that different societal groups have the resources and capacities to voice their interest within given participative formats.

Statute of the Local Government

While involvement can sometimes be on an ad hoc basis, formalised mechanisms for citizens' involvement can sustainably support the implementation of UN CRPD provisions

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36   Rohrmann et al. 2014.

with regard to participation. A statute on citizen participation or the participation of persons with disabilities in particular can enable a systematic approach towards participation, including social groups which face challenges in voicing their interests in public. A statue can suggest formats of participation and self-representation with respect to the local parliament, the participation of persons with disabilities in local bodies and committees, and the competencies and scope of action of a local representative of persons with disabilities. By adopting a statute, a local government can officially set out how the participation of persons with disabilities and other social groups is to be ensured.

Committees and Structures of Political Representation/Advocacy

There are different ways of ensuring that the interests of persons with disabilities are considered in local committees, for example through advisory bodies of persons with disabilities or associated experts with a right to speak and to table motions. In any case, it is important to protect participation rights through local regulations. In this way, areas can be defined in which the representative body can veto a decision and must at least be consulted. Finally, it is important to note that self-representative bodies should not be in charge of coordinating local planning processes for inclusion. They should rather have the task of providing critical support to such change processes.

Participation Beyond Formal Structures

In addition to the continuous involvement of representative bodies, participation in the development of concrete projects and measures plays an important role.

The implementation of accessibility, the development of inclusive care and education services, and the planning of support services in the context of awareness-raising and capacity development for inclusion requires the full and effective participation of persons with disabilities and their representative organisations.

Commissioner for Matters Relating to the Rights of Persons with Disabilities

Commissioners can play an important role in the implementation of the UN CRPD if appropriate conditions exist for their work. As representatives appointed by a municipality or district, they primarily work in the administration, are available as contact persons and take on coordination tasks. In smaller municipalities, such commissioners can be appointed as volunteers, while in larger cities and districts that position should be carried out by full-time employees. It seems obvious that the tasks of implementing the UN CRPD should be assigned to these commissioners. However, this is only effective if the job description includes a planning profile and the position has been anchored in the administration with a right to speak, table motions and veto decisions that are not in line with the UN CRPD in all local planning processes. Moreover, the availability of sufficient resources for the tasks of developing an inclusive community are key.

Self-Representation

Self-representation is a multi-faceted phenomenon. In many cases, it has become an indispensable component of local support structures, partly based on the criticism of established support structures. Self-representation can be involved in the shaping of local policy in various ways. There are self-help groups that focus entirely on mutual support and reject political activities. For other initiatives, the impact on the social and built environment, as well as political change, have a high priority. Often self-representatives are actively involved in municipal or district bodies.

A general openness towards self-representation can be promoted in a municipality or district and offers of participation can be made by the local parliament and administration. The strength of self-representation lies in developing sensitivity to the risks of exclusion based on personal concern and building up expert knowledge of very specific aspects of accessibility and adequacy of local infrastructure as well as specific support needs. The implementation of the UN CRPD at the local level is a change process that requires a participative approach. Strategic participation and collaboration with key stakeholders will

enhance the quality and credibility of decisions made during this change process. Participation allows using collective resources and intelligence, leading to more creative approaches towards UN CRPD implementation. It can improve the quality of relationships between key- stakeholders and increase the outreach of measures taken through the quantity and diversity of involved stakeholder groups. Participation creates ownership for decisions taken among stakeholder groups and consequently increases the likelihood of implementation.

1.1.3 Raising Awareness

In modern societies, diversity is no longer seen as a problem but as a chance and basis to develop new solutions to societal challenges. Examples can be found in nearly all disciplines, for example, pedagogics and economics. In this context, it is important to note that the acceptance for difference is usually not unlimited[37]. This aspect is reflected in Article 1 of the UN CRPD which states that "various barriers may hinder [persons with disabilities in] their full and effective participation in society on an equal basis with others"[38].

Barriers in the context of the convention are not only to be taken literally. As well as physical and communication barriers, the convention also refers to the ways people think about disability and persons with impairments. In more precise terms than in Article 1, the convention explicates "respect for difference and acceptance of persons with disabilities as part of human diversity and humanity"[39]. Therefore, local planning for inclusive communities needs to take into account awareness-raising on the rights and needs of persons with disabilities. In this context, it is possible to refer to broader frameworks and concepts such as diversity mainstreaming (see Infobox).

37   Meuser 2013, 178.

38   United Nations 2006, art. 1.

39   Ibid., art. 3d.

Infobox: Diversity Mainstreaming

Diversity mainstreaming describes the efforts being made to recognise and promote human diversity as a positive value at all levels. For local communities, it means that equal opportunities are taken into account in planning, implementation monitoring and evaluation of local development processes. Local policies, strategies, measures, procedures and services should therefore be examined with regard to how they affect the lives of all people and, if necessary, be adapted to their rights and needs.

According to Rohrmann et al., concepts of diversity mainstreaming play an important role in both the planning and development of inclusive communities. In this context, they refer to the greatest amount of openness and acceptance as a requirement for ensuring all people's human rights[40].

Due to the importance of openness and acceptance in the context of diversity, it is crucial to analyse social values, structures, ways of communication and interaction with regard to their impact on equality and participation in society. Diversity mainstreaming will then have a positive impact on all members of a given society.

Awareness Raising as a Task in Planning Inclusive Communities

All articles of the UN CRPD focus on equal rights for persons with disabilities. With reference to awareness-raising, Article 8 obliges States Parties to "raise awareness throughout society, including at the family level, regarding persons with disabilities, and to foster respect for the rights and dignity of persons with disabilities". To obtain this goal, the convention refers to a broad variety of measures addressing States Parties as well as private actors (e.g. families, employers, the media)[41]. Referring to persons responsible for planning inclusive communi-

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40   Rohrmann et al. 2015.

41   Ibid., 90.

ties, the convention promotes the following measures in order to foster awareness:

- **Public campaigns** in the context of overall mainstreaming concepts (see e. g. Art. 8 No. 2a UN CRPD);

- **Training programs** for different target groups (e. g. children, families, staff in educational institutions, police, justice, administration) (see e. g. Art. 8 No. 2b, Art. 16 No. 2, Art. 24 No. 4, Art. 13 No. 2 of the UN CRPD);

- **Promotion of information** on contexts of the UN CRPD (see e. g. Art. 31 No. 3 of the UN CRPD).

In this context, it becomes clear that reflecting the needs of persons with disabilities in the planning process addresses the general public but also and foremost politicians and administrative staff.

Raising Awareness in Local Planning Practice

The aforementioned proposals can be referred to in local planning practice in different ways. Rohrmann et al. promote concrete measures to make sure that persons with disabilities and their needs are fully reflected in public policies[42]. These include (amongst others):

- Awareness raising events;
- Creating opportunities for encounters that enable the exchange of experiences between different population groups;
- Training measures on open and respectful attitudes and behaviour;
- Empowerment and support of organisations of persons with disabilities;
- Involving persons with disabilities as the experts of their own experience in local planning processes;
- Including disability aspects in general public relations work;
- Developing and implementing mainstreaming strategies.

42   Rohrmann et al. 2015.

It is important not to speculate about individual needs but to proactively engage with persons with disabilities. In this way, the needs of the target group can be reflected on in a participatory way. This is directly linked to a participative understanding of the local planning process. Understanding planning as a participatory process does not end with asking people about their needs but can lead to concrete changes in the behaviour of politicians and administrative staff who might take into account those needs in their daily decisions and routines.

1.1.4 Accessibility and Universal Design

Accessibility

Accessibility is one of the eight general principles of the UN CRPD[43] and is further elaborated in Article 9, which says that "to enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas"[44]. General Comment No. 2 on the UN CRPD Article 9 (Accessibility) explicates the rights to accessible environments and stresses the obligation of duty bearers in that regard[45].

Appropriate measures should be taken by States Parties to identify and eliminate obstacles and barriers to accessibility. Furthermore, it is requested to develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public, inter alia, roads, buildings, transport systems, information and communication systems including the internet. Implementing the general principle of accessibility is a very relevant area for local planning activities.

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43   United Nations 2006, art. 3f.

44   Ibid. art. 9.

45   Committee on the Rights of Persons with Disabilities 2014.

Universal Design

Universal design is defined in Article 2 of the UN CRPD to mean "[…] the design of products, environments, programs and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design"[46]. It is further stated that universal design "[...] shall not exclude assistive devices for particular groups of persons with disabilities where this is needed"[47]. Universal design is also stated among the general obligations in Article 4, including "to undertake or promote research and development of universally designed goods, services, equipment and facilities [...] and to promote universal design in the development of standards and guidelines"[48]. The fact that universal design is mentioned in these more general sections supports the notion of universal design as a more overarching concept than accessibility, whereas accessibility can be seen as one of the results of universal design.

Universal design is closely related to the fields of 'design for all' and 'inclusive design'. They have different origins, but are all working towards an inclusive society, with similar goals and methods. Universal design started to develop in the 1980s in the USA, with Ron Mace, an architect who was also a wheelchair user, at the front of the movement[49]. Universal design is still often thought of as being primarily linked to disability. In the definition of universal design, as it is stated in the UN CRPD, it is evident that the target group encompasses all people, not only those with disabilities. It stands for an inclusive perspective on diversity, where design and design processes can include people who are tall or short, left-handed or right-handed, introvert or extrovert, as well as people who have difficulties with mobility, seeing, cognition or hearing.

Principles of Universal Design

Universal design can be seen as a vision, a strategy, a method, and/or a field. It can be both a verb (to design), and a noun (a design). Many authors now stress the process perspec-

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46   United Nations 2006, art. 2.

47   Ibid., art. 2.

48   Ibid., art. 4f.

49   Story, Mueller, and Mace 1998.

tives of universal design. Steinfeld and Maisel (2012, p 29) state that "universal design is a process that enables and empowers a diverse population by improving human performance, health and wellness, and social participation"[50]. Other authors state that "universal design is a process, not an outcome"[51], and also that "universal design is not just about 'one size fits all'"[52]. Instead, "the aim is to provide the same (or equivalent) experiences, activities and services to everyone. It is accepted that these may have to be provided through slightly different routes or interfaces, but designers should strive to create a design that does not exclude or segregate"[53]. This is closely related to the seven principles of universal design (see Infobox), where equality and flexibility are at the forefront[54].

Infobox: Principles of Universal Design

1. Equitable use

2. Flexibility in use

3. Simple and intuitive use

4. Perceptible information

5. Tolerance for error

6. Low physical effort

Each of these principles has its own guidelines, making them valuable tools that can be used in a variety of ways in the practical work towards a more inclusive society. They can also be seen as a range of perspectives on inclusion that encompass equality, flexibility, cognition, perception, tolerance for error, effort and size and space (See Figure 1).

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50   Steinfeld and Maisel 2012, 29.

51   Centre for Excellence in Universal Design n.d.

52   Ibid.

53   Ibid.

54   Story, Mueller, and Mace 1998.
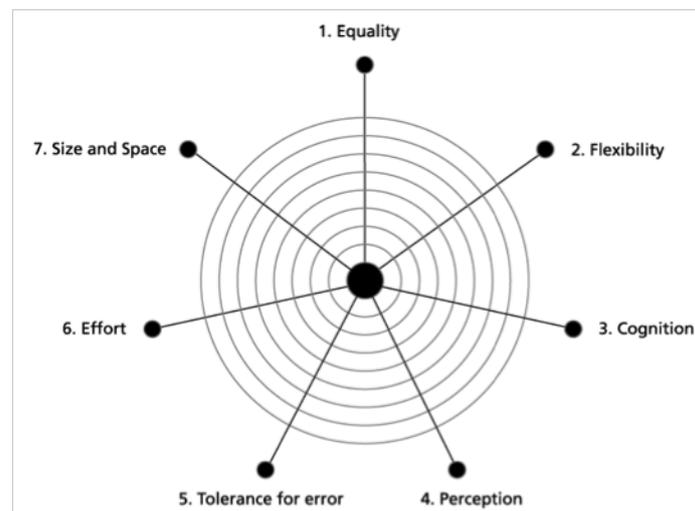
Figure 1. Overview of seven perspectives on inclusion within universal design (illustration: Per-Olof Hedvall)

There is a huge variety of areas in which universal design-thinking can be applied to create added value for all. This can start from designing inclusive playgrounds to communicating elevators and single-lever mixers.

Universal design does not exclude assistive devices for particular groups of persons with disabilities. It also does not contradict the need for reasonable accommodation, which specifically refers to the "necessary and appropriate modification and adjustments […] to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms"[55].

Activities towards accessibility, starting from the thought structures of universal design, focus on the universal usability of the solution to be developed from the beginning and not as an afterthought to be added later. Even though some barriers may have effects of direct discrimination and should be eliminated immediately, accessibility should also to be seen as an area for progressive implementation, which can be realised through local planning activities.

55   United Nations 2006, art. 2; 4.

Three Dimensions of Accessibility

For planning purposes, the general principle of accessibility of services and infrastructure for the public, can be structured in three dimensions.

1. **Findability** refers to all kinds of signage and information systems which visually, in auditive or tactile form, support people in finding their way to their destination, service or facility they wish to use physically or virtually. It has significance for finding the destination or object from outside as well as inside an organisation or building (e.g. public building).

2. **Personal accessibility** implies the possibility, (e.g. in form of mobility) to come to, reach or contact the destination, service or other facility persons with disabilities want to use from outside (physically or virtually). Barriers could exist in various forms, such as in material form (e.g. stairs, missing ramps), sensorial form (e.g. missing braille information or integrated guiding systems), communicative form (e.g. no sign language, no easy-to-read information) or cultural form (prejudices, stigmatisation).

3. **Usability** refers to the terms of use of a certain service, public infrastructure or institution of public life. These terms of use should be inclusive and not narrowly focused on the format and competences of the average able-bodied person. They should allow persons with different impairments to act independently in public life and participate without having to use discriminative means of support. This relates to the challenges of universal design that should be followed when designing both the conditions of the material world (e.g. buildings, mobility facilities) and simplifying the processes and routines of interaction between individuals in various contexts of public life (e.g. easy language, forms of administrative communication).

Once Universal design and accessibility are accepted as guiding principles, these dimensions can help services or organisations to develop criteria for the identification of barriers or for the need of accommodation measures to modify and adjust their conditions and working routines.

Local Planning Perspective

From a local planning perspective, it is important not to look at single organisations or areas in a municipality, but at the given territory as a whole. Public agencies should still perform as practical role-models for accessibility and universal design thinking. It is also effective to establish a local complaint and removal system for barriers that is open to citizens. Experiences show that many planning projects have reached their limits when trying to do a full-scale inventory of barriers and accessibility problems in a municipality or district. Therefore, it is recommended to concentrate planning activities on the establishment of a systematic monitoring of accessible infrastructure, conducted by smaller social units such as villages or neighbourhood communities. From this perspective, it makes sense to develop instruments to assess the accessibility of local social spaces. These instruments could require cooperation with disabled people's organisations to identify and overcome barriers. Moreover, they could contain incentives for active citizens to apply them, identify barriers and report to the more central planning unit in the municipality.

1.1.5 Developing Flexible and Inclusive Services

Persons with disabilities have to cope with the same challenges in their life-course as people without disabilities when developing their biography. Due to functional impairments and environmental barriers of various kinds, they must also cope with additional problems that most people without disabilities are not confronted with. Persons with disabilities frequently require specific and continuous support for developing their potential as a person and for coping with activities of daily life. Their rights and entitlements for flexible services are fundamental and must be respected. Inclusion does not mean renouncing sometimes highly specialised individual support services, but rather implies certain conceptual conditions for those.

In past decades, the international discourse on disability services has been shaped by what was called the "shift of paradigms"[56]. This entails a major change in the understanding of disability and, as a consequence, the way services are conceptualised and provided. The principles of inclusion and the right for participation "on an equal basis with others" change the direction of services' concepts. Support services should allow participation on an equal basis with others and avoid exclusion. Wherever possible, there should be regular services and community services that persons with disabilities can use according to their needs. Persons with disabilities should have the right to choose which provider organisation supports them and not be exclusively dependent on specialised facilities.

There are a number of relevant articles in the UN CRPD that refer to services for different age groups of persons with disabilities and at various stages of life (e. g. Article 24 on inclusive education or Article 27 on employment).

Article 19 has a prominent position in that regard, as it indicates the UN CRPD's philosophy on inclusive services:

"Article 19 – Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

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56   Hohmeier 2004.

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs."

From a local planning perspective, it is important not to look separately at single services in a municipality. It seems appropriate to follow a more comprehensive life-course approach and assess the service environment for children, young adults, adults and elderly persons with disabilities in the local region altogether. The following list envisions a structure for services for people with disabilities and their families that should be available in a region. The structure follows a life-course approach.

Life-stage early childhood – services related to early diagnosis and early intervention services

The birth of a baby is often related to a period of uncertainty for most families. In this new situation, many parents need some sort of advice and guidance. Having a baby or young child with disabilities brings special challenges, but also additional dependencies. Psychological stress in their everyday lives can also make it difficult for mothers and fathers to deal with responsibilities as parents. With regard to educational questions or issues of specific therapeutic or medical treatment, parents often cannot rely on their own experiences. They depend on professional support of various kinds. Access to good medical treatment, self-help groups, and early childhood intervention support services from an early age onwards

are key factors, both for the child's personal development and for parents to succeed in coping with this situation. The UN CRPD states in Article 23 the rights for respect for home and the family. In addition, access to understandable information on entitlements and social rights are necessary. Sometimes parents are not able to have their child with disabilities in the family. In these cases, quality child care services are needed to provide a good alternative to family education.

Life-stage childhood and family – services for pre-school education and support families

Children with disabilities have the same needs as all children. The rights of children with disabilities in the UN CRPD are stated in Article 7. Children want to play with their peers, make friends outside the family, and experience themselves as part of a social group. Preschool services such as kindergartens provide care and education for younger children. They prepare children for school and give them the opportunity to interact with their peers. Young girls and boys can expand their life experiences there and develop their social skills. Article 24 of the UN CRPD states the right to inclusive education. In order to benefit from preschool education, disabled children need easy access to facilities and assistance of staff who are well trained with regard to the needs of children with disabilities. Day-to-day life with a disabled child with high care needs is often very challenging for the main carers. To make it a fair alternative for the whole family, good respite care services are needed.

Life-stage children and school – services related to education

For all children, going to school plays an important role in their upbringing. Schools provide education, knowledge and are crucial for socialisation. They offer the opportunity to broaden social skills and contacts with peers. Article 24 of the UN CRPD states the right to inclusive education. Children with disabilities also require high-quality education and have a right to access ordinary schools. Pupils with disabilities need adequate support in the classroom and well-trained teachers with regard to their specific needs.

Life-stage youth and young adulthood – services for young adults

Successful transition from school to work is usually closely related to career choice and vocational training. After leaving school, young people need to have access to a training system or a job that suits their interests and abilities, and with which they can earn a living. They also develop individual needs and ways to spend their leisure time with peers of both sexes. Vocational training prepares them for entry into the labour market and therefore represents an important step into adult life. Youngsters and young adults with disabilities need adequate support services tailored to their needs. The UN CRPD states in Article 27 the rights for participation in vocational training and employment.

Life-stage adulthood – services related to housing and independent living

Growing up also means making decisions about how to live. Questions arise including whether or not to continue to living with the family or living with a partner and starting a family or living with one or more friends in a shared flat.

To have privacy, a place to retreat, to feel safe and comfortable in and to realise one's own idea of how one wishes to live is of great importance to people in our society. For people with disabilities, finding their own way of life is a big challenge. They have limited options as they need an accessible environment and lifelong support. People with disabilities do not only need good services, but also individual counselling to implement their idea of living. Article 19 of the UN CRPD states the right to community services and independent living.

Life-stage adulthood – services related to participation in cultural life, recreation, leisure and sport

Leisure includes any time outside of work to relax or find a balance in contrast to everyday life. Leisure time activities, sports or recreation can be organised individually, in clubs or in a variety of other organised cultural or social formats. In Western societies, people act in their leisure time with less formal restrictions and try to achieve a high degree of satisfaction and self-determination in their activities (e. g. Article 30 of the UN CRPD).

Adult education, assuming the idea of lifelong learning, can be seen as part of individual leisure activities, sometimes in relation to work, or the expectation that a particular offer may be conducive to personal careers. People sometimes take part in educational programs to do something for their personal well-being, health or general personal development.

People with disabilities need suitable offers, individual support and barrier-free infrastructure when it comes to organising their leisure time and visiting adult education programs. To ensure successful participation, recreational and adult education programs for people with disabilities often need to be regularly and systematically planned and organised. Article 30 of the UN CRPD states the rights for participation in cultural life, recreation, leisure and sport.

Life-stage adulthood –services related to employment

Having a job or employment in daily life is, at the very least for financial and social reasons, an important indicator of inclusion and quality of life. Going to work not only structures days and weeks, but also has a significant impact on the development of personal identity. Employment also provides access to the social security system and is an important basis for participation.

For people with disabilities, the transition from school and vocational training to the employment system often needs to be systematically planned and organised. There are dependencies related to suitable workplaces, supporting tools, individual support and an accessible infrastructure to ensure successful access to the adult world of work. Article 27 of the UN CRPD states the rights for work and employment.

Life-stage ageing – services for the elderly

Ageing involves a number of new challenges: retirement, reorganising and reasoning in everyday life, but also making use of life experiences in difficult situations and learning to cope with losing physical strengths. In old age, everyday life often requires a higher level of support and social dependencies increase.

This can mean that one's familiar living environment must be surrendered if/when home care can no longer be sufficiently provided in the familiar environment. However, most people do not want to give up their habitual environment when their need for support becomes greater and more complex. They prefer support arrangements based on outpatient care services that are reliable and flexible. This is also the case with older people with disabilities.

Health care services

Article 25 of the UN CRPD states that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. Thus, states shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. Access to health care, such as medical doctors, therapists or hospitals on an equal basis with others is crucial for people with disabilities.

1.2 Local Planning – Theory and Practice

Following the basic concepts presented before, this chapter introduces the theoretical background of UN CRPD-related planning as a process. This includes information about stakeholders in the disability field, their interests and possible coalitions among them. The section will also present planning as a cyclic process as demonstrated by the CISCOS curriculum that proposes a planning loop with ten elements that reflect the figure of the systemic loop. In this section, you will learn about:

- Different levels of planning;
- The legal basis of local self-government in European countries;
- The legal basis of local planning obligations in relevant areas, such as social services for persons with disabilities, persons with long time care needs, rehabilitation, mental health, education, youth care, accessibility of public infrastructure, housing and public transport;
- The difference between a field's polity, policies and politics;
- Main stakeholders and their interests in the disability field.

1.2.1 Challenges of Integrated and Cross-Sectoral Planning

Planning in municipalities or districts (local planning) supports decision-makers in developing policies for their various areas of responsibility. In the CISCOS curriculum we distinguish between three levels of local planning:

- General development planning with regard to the overall development of the municipality;
- Sectoral planning with regard to different sectors of local government (e.g. housing, transport, water and energy, health care, education, social planning);
- Field-related planning within a sector with regard to different subjects (e.g. within the sector of social affairs: child-care planning, drugs and addiction, long-time care for the elderly).

Planning processes aiming to locally implement the UN CRPD need to reflect the Convention's principles on each level. This does not happen automatically. A coordinated approach requires a political decision by the local parliament to legitimise appropriate measures. With a strong political mandate, a planning unit can be established within the local administration to coordinate different sectors and stakeholders. The planning unit for the implementation of the UN CRPD can initiate processes, develop a strategy and set up a planning structure to implement inclusion and full participation of persons with disabilities in a given community.

In doing so, the planning unit will face a number of challenges with regard to the fact that inclusion and disability touch many aspects of society. Therefore, UN CRPD-related planning needs a cross-sectoral approach. As disability results from the interaction of a person's impairment with environmental factors, planning activities for inclusive communities must find ways to involve all relevant sectors in the process (e.g. housing, health, education, social services). In social planning, the focus is on the development of inclusive social environments and good service provision. In educational planning, the focus is on the inclusive orientation of educational services (pre-school, school, adult-level). Finally, in transport, the focus is on

the realisation of an accessible infrastructure. The sector-related planning should independently operationalise the principle of inclusion in its context. In addition, UN CRPD-related planning requires an enhanced and institutionalised cooperation between different sectors.

A major challenge lies in the fact that some competencies, which are relevant for UN CRPD-related planning (e.g. health care, labor market, education), might be dealt with on different administrative levels. In terms of cultural life and leisure time activities, but also with regard to services or labor market issues, actors from the private sector will play an important role. The planning unit will have to find ways to integrate actors from all different sectors in the planning process.

The final challenge is to connect the planning activities with the world of daily living, i.e. neighborhoods, villages, small towns or urban quarters. Even though planning must be based on the collection and assessment of data according to formal standards, it must not be organised in a bureaucratic way. Planners can involve interested parties in the community through various avenues of communication. Participation and the option to learn are essential elements of a successful planning process.

1.2.1 Knowing About Legal Frameworks and Policies for Local Planning

The "European Charter of Local Self-Government" was accepted by the Council of Europe in 1985[57]. Today nearly all EU member-states have incorporated its principles in their constitutions and domestic legislation. In spite of different terminologies, local self-government is seen as one of the pillars of the democratic system across Europe. The concept of local self-government reflects the idea that local authorities should manage substantial public affairs under their own responsibility, with the interests of the local population in mind. This right is exercised by democratically elected executive bodies such as local administrations[58].

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57   European Council 1985.

58   Klobučník and Bačík 2016.

In practice, EU member-states have made different decisions on their governmental systems. Smaller states usually have only one local government level. Nine of them (Austria, Cyprus, Malta, Bulgaria, Estonia, Latvia, Lithuania, Luxembourg and Slovenia) only have municipalities. Ten member states have a two-level system with municipalities and regions. These are Denmark, Greece, Hungary, Ireland, the Netherlands, Portugal, the Czech Republic, Romania, Slovakia and Sweden. Six member states (Germany, Belgium, Spain, Italy, France and Poland) have a local government system with three levels. Those consist of a municipal, an intermediate (i. e. province, counties, districts, departments) and a regional level. Some countries (UK, Lithuania) have either one or two levels of local government, depending on regions.

In recent years, many tools have been developed to inform citizens and solicit their inputs. They are involved in citizen's committee or partnership boards and through referendums. Generally, it is important to see these forms of participation as complementary to elected assemblies such as local parliaments. "Participative democracy must not compete with representative democracy that is embodied by elected lawful councilors"[59].

In the planning concept presented in the CISCOS curriculum, local authorities play an important role. Therefore, it is necessary to know and understand the system of local government in your country. In UN CRPD-related planning processes at local government level, a number of political fields are relevant. These include accessibility of public infrastructure, housing, public transport, social services for persons with disabilities and persons with long time care needs, rehabilitation, mental health and education. All these fields relate to a specific legal framework. A part of this legal framework may relate to planning obligations of local authorities. In the process of initiation and conceptualising a planning process, it is important to be aware of the given legal frameworks of different sectors. It is also crucial to reflect previous planning activities in the relevant sectors and their results[60].

59   Guérard 2014, 240.

60   A template for a systematic review of legal obligations can be found in the CISCOS toolbox.

1.2.2 Planning with Different Stakeholders

In order to understand a certain field of action, political science suggests differentiating between a field's polity, policies and politics. Polity refers to the set of political actors (stakeholders) in a field, policy is understood as the strategies that those actors develop and pursue, and politics relate to the concrete actions that are undertaken by individuals or organizations.

As a successful planning process relies on it, planners should be aware of the different perspectives to be coordinated. When actions are planned to improve living conditions for persons with disabilities there might be reasons for some stakeholders to oppose or avoid them. In local planning processes, some actors might also interact with others from local networks and cultures. However, actors in a community should not be seen only as stakeholders for their own maximum interests. As people are generally interested in finding ways of good coexistence with others, actors have common interests sharing space and time as locals. This common basis of interests does not only refer to environmental conditions (e.g. clean air) but also to the quality and accessibility of public infrastructure. Keeping this in mind, collaborative planning approaches aim to achieve more than win-win results but cooperative problem solving for the benefit of the general public. In this context, they also aim to reframe how people think about winning and losing[61].

In the following sections, four groups of stakeholders that are relevant for UN CRPD-related planning processes are listed. They are characterised by their perspectives. Further stakeholders can be added if necessary.

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61   Healey 2006.

Disabled People's Organizations (DPOs)

Representatives from this group might typically have the following characteristics:

- Strong expertise on disability rights, needs and risks of discrimination;

- Strong interest in the improvement of individual, disability-group related conditions;

- Some lack of knowledge and skills with regard to planning approaches;

- Some lack of knowledge on service models and implementation strategies;

- Some restrictions in time, flexibility and financial resources;

- A high degree of credibility and commitment;

- A high degree of knowledge on particular disability-related issues.

Service Providers

Representatives from this group might have the following characteristics:

- Experienced practitioners with formal qualifications;

- Professional background in disability-related service provision;

- Need to compromise between professional standards and organisational necessities and therefore a theory-practice implementation gap;

- Locked into organisational and sector-specific routines and path-dependencies (see Chapter A 1.3 of this manual);

- Administrative and bureaucratic procedures;

- Limited financial means;

- Competitive conditions due to market-orientation;

- Interest in new service models;

- Interest in assuring financial resources;

- Need for legitimation for funding agencies and the general public;

- Awareness of the power of their political role between organisational and collective interests.

Services for the General Public (schools, cultural and leisure time services, companies)

Representatives from this group might have the following characteristics:

- Commitment to becoming more inclusive;
- Some lack of knowledge regarding the needs and rights of persons with disabilities;
- Some lack of knowledge and skills regarding participative planning approaches;
- Lack of support within their organisations.

Local Government

Representatives from this group might have the following characteristics:

- Administrative correctness;
- Responsibility for public resources (i.e. financial means);
- Responsibility for provision of services for the general public;
- Bound to legal regulations;
- Commitment for making service systems more inclusive;
- Some lack of knowledge regarding the needs and rights of persons with disabilities;
- Some lack of knowledge and skills regarding participative planning approaches;
- Lack of political support.

1.2.3 Basic Assumptions of Local Planning

UN CRPD-related local planning activities can be regarded as a form of intervention into established planning structures, processes and practical routines of a municipality or district. Planning for disability-inclusion often requires changes in such structures, processes and routines, to ensure that the rights and needs of persons with disabilities are assessed and considered in district health planning or urban mobility planning. The planning unit is mandated for this intervention by the government and they might also have clear objectives with regards to desired results. However, it cannot be assumed that these objectives will easily be transferred into practice by order.

There are various interdependencies between governments and other stakeholders and thus, actors from many different organizations and sectors have to be involved. In this context, power structures are not always clear, so decisions must be negotiated between different actors. Local government officials are just one group of stakeholders, but a powerful one. When it comes to making decisions (e.g. on planning fields, procedures or recommendations) planners need to shape a political process. This means to promote collective action under conditions lacking consensus[62]. From theories of organisational change[63], we know that certain constellations of actors can effectively support the implementation of innovations. Planners should therefore try to form a supportive coalition for their project. This coalition would then function as a political power, and should preferably contain promoters with influence, competence and communication skills.

All local communities have their specific history and traditions, rituals and culture. How the people in the community deal with persons with disabilities or other vulnerable groups is also embedded in this tradition and culture. This has led to taken-for-granted assumptions and behavioral routines that local people usually follow when they interact with persons with disabilities. In this context, planning processes that attempt to implement new perspectives can also be regarded as learning processes for the general public. It may therefore be necessary to bring additional knowledge to the local setting, in order to improve non-discriminative practices, universal design or new forms of inclusive services. Such learning processes in the disability field can become exemplary and stimulate the development of an inclusive, local culture.

The implementation of the UN CRPD can mean substantial changes for certain actors. Those changes might be related to high uncertainty, as well as material and immaterial transaction costs. Therefore, efforts to promote such changes in both concept and practice

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62 Scharpf 1973.

63 Kristof 2010.

must make sense for decision-makers in affected organizations. It is an important task for planning activities to produce and communicate this. Making sense in planning processes means to develop and communicate strong arguments and perspectives to convince the actors to give their support.

The objective of developing strategies is to "organise thinking on a topic in a certain direction"[64]. In our context, the vision of an inclusive community could be a leading concept of strategic importance. Strategies have the important function of reducing complexity for those actors and organizations that adopt them for their development. The adoption of a strategy facilitates decision making as it helps to concentrate on solving day-to-day-problems. But even if the vision of an inclusive community is accepted, decision-makers can not strictly follow a given concept of implementation. There will be necessary adaptions for each organisation, but decision-makers in organizations can refer to the overall vision in their daily work and apply the plan. The more this happens, the more the local systems will gradually become inclusive.

Planning processes can be distinguished from everyday routine. More precisely, they can be described as temporary interventions in a permanent environment. To be successful they must involve different actors. As joint action is required to bring about sustainable change, cooperation needs to be formalised. The main reason is that single actors are often not able to meet the demands of a collective change on their own.

With this in mind, it is important to understand how decision-making processes work in cooperative settings. In most organisational settings, decisions can simply be made in a hierarchical way. This is not an option for cooperative planning processes, that rely on the joint actions of various actors. In such settings, decisions must be made possible through more or less structured cooperation and negotiation among the different actors.

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64   Healey 2006.

If partners succeed in formulating a common objective that fits their particular interests, a certain dependency arises from the fact that such an objective cannot be achieved by one of the partners alone. Nevertheless, such coalitions are based on voluntary commitment, successful negotiation among the actors involved and an ongoing shared interest and benefit. If there are questions or doubts regarding this, actors might reduce or withdraw their investment during the change process. Additionally, attempts to bring about decisions through hierarchical behavior can jeopardise the cooperation as a whole. Therefore, cooperation processes and cooperative decision-making does not work by chance but should be seen as a strategic process requiring proactive initiation as well as professional and sensitive steering.

For cooperative change processes as previously described, the CISCOS curriculum recommends an approach based on the concept of the systemic loop. This divides processes into the following basic steps:

1. Observation and collection of information
2. Analysis and interpretation/hypothesising
3. Developing different options for action
4. Intervention
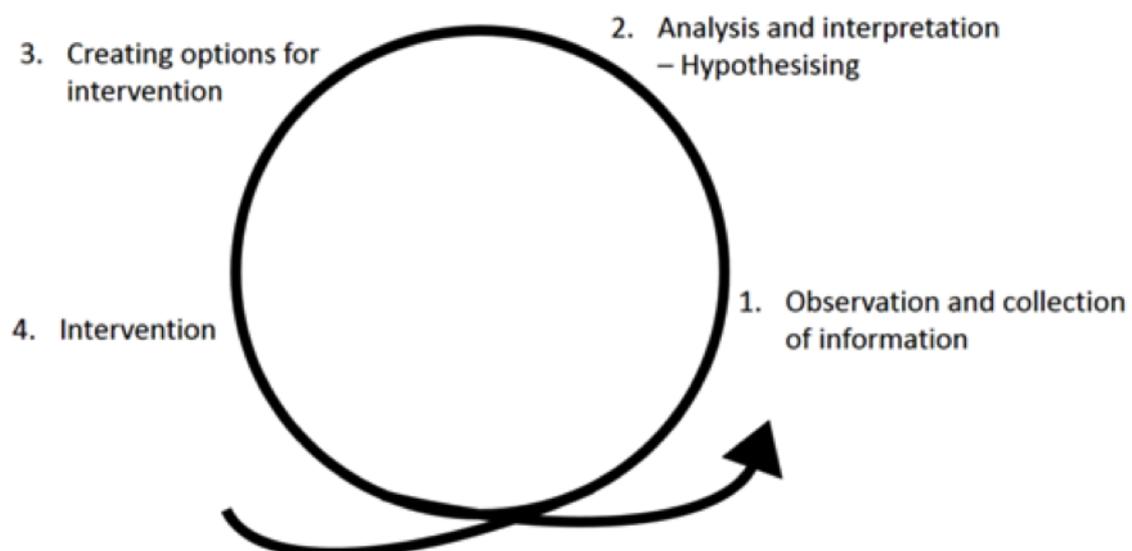
Figure 2. Systemic loop

As part of systemic development theory, the systemic loop is a learning-oriented model that can help deal with complexity and the understanding of a system that is to be changed through strategic action. Its four steps are the basis for cooperative change processes and allow professional coordination as they continuously generate the information needed for proactive and informed steering of the process. Following this basic concept, the CISCOS curriculum proposes a model that specifies the loop process for the initiation and coordination of change processes in fields of local policy-making and implementation.

1.2.4 Local Planning as a Looping Approach

Temporary interventions or planning projects must be actively initiated by people in their daily actions. They require activities for agenda setting, like public mobilisation and PR work. Based on strategic considerations, relevant actors, such as political leaders, must be convinced to agree to a planning project, organise political support, provide resources and initiate the planning process itself. This is not always easy as there are many other important issues in the public sphere. In this sense, planning processes are always political processes.

Impulses for initiating UN CRPD-related planning processes can be promoted by different actors, including civil society committees or organizations, service providers, local representatives of political parties and administrators of welfare agencies. Practical experience shows that the agenda-setting for a planning project is easier if initiators manage to form local coalitions of different actors and campaign together effectively. Effective coalitions for change include individuals or organizations that have political power, professional expertise and communicative skills[65].

65   Kristof 2010.

Local planning processes for inclusive communities can be illustrated with a planning loop structured in different parts[66]. The image of the loop reflects both the idea of the systemic loop and planning as a circular process.
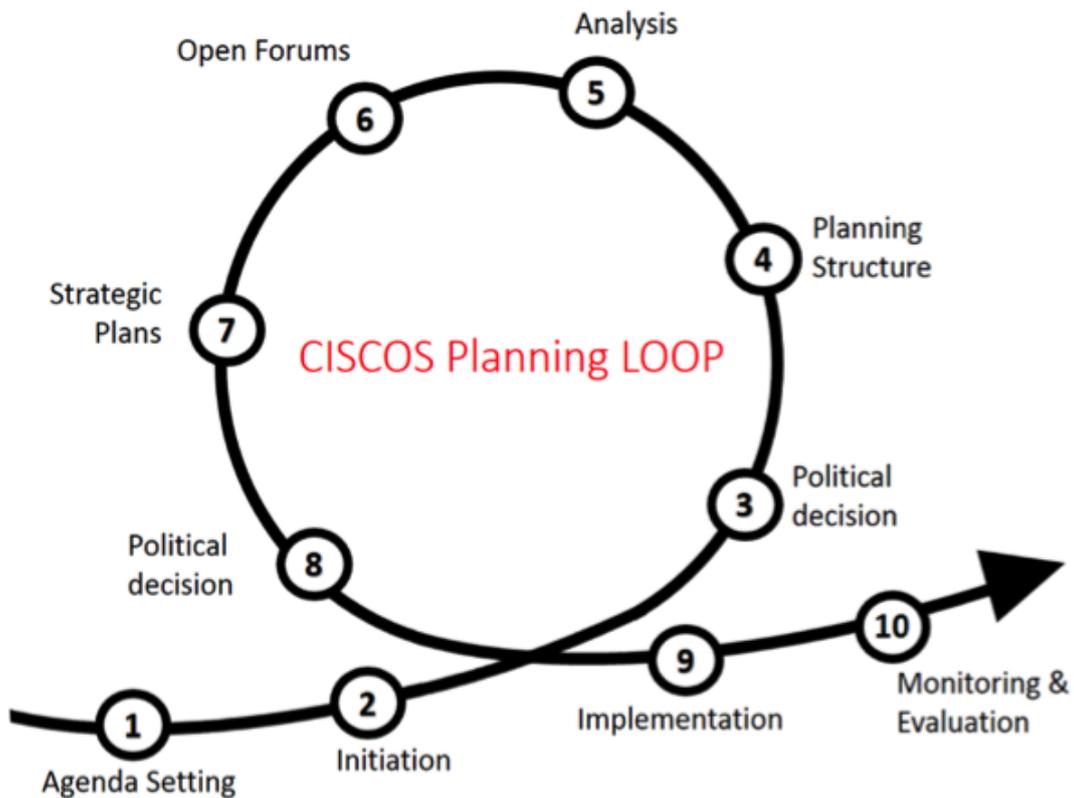
Figure 3. UN CRPD-related planning as a looping process

After successful agenda-setting, the idea of the planning project must be reflected in an initial concept paper that can be formally presented to the local parliament. This paper should contain all information necessary for a political decision, i.e. conceptual ideas, a description of procedures, structures, a timeline and the costs of the planning process. When the formal decision to conduct the project has passed the parliament, planning structures, such as a communal planning unit, rules and timeline for procedures and a steering committee with external stakeholders can be established.

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66   Rohrmann et al. 2014, 47.

Mandated by the local parliament, the planning process can begin with an official kick-off event, where the objectives and methodology are presented to the public. Practical planning begins with the collection of data and information on the current situation with regards to inclusion and participation in the selected dimensions. It might be helpful to organise additional professional support, such as services for data collection and processing.

The results of such assessments should be evaluated by planning experts in the form of short reports and prepared for discussions in one or more planning forums. As a result, recommendations and concrete measures are developed and put together in a draft version of a written action plan. This plan is then made the subject of decision-making in local and regional political bodies, in order to achieve official recognition. The greater both public attention and mobilisation are to this end, the easier the recognition process becomes.

The adoption of the action plan by the local parliament does not mean the end of the process. The challenge then becomes implementing the plan for an inclusive community by using it in local practice. It is necessary to assure continuous monitoring and evaluation of the status of the formulated measures. This should become part of existing planning and monitoring routines in different sectors of a municipality. The more successful such a planning episode is, the more likely it is that it becomes an encouraging part of a "collaborative local governance culture" along with a higher awareness of equality, social justice and non-discrimination[67]. The following subchapters introduce the different elements of the CISCOS Planning Loop.

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67   Healey 2006, 327.

Agenda Setting

Agenda Setting
Put disability-inclusion on the local political agenda.

Tools available @ CISCOS Toolbox

Tool 1: Building a group of promotors for change
Learn how to bring together like-minded actors to change including resources, professional expertise, political power and networks which might assist in initiating a change process and putting it on the local political agenda.

Tool 2: Stakeholder Mapping
Get a better understanding of the social and institutional landscape in which a particular change process is planned to be initiated. Identify and analyse all individuals and organisations who hold at least a potential stake that process

Tool 3: The Interest - Influence Grid
Develop a strategic view of the stakeholder landscape by identifying the particular interest and influence on the change process of key stakeholders.

Tool 4: Effective agenda setting
Find out more about the composition of local political agendas. Learn how to successfully put a topic like the inclusion of people with disabilities on the political agenda of a local parliament.
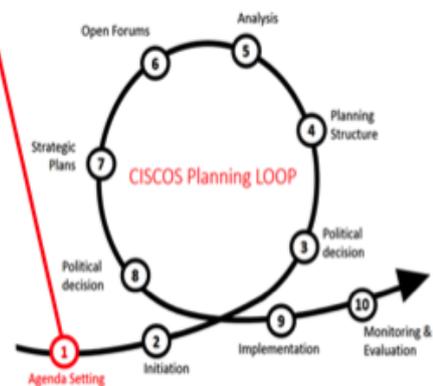
Open Forums — Analysis

6 — 5

Strategic Plans — 7 — **CISCOS Planning LOOP** — 4 — Planning Structure

Political decision — 8 — 3 — Political decision

1 — 2 — 9 — 10 — Monitoring & Evaluation

Agenda Setting — Initiation — Implementation

In the initial phase of a change process in a district or municipality, promoters must identify a common need for action, find support from other local actors and organise the start of the change process. This initial phase of agenda-setting, especially when it comes to bottom-up initiatives, is often a demanding process. It requires specific knowledge, skills and proper timing. However, it is important to consider how an issue becomes or fail to become a concern and interest within the composition of political actors (respectively the polity) in a district or municipality.

The design of a local level government agenda is in many instances not the result of a rational process preceded by the in-depth assessment and definition of a specific problem. It is more or less a product of chance and the influence of various governmental and non-governmental actors and coalitions. Understanding the dynamics of agenda-setting processes in a district or municipality requires exploring how local governments, as a set of

organizations with limited rationality, resources and capacities, deal with seemingly unlimited public problems in their territory and why some public issues gain relatively more governmental attention than others[68].

The agenda can be defined as a list of subjects or set of issues that government officials and people outside of government are paying close attention to, and are also subject to debate and decision making within a given political system at a specific point in time . It is important to differentiate between the general societal agenda, a set of issues that are under discussion in society, and the institutional agenda, defined as the set of issues being discussed in a particular government institution[70].

Considering this background, agenda-setting can be defined as "a process in which certain public problems are identified, recognised and defined, and specific solutions or alternatives are generated, considered, and attached to these problems"[71]. The list of issues that make it to the local agenda is usually rather short, due to the limited attention span and information-processing capacity of local governments[72]. Therefore, it is important to note that the composition of the political agenda is in itself a fundamental part of the political process[73]. Hence, while the authority of local governments to choose between alternatives in their decision-making is an important feature of political power, the ability to control what alternatives are under discussion in the first place (agenda-setting) seems to be even more important[74].

With regard to questions of what problems attract attention and how and by whom local policy agendas are set, political science introduces the multiple stream approach[75] that provides orientation and a useful perspective on the complex dynamics of local-level policymaking. The approach includes three separate and partially independent streams: problems, policy options or alternatives and politics.

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68   Liu et al. 2010.

69   Kingdon 2011; Baumgartner 2015.

70   Baumgartner 2015.

71   Liu et al. 2010.

72   Ibid.

73   Baumgartner 2015.

74   Ibid.

75   Kingdon 2011.

In the problem stream, problems rise and fall to the attention of decision-makers through the introduction of new or apparently new information into the agenda-setting process. This attracts the attention of local decision-makers, usually associated with changing social conditions and problem indicators[76]. Specific events that emphasise the occurrence of specific problems (e.g. natural or man-made crises or disasters) or feedback to policymakers on current or past governmental programs (from implementing agencies, organizations or local citizens) as well as new public problems and budgetary considerations can increase or decrease the relevance of a public issue for the local agenda.

In the policy options or alternatives stream, the specification of options or alternative solutions is usually advanced by hidden specialists, who have detailed knowledge of, and proximity to solutions, ideas, and recombinations of previous ideas[77]. For a proposal to survive alternative selection, Kingdon[78] introduces three important characteristics: the logical consistency and technical feasibility of an alternative, its compatibility to a mainstream value of a policy system, and the extent to which a proposal considers future constraints like budgetary limitations, public acceptance as well as the support or opposition of local officials. In addition, the compatibility of a proposal with existing policies at the local but also regional, national and supranational level increases the chance of it being considered in local policy selection processes.

In the politics stream, various issues like the political mood, interaction among organized political forces, elections, change of government personnel or jurisdiction as well as consensus and coalition building can highly influence the chance an issue has to make it to the local agenda. It is important to note that the local policy process is influenced by the regional and national level of government.

76   Liu et al. 2010.

77   Ibid.

78   Kingdon 2011.

According to Kingdon, these three streams influence the opening and closing of windows of opportunity for an issue to be considered on the agenda. An issue is most likely to receive serious attention and agenda-setting is enabled through the interaction of these three streams. Coupling these streams successfully necessitates the facilitation of advocates who invest resources including time, energy, reputation and money[79]. It is these advocates who develop (or support the development of) alternatives and couple them with problems to present solutions to policymakers at the right time[80]. In other words, they "frame issues by explaining the causes of a given problem with a narrative justifying a particular governmental response"[81]. Hence, the definition of specific public problems and the ability to define and influence or change such definitions plays a major role in agenda-setting processes.

Episodic periods of high agenda status usually enable more comprehensive and sustainable policy changes. This is because such high agenda status periods often go together with the development of new or changing institutional procedures that enable political institutions and policymakers to settle into stable routines, sometimes persisting for decades[82]. Therefore, agenda-setting can disrupt longstanding routines of behaviour and power and, if successful, replace them with new ones[83].

With regard to the relevance of various actors in local-level agenda-setting processes, two groups are of particular relevance. The first is, perhaps not surprisingly, the group of government actors. However, in many instances, it is not only the local government but all levels of government that influence local policy processes. The second is interest groups inside and outside the local government. These include specialized and lobbyist groups, that often focus on one specific policy area and whose influences are particularly strong in their specialised fields[84]. Further relevant actors can include specific government departments or agencies, regional councils of government, experts from academia and consulting, poli-

79   Ibid.

80   Ibid.

81   Baumgartner 2015.

82   Ibid.

83   Ibid.

84   Ibid.; Liu et al. 2010.

tical parties and campaigners, civil society organizations, private sector businesses, and the local media. As each of these actors will likely be driven by specific self-interests, the ability of each of them to influence and control the interpretation of a problem and consequently the development of policy options or alternatives is a crucial feature in agenda-setting processes. Against this background, it is very important in the initial phase of a change process, to get a clearer picture of these actors, their relationships, resources and political influence with regard to a specific change subject.

The impulse to initiate an agenda-setting process based on the inclusion of people with disabilities in a district or municipality can come from very different actors. Political parties, administrative staff or working groups, represented in the local parliament, may demand that the UN CRPD be implemented across local policy areas. A process can also be initiated by existing bodies such as a disability advisory board or a working group for local UN CRPD coordination. Newly formed interest groups and initiatives or established support services and institutions related to disability issues can also make a case for putting the development of an inclusive district or municipality on the local agenda. In the initial phase of a change process in a district or municipality, promoters must identify a common need for action, find support from other local actors and organize the start of the change process. This initial phase, especially when it comes to bottom-up initiatives, is often a demanding process requiring specific knowledge, skills and the right timing.

The tools in Chapter E 1 can provide guidance for initiating and coordinating agenda-setting processes towards making districts or municipalities more inclusive of people with disabilities.

Initiation

Initiation
Convince stakeholders of developing towards an inclusive community

Tools available @ CISCOS Toolbox

Tool 5: Developing Scenarios
Find out how to explore various options for action enabling you to plan for an uncertain future where actual circumstances might change. Understand the impact of different factors and potential decisions made during a change process.

Tool 6: Devise and decide on options
Explore available options of a change process to decide on a preferred option more systematically. Develop alternative strategic approaches and finally come to an informed and conscious decision on the most adequate strategic focus.
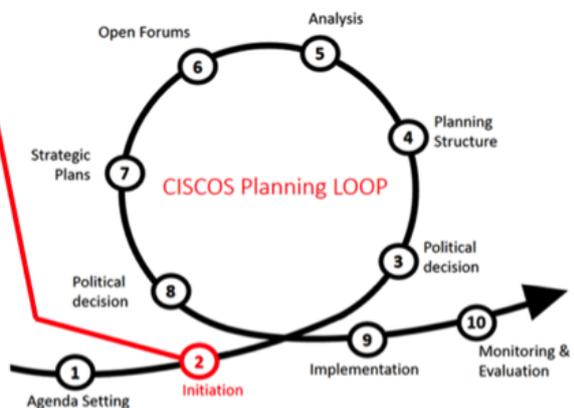
The UN CRPD does not only affect people with disabilities but also other groups of people. As a consequence, it is relevant for entire districts, cities or municipalities. Agenda-setting can be considered successful if it has been possible to bring this consideration to the attention of the relevant actors in a given community. For the following planning process, it is important to ensure that local authorities take the lead in order to make the involvement of a variety of different actors possible.

Part of the initiation of the planning process can consist of open forum discussions with different stakeholders. Their aim would be to familiarize stakeholders with the idea of local development towards an inclusive community. Regardless of the concrete form, it is of central importance that the relevant groups of people can participate in the process. This applies to people with disabilities as well as others.

One idea in this context is to organize round table discussions that intensively reflect on the meaning of the UN CRPD articles and the resulting challenges for the planning and development of an inclusive community.

Organising open forum discussions on UN CRPD-related topics is just one aspect of initiating a planning process. It also makes sense to discuss formal structures. In this context, it can be very helpful to reflect on the given framework for the planning process. This can include examples of good practice and exchanging experiences with other municipalities. In particular, It is especially important to harmonize or network one's own planning activities with the activities of the other state structures at this early stage.

At the end of the initiation stage, the actors should have a clearer idea of the upcoming process, the related policies and the planning processes governance. Actors in this case means the actors in the lead within the local authority but also people belonging to relevant groups of stakeholders. The ideas, policies and papers need to be concrete enough to be passed to the local parliament for decision in the next step. This aspect clearly shows that the relevant stakeholders include representatives of the political parties represented in parliament. The various stakeholders and their significance for the planning process underlines the concern represented here to understand the planning process as a participatory one. It seems inappropriate or even impossible for administrations to attempt to carry out planning processes against the interests of the relevant stakeholders.

Political Decision

Political Decision
Get the planning process authorized through a political decision of the local parliament

Tools available @ CISCOS Toolbox

Tool 7: Effective advocacy on the local level
Learn how to advocate for perspectives, voices, rights and needs of citizens, particularly those living in vulnerable conditions, to be heard and addressed by local decision makers. Find out how to use advocacy as part of your change initiative in a municipality/district, nested in with other components.

Tool 8: Draft resolution to pass the local parliament
Find an example of a draft resolution on the development of a local strategy for the implementation of the provisions made by the CRPD.

The initiation of the planning process concludes with a political decision in the responsible parliament. The main function of the political decision in this context is to legitimate the following measures. In addition, the political decision frames the following planning process by formally establishing the planning structure. It also ensures the provision of financial and other resources needed throughout the process.

In practice, the political decisions vary, even between parliaments within the same national framework. Keeping this in mind, it is helpful to reflect the following aspects when proposing a paper for political decision.

As stated above, the main function of the political decision here is the legitimation and institutionalization of a continuous planning process. Ideally, the planning process, once initiated, is repeated again and again. Although it is important to keep in mind that with

every repeat of the planning process formal legitimation is required. A first initiation can serve as a formal starting point to the ongoing process.

Formal political decisions should include overall aspects of community development as well as specific planning tasks. In order to maintain the local focus of the planning process, it is of crucial importance that the given local entity assigns the lead of the planning process to its own institutions. This helps to focus the planning process on locals needs, as stakeholders with diverse functions and interests are usually involved.

Practically, taking the lead in the planning process means to assign tasks of steering, moderations and evaluation to employees of the local administration. In this context, it is of crucial importance to set responsibilities and formally ensure the resources needed (e. g. working time, percentage of position, financial resources). Tasks and responsibilities should be precisely defined. This is also important in case some aspects of the planning process are delegated to external suppliers.

As planning inclusive communities is a cross-cutting process, it is important not to establish the planning process as an additional, special plan. The formal decision should reflect the UN CRPD as well as past planning processes, existing forums and precise milestones for further development.

Establishing a Planning Structure
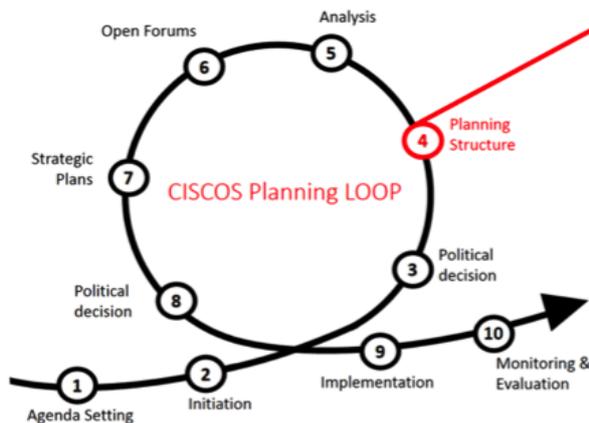
Planning Structure
Define responsibilities, participation and communication formats

Tools available @ CISCOS Toolbox

Tool 9: Building a steering group
Learn how to build up and run a steering group to organize key actors and to enable them to steer a change process successfully.

Tool 10: Agreements in Stakeholder Dialogues
Get to know different formats of joint agreements to at least partly formalize the commitment of all actors to be involved. Find out how to strengthen cohesion and cooperation and give orientation for a cooperative development process.

With the formal decision to initiate a planning process a first concept for a planning structure is already fixed. Nevertheless, it is important to keep the further development of the planning structure a dynamic process. The objective would be to establish a planning structure that is linked to existing planning structures, processes and routines, but is also flexible enough to deal with upcoming tasks. This bears the risk of involving too many stakeholders in the planning structure. Therefore, it might be helpful to establish a smaller group and involve other stakeholders only for fixed tasks and smaller amounts of time. The concept of inclusive development is to be regarded as a cross-cutting framework for all aspects of planning and development within a given community. This is especially important for those fields of planning where the legal competence lies with cities and municipalities.

The planning structure can be formally set in order to make it transparent for the stakeholders involved. This includes fixing responsibilities but also defining the stakeholders involved and the forums to be established. Reflecting on stakeholders here involves the inclusion of people with disabilities and other groups in the process and its structure.

Analysis of the Given Situation

Analysis
Assess the baseline situation of a desired change process

Tools available @ CISCOS Toolbox

Tool 11: Assessing participation
Find a framework for assessing the participation of persons with disabilities in local planning and decision-making.

Tool 12: Assessing awareness raising
Find a framework for assessing local initiatives on raising awareness on the rights of persons with disabilities.

Tool 13: Assessing accessibility
Find a framework for assessing the accessibility of local infrastructure and communication.

Tool 14: Assessing services
Find a framework for assessing local service networks for people with disabilities

Actors and committees in charge of the planning process need to assess the base-line situation in their given context in order to plan appropriate concrete measures. In this context, it is necessary to collect and analyze data from various sources. References to data can help to legitimate both starting and ongoing planning processes. At the same time, data can be used to get necessary information about a given situation in a local community.

Both of these functions lead to data collection being referred to at several stages of the planning circle. Data collection can be important before or within the stage of agenda-setting. The amount and types of data collected then directly influences the initiation of the planning process. At this early stage, data can also play a crucial role as a means to legitimize the planning process in political debate. At a later point, data can also be collected to analyze the situation within a community. The information gained builds a basis for discussions in open forums and arenas. Data can also be collected as a means of monitoring and evaluation. Following the idea of the planning loop, at the end of the process, evaluating

data can lead to another planning process to be initiated. Keeping this in mind, exemplary data collection and analysis is discussed below.

As planning is meant here as a continuous process, it is helpful to stick to data that is already available and collected on a regular basis. In addition, it might be necessary to ask relevant stakeholders about their views, situations and perspectives. Data collected from local stakeholders might be highly subjective and influenced by others. Therefore, it is important to get from data to information. Extracting relevant information from data means reflecting on subjective interests as well as underlying aspects of individual positions. Data collection has become easier through digital media. Vast amounts of data can now be easily collected through publicly available sources. New opportunities presented by digital media allow people involved in local planning processes to collect more data on their own. In this context, it is helpful to refer to the image of the planning loop and its stages again. Planning as a looping process can only be possible if workloads seem reasonable for the people involved. It is therefore important to reflect on what data is actually needed to obtain the required information. The more data that can be collected from existing databases, the better. Data that is already collected on a regular basis is more likely to be available for future planning loops, compared to data that needs to be collected in time-consuming procedures[85].

Collecting data is not an end in itself, but it can lead to the first assessment of a given situation. This analysis can then be discussed in open forums to develop a more precise perspective. Data referred to in the planning process can exist in many different forms and derive from a variety of sources. There are two types of data that need to be distinguished:

- Existing data that is continuously available from public databases, state, national, regional or local governments, service providers or other private actors;

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85   Rohrmann et al. 2015, 55.

- Data that is needed but not yet available has to be collected before or during the planning process (e.g. interviews with mayors or administrative staff in a given district). In these cases, it is important to reflect on the need for the related information.

Data can be collected and presented using a vast variety of methods. The data format and collection method needs to be chosen carefully. Data collected in the planning process can be:

- Statistical data collected through questionnaires (online and pen-and-paper);
- Compilations of statistical data collected from external sources;
- Qualitative data collected through open interview schedules and interviews (e. g. interviews with persons with disabilities, planning executives and service provider personnel).

Open Forum Discussions
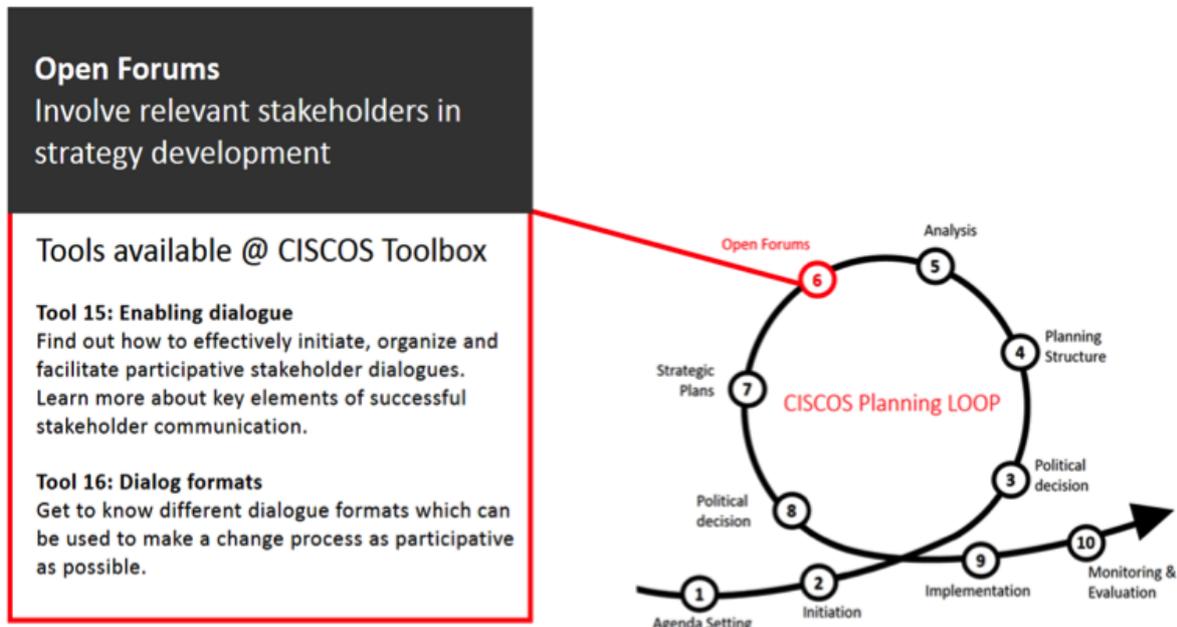
Planning processes for inclusive local communities as conceptualized here are meant as participatory processes. This means that in the process of developing aims and planning documents it is crucial to find ways to involve people with disabilities, their relatives and also the general public and other relevant stakeholders.

In addition, to involve the aforementioned groups, it is also important for a successful planning process to involve local politicians and to legitimate the planning efforts by demanding political decisions (e.g. on initiating the planning process, legitimating concrete measures and finally legitimating the complete plan).

The role of open forums, arenas and parliaments in the planning process is discussed below. While parliaments will always play an important role in democratic legitimation of planning processes, open forums and arenas can be seen as opportunities for a participatory planning process.

Open forums can play an important role in the initial phase of the planning process. In this stage, they are meant to foster reflections on the UN CRPD within the local community. In addition, they are meant as a platform for developing first ideas on concrete measures. Open forums at this stage could be organized as round table discussions on matters of the UN CRPD. Another option would be to invite people to a public event that relates to both the Convention and the concrete planning process.

Within the planning circle, open forums also occur as a possibility to discuss the results of a first analysis of the given situation. The forums consist of the aforementioned stakeholders. The intention is a critical reflection on the given situation that among other measures leads to a written plan with more concrete measures.

Forums as depicted here are the most open form of the three that are to be discussed here. While parliaments are the most formal committee, arenas can serve as a link between open and formal structures.

Arenas can serve as a link between the generally open forums and parliament decisions. They represent smaller groups and might include experts from self-advocacy groups and local administration that meet on a regular basis. Arenas can help to structure data gained

during the previous step and from open forum results. They can also be used to come to terms on conflicts and to discuss concrete measures to be included in a final strategic plan. The planning process is technically initiated and politically legitimated by a decision of the local parliament. In addition, parliament decisions not only give legitimation to the process but also help to structure it. In this context, they are meant to initiate a continuous development process towards an inclusive community. It is the district, city or municipality who should claim the lead in coordinating the initiated planning process.

In the CISCOS planning loop, parliament decisions are proposed in the very beginning of the process and after a strategic plan is developed and proposed for implementation.

Strategic Plans
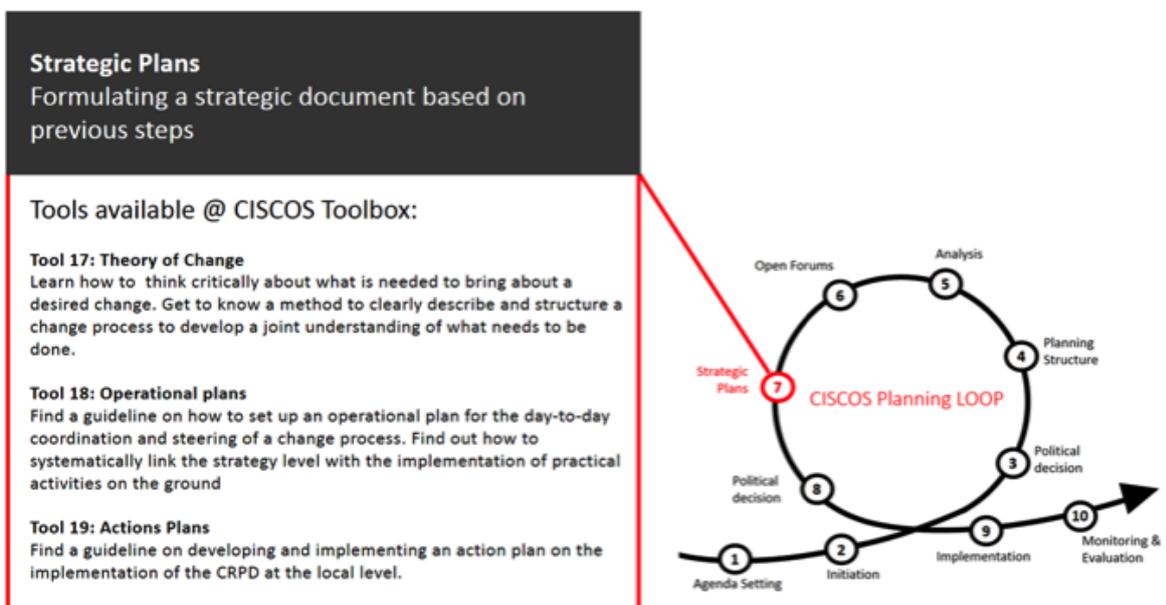
A central step in planning processes for inclusive communities is the creation of strategic plans. Plans are regularly drawn up or updated in areas where there is a legal obligation or a municipal tradition to do so, for example at the level of the general development planning of a municipality, at the level of individual sectors (e.g. health planning) or also at the level of specific subjects (e.g. childcare).

With regard to the implementation of the UN CRPD, the concept of 'action plans' has established itself worldwide. At the local level, we also often find 'participation plans' or 'inclusion plans'. There are different recommendations for the development of such plans, which are explained in more detail in the CISCOS Toolbox. The practical preparation of an action plan, however, is a demanding task. Before a comprehensive plan can be drawn up, it must be made clear which precise objectives the plan should pursue, as well as the challenges and problems of a municipality that these objectives relate to and how the change process between the initial situation and the objective could look. The CISCOS Toolbox includes a method for dealing with these questions (see Tool 17 „Theory of Change").

Even after a plan has been drawn up, the planning process is not complete. Assuming a plan defines clear objectives, measures and responsibilities, these often require further concretization and operationalization, to enable the implementation of the plan to be controlled systematically and proactively. The CISCOS Toolbox presents a framework for this operationalization process (see Tool 18 „Operation Planning"). The monitoring and evaluation of plans also plays an important role and should be taken into account in the development process (see B 5.10).

Political Decision
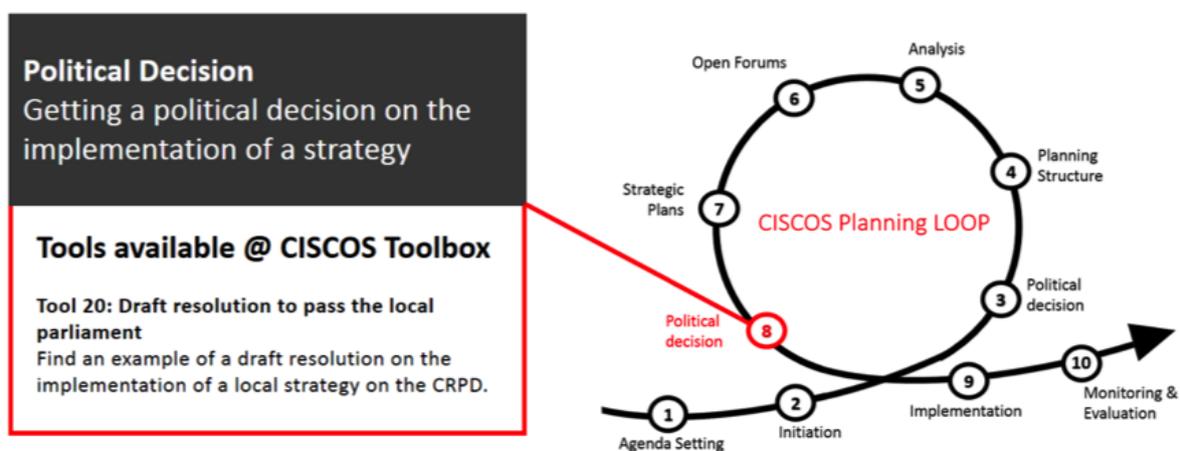
After finalizing the implementation plan it is important to pass it to the political committees again. This serves several aspects with regards to the subsequent implementation

process. Political committees at this stage serve as forums for additional discussions on aspects of the implementation plan. Their primary role, however, is to take the final decision on the implementation of the planned measures in so far as they fall within a given committee's area of responsibility. With regard to recommendations concerning the areas of responsibility of other actors, the way in which those recommendations are communicated must be decided on an individual basis.

With regards to final political decisions, it is important to note that the planning circle and its elements should be seen as a model. The single elements are not intended as a strict order to be followed under all circumstances. A good planning structure would, for instance, involve local politicians and therefore maintain a political commitment to the finalized implementation plan during its development. This perspective means the planning process and the implementation plan are already part of the decision-making process. However, a formal political decision on the implementation plan helps to legitimate it with regards to relevant stakeholders and the general public (see Chapter E 3.1). It can encourage the aforementioned groups to identify with the implementation plan in order to work on the common task of developing of an inclusive community.

Implementation of Strategic Plans
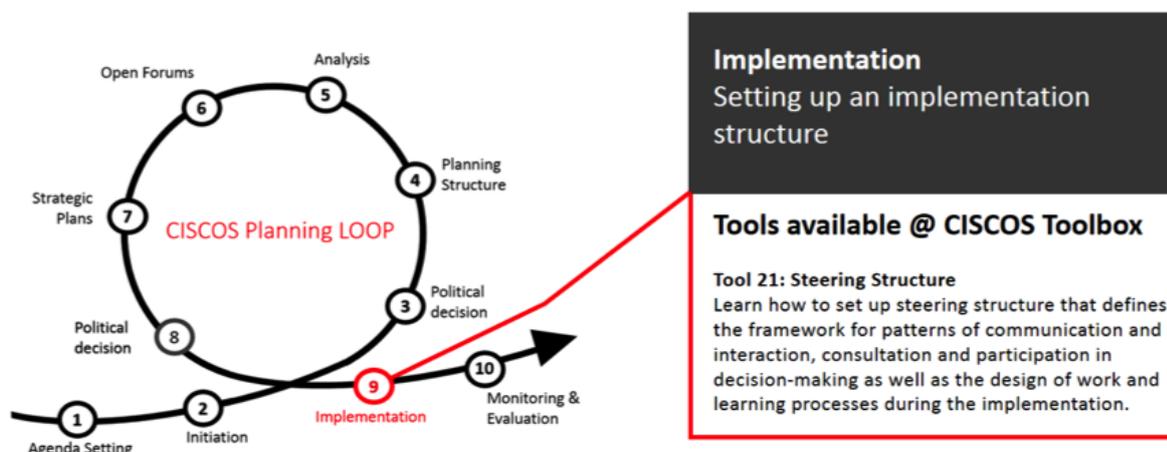
Once an operational plan has been drawn up and responsibilities are determined, the implementation of a planned change process begins. However, the planning process is not completed with the operational planning, but should also include the implementation up to the evaluation. Even a professional operational plan does not allow control of the implementation in an autopilot mode. The CISCOS approach follows a cyclical planning approach, in which the control of the implementation takes place in continuous loops of planning, implementation, observation, analysis and renewal or adaptation of the plan. Participative implementation and management of a change process in cooperation with different actors requires special attention to the structure and organization of the management. Considering how management can be continuously provided with relevant information about the implementation of the measures and their impact is of crucial importance in enabling informed and proactive guidance.

Setting up a controlling structure and a monitoring system are important elements to enable effective control and cooperation systems with different actors. This approach forms a learning-oriented planning concept. The continuous loops of planning and monitoring make it possible to understand the complex social and spatial environments and the actors affecting them, in which targeted changes are to be brought about by planning processes. These loops also make it possible to remain sensitive to changes in these environments and to react to them through proactive control and adaptation of planning during implementation. The cyclical course of planning and monitoring continuously generates information for informed decisions on next steps for further local development.

To reflect on how innovative proposals could be implemented is also part of the planning activities both in the process and when it comes to implementation of results. This should be considered in an evaluation framework for planning activities. The monitoring system and particularly the indicators it contains can provide important information for the evaluation.

Monitoring and Evaluation
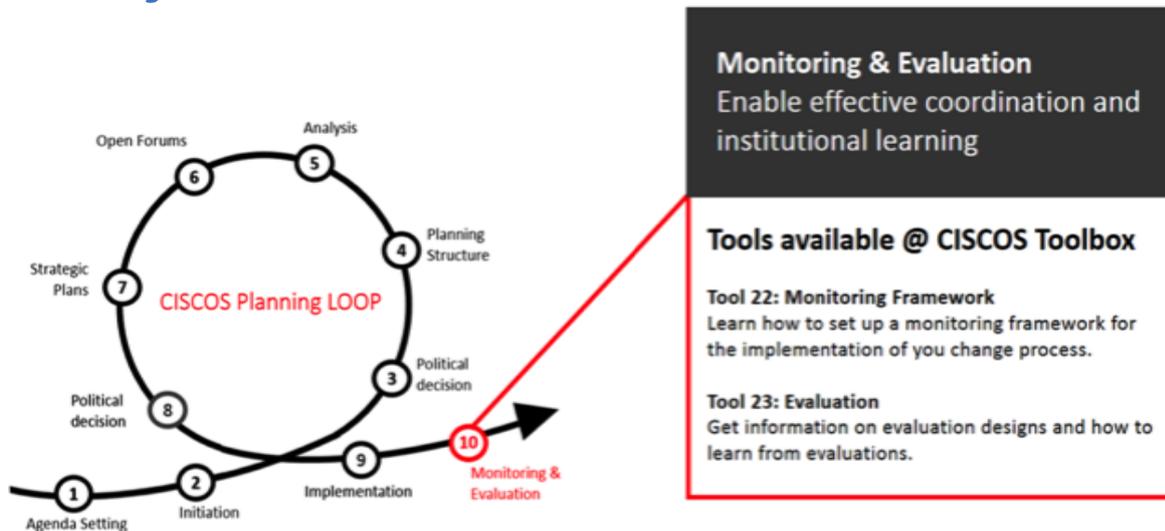
To understand why an initiative brings about change, it is important to observe activities and outcomes during a change process. This means continuously or periodically monitoring the way activities are carried out and the intended and unintended impact of these activities on the environment in which change is to be brought about.

A monitoring system is an important instrument for the systematic coordination and implementation of change processes on the basis of valid information on the status of implementation and target achievement. Monitoring and operational planning are closely linked. While the operational plan manages the daily implementation, a monitoring system makes it possible to check the progress of the implementation on the basis of predefined indicators and identify implementation gaps and challenges. Since change processes are usually very dynamic, coordination in autopilot mode is not possible. Systematic monitoring enables learning-oriented coordination and control of a planning and change process, as it provides information that can be used to take corrective measures on strategies and operational plans at any time. Operational planning and monitoring should be a continuous looping process throughout the implementation of a change process. A monitoring system also provides information for reporting obligations and transparent communication about a change process as well as for the evaluation of a change initiative at a later

point in time through systematic progress documentation. The CISCOS Toolbox provides a guideline on how to set up a monitoring system.

Evaluations are characterized by the fact that they relate to a clearly defined object. These can include political processes, programs and interventions such as a plan to develop an inclusive community and its implementation process. Evaluations are usually carried out by experts on the basis of precisely defined and transparent criteria, which refer explicitly to the subject of evaluation. Professional evaluations differ from everyday evaluations by using objectifying empirical data collection methods and comparative methods for the collection and assessment of information. Even though evaluation is based on standards of empirical social science, it differs in its clear reference to practice and exploitation. Evaluation aims to produce directly usable results for the improvement of social practice.

Evaluation can pursue different goals simultaneously. These include:

- Acquisition of knowledge or learning. A rational basis for steering decisions, quality of processes, acceptance of an intervention in the field, cause-effect relationships between intervention and change, short, medium and long-term effectiveness.

- Exercising control. The status of achievement of objectives, the effectiveness and efficiency of implementation and the acceptance and sustainability of effectiveness. Even if evaluations do not primarily serve to monitor implementation, they usually generate information on the extent to which the actors involved fulfil agreed tasks and obligations and whether their capacities are sufficient to do so. Thus, evaluation usually also has a control dimension.

- Creating transparency and opportunities for dialogue in order to promote developments. Any results of evaluations usually provide information that can be used for the further development of processes. Disclosed outcomes can foster dialogue between stakeholders and promote learning processes for further cooperation and process design.

- Legitimisation of measures implemented. Evaluation results can legitimize processes and interventions by generating information about the means used to provide services as well as the effects that were achieved. For example, the effectiveness and efficient use of financial resources can be proven. Evaluation after the completion of a process or an intervention can also provide insights into its sustainability.

What should be evaluated by whom on the basis of which criteria and with what purpose? This is the initial question to be answered at the beginning of every evaluation. Evaluations that focus primarily on the development function or on learning, are often carried out internally. Evaluations relating to knowledge and control are carried out externally and internally. If evaluations serve legitimation, they are usually commissioned externally in order to achieve a high degree of objectivity and credibility. With regard to the planning of inclusive communities, it must ultimately be decided on a case-by-case basis to what extent a planned evaluation should address these objectives.

In addition, and on the basis of this information, a decision must also be made as to when the evaluation should take place. Evaluations can relate to different phases of a planning and change process. In the CISCOS planning loop, evaluation is the last step at the end of the implementation of a plan. An evaluation carried out after the completion of such a process (ex-post evaluation) has the task of recording and evaluating the effects of the planning and change process, identifying cause-and-effect relationships and examining the sustainability of the process.

Evaluations can refer to the phase of process development including its conceptualization and planning (ex-ante, input or pre-formative evaluations). Their task is to examine the material, personnel, institutional, financial and theoretical framework conditions of a planning and change process and thus provide important information for the design of a planning and change process. Evaluations often take both functions into account when the evaluation of impacts achieved provides an analysis of the current situation and steps to be taken

in the next planning episode. Recommendations from the evaluation represent important guidelines for the subsequent planning process.

It is also possible to carry out evaluations during the implementation phase of a planning and change process in order to support the control of such processes (on-going or formative evaluations, often also referred to as accompanying research). This can be useful in addition to accompanying monitoring, especially for longer and more complex processes. While monitoring focuses more on routine issues and serves to monitor the implementation status, evaluation enables a deeper analysis of the effects of a planning and change process and focuses more on cause-and-effect relationships. Evaluations also look at the overall concept of a planning and change process and check plausibility and quality. Formative evaluations pursue similar goals to implementation research. Since the development of an action plan for an inclusive community should cover various planning levels (general municipal development planning, sector planning, planning on specific subjects) and all areas of life, it could make sense to support the planning and change process with accompanying research.

Overall, there are numerous evaluation approaches and a whole series of guidelines for organizing evaluations. A good overview can be found in the literature below, which is the source of this brief overview.

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1.4 Examples and Exercises

Example 1. Physical and socio-economic factors

Physical factors. Impairment (physical, visual, hearing, intellectual, mental), size, weight, etc.

Socio-economic factors. Socio-economic status, inclusion in society, educational level, etc.

Example 2. Environmental factors

Accessibility. Topography of a city or town, accessibility of buildings, accessibility of information, etc.

Legal framework. Existence of protection from discrimination, policies that refer to disability rights.

Socio-economic conditions. Rural or urban environment, economic conditions of the region, community awareness of disability.

Social environment. Cultural norms and attitudes ranging from solidarity and tolerance to rejection of persons with disabilities in day-to-day life.

Services. Inclusive or segregated services (health, education, housing), community-based rehabilitation, etc.

Example 3. The intermediate and local level in Germany

The German Intermediate Level (NUTS 3): 294 counties (Kreise) and 107 independent cities (Kreisfreie Städte). The county assembly (Kreistag), which is the legislative body, is composed of members elected by direct universal suffrage. The county president (Landrat) is elected either by the county assembly or by direct universal suffrage. The county office (Landratsamt/Kreisverwaltung) is the county's executive body and is composed of civil servants recruited by the county or region. The counties' competencies comprise the following areas: construction and maintenance of intermediary roads, social services and youth, collecting and managing household refuse, health care, food safety, protection of nature and environment, foreign affairs, disaster management and public transport.

The German Local Level (LAU): 11 500 municipalities (Gemeinden) and cities (Städte)

The local council[86] and the mayor (Bürgermeister) are elected by direct universal suffrage. The local council is the municipality's central body. It forms the legislative organ and makes most of the decisions. The local council holds a monitoring and controlling function vis-à-vis the mayor and local administration. The municipalities' and cities' competencies comprise the following areas: urban planning, municipal taxation, public security and order, muni-

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86   The council system exists in all German regions except for the region of Hessia which is based on a magistrate system (Magistratsverfassung).

cipal roads, public transport, water supply and wastewater management, flood control and management, firefighting, social aid and youth, child care, housing, school building and maintenance and cemeteries.

Source: http://www.ccre.org/docs/Local_and_Regional_Government_in_Europe.EN.pdf

Example 4

A service provider runs a residential home for 30 persons with intellectual disabilities. The home was established 15 years ago. Staff and residents are familiar with the day-to-day routines of the home, the funding is stable but criticism of its segregating effects is increasing. The management must make a decision whether to dismantle the residential institution and replace it by community services or continue as it is.

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Curriculum Element 2:

Community Development and Subsequent Implications for Service Providers

Curriculum Element 2: Community Development and Subsequent Implications for Service Providers

The second element, (CE2) in the CISCOS training course, is focused on community development, and subsequent implications for service providers and persons with disabilities. Its aim is to provide a reference point and guide for key stakeholders that seeks to support community work for the promotion of social inclusion, social justice and equality and as an intervention for social change. These stakeholders include communities, community workers, program implementers, employers, policymakers, funders, organizations, groups and community work educators.

In the following chapters, you will learn about community and community development, primarily from the perspective promoted by the European Network for Community Development (EuCDN). You will also learn about how the public sector, service providers and other stakeholders at the local level can interact to ensure equal rights for persons with disabilities.

The implementation of the UN CRPD at the local level poses a demanding challenge. Although there is a request for the development of inclusive services in the European Union, two main barriers prevent it from happening. Firstly, the ongoing changes in the socio-economic environment and secondly the lack of knowledge and tools of both service providers and local authorities. These two barriers contribute to increasing uncertainty about the process of developing inclusive communities. For service providers and local authorities, it is not a matter of whether inclusive services will benefit the community or not, it is a matter of whether stakeholders can endure the transitional costs from one model to another.

2.1 Introduction

The first element of the CISCOS training course (CE 1) develops the human rights approach and a set of tools for inclusive social planning. It focuses on the identification and selection of key stakeholders for inclusive projects, and training using tools to put the planning process in motion. If all the steps of the planning circle are successful, a culture of collaborative local governance is established in the community. Key stakeholders are working together for social change, awareness has been raised among the general public and local authorities compromise to develop accessible infrastructure. Now is the time to focus on the concrete resources of the community.

The focus of the second element is community development. This stage develops the concepts related to community development from a rights-based understanding and the tools to assess community structures, living conditions of people with disabilities and skills of service providers. It will develop the characteristics of the new roles that service providers must adopt in a community development approach.

Chapter CE2 reviews the approaches to and practice of community development and explores the intersection between disability and community development. When you finish this curriculum element, you will have the knowledge and tools necessary to take on the task of developing inclusive services for people with disabilities from a generalist point of view.

2.1.1 What is Community Development?

Community development is a key approach of social work when it comes to supporting disadvantaged groups, especially in urban environments. It has a long tradition that goes back to the 'settlement movement' in Britain and in the United States at the end of the 19th century. In this period, committed persons from middle-class backgrounds were seeking ways to fight mass poverty and miserable living conditions in deprived quarters of big cities like London and Chicago. People including Jane Addams and Samuel Barnett saw the causes of problems people had, not related to their individual characteristics, but poor li-

ving conditions, and lack of access to education or health care[87]. Community development for them, meant organizing the individuals in a neighbourhood, and supporting them to become heard by politicians.

This political and explicitly radical approach was continued by social work activists like Saul Alinsky in the late 1960s. Alinsky developed an action-based theory on mobilisation of political power among marginalised groups in disadvantaged urban areas, to work for their rights as citizens and for equal living conditions in their communities[88]. Since the early 1920s, these approaches and practical experiences were well received in the international discourses of social work.

Considering this tradition of community development, the CISCOS training course also takes orientation from the results of the European Community Development Network (EuCDN)[89], that published a Framework for Community Development in 2014[90]. This framework outlines the purpose, value and processes, methods, and outcomes of community development. It also provides many examples of community development projects in different parts of Europe, but rarely projects that involve persons with disabilities. That is something that the CISCOS materials try to rectify in this manual.

Community

In order to understand community development, it makes sense to start by defining what a community is. As with the concept of community development, there are many conflicting definitions of the word community. One simple definition that covers many more specific definitions, is that of the European Community Development Network (EuCDN), stating that "community is taken to mean people who share a common neighbourhood as well as those with a common identity or interest"[91].

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87   Addams 1910.

88   Alinsky 2011.

89   EuCDN is a European NGO with eleven member organisations that
      published a Framework for Community Development in 2014..

This framework was developed within an EU project, building on the Budapest Declaration regarding community development.

90   EuCDN 2014.

91   Ibid., 15.

Different Kinds of Communities

The term community needs to be unpacked further. The literature demonstrates that place or space (e.g. urban neighborhoods) are an integral part of the conceptualization of community. However, some authors question this connection of place with community. For them, a neighbourhood, small town, or village is automatically assumed to be a community, regardless of whether it is cohesive or not. This assumption conceals another understanding that goes beyond its connection with place, i. e. organic solidarity or a solidarity-based upon shared interests or circumstances.

A place-based understanding of community fails to take the radical social change brought about by modernity into account. Modernity divests place of this significance, as most social activities can no longer remain confined in the place but must be oriented to unknown people in unknown places[92].

Bhattacharyya concludes that "understanding community as solidarity (shared identity and norms) serves to define the concept in a distinctive and intrinsic manner, making it possible to distinguish a community from all other types of social relations. We can say that any social configuration that possesses shared identity and norms is a community"[93].

Taking these arguments into account, communities can be categorized as follows:

1. Location-based communities range from the local neighbourhood, suburb, village, town or city, region, nation or even the planet as a whole. These are also called communities of place.

2. Identity-based communities range from the local clique, sub-culture, ethnic group, religious, multicultural or pluralistic civilization, or the global community cultures of today.

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92   Berger, Berger, and Kellner 1973; Giddens 1984.

93   Bhattacharyya 2004.

They may be understood as communities of need or identity, such as disabled persons, or frail aged people.

3. Organizationally based communities range from communities organized informally around family or network-based guilds and associations to more formal incorporated associations, political decision making structures, economic enterprises, or professional associations at a small, national or international scale.

This way of reasoning underlines that it makes sense to work with a broad understanding of community, and to be open to many aspects of sharing in different forms of communities, even virtual ones. However, a place-based concept of community that is aware of the conditions of the physical environment of persons remains the most relevant perspective[94]. This becomes evident when aspects of community development for persons with disabilities are discussed, as it is the case within the CISCOS training course.

In the CISCOS context, a **community** is a socio-ecological structure, (small or large unit) that has something in common. Its members share a place that is situated in a given geographical area (e.g. a country, village, town, or neighbourhood) and they share by their physical existence basic interests such as healthy ecological conditions and sometimes norms, religion, values, or identity.

Exclusion, Inclusion and Belonging

Communities, by definition, exclude and include, so notions of community and community development are fundamental to **disability activism and policy**, involving ideas about **citizenship and rights**. Dorn and Metzel[95] show the process of **deinstitutionalization** for a **community integration** of people through the establishment of **social links to a territory**, creating a feeling of **belonging**.

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94   DeFilippis and Saegert 2012.

95   Dorn and Metzel 2004.

2.1.2 The Concept of Community Development

Community development has been defined by EuCDN as "a developmental activity comprised of both a task and a process. The **task** is social change to achieve equality, social justice and human rights, and the **process** is the application of principles of participation, empowerment and collective decision-making in a structured and coordinated way"[96].

This definition has been adopted by the member organizations of EuCDN and has become a part of the All Ireland Standards.

The Budapest Declaration "Building European civil society through community Development"[97] describes community development as "a way of strengthening civil society by prioritizing the actions of communities, and their perspectives in the development of social, economic, and environmental policy. It seeks the empowerment of local communities and strengthens the capacity of people as active citizens through their organizations and the capacity of institutions and agencies to work in dialogue with citizens to share and determine change in their communities"[98].

Although persons with disabilities and their organizations are not excluded from the definitions and goals of community development, there is unfortunately little evidence that they are regularly included in this work[99]. In the context of the CISCOS training course, it is therefore important to highlight this fact and provide examples of how people with disabilities can be included in the community development processes.

Values and Processes of Community Development

In the UK, the Community Development National Occupational Standards state that community development is a long-term, value-based process which aims to address imbalan-

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96   EuCDN 2014.

97   In March 2004 there was an international conference in Budapest in preparation for ten accession states for membership in the European Union. The conference was sponsored by the International Association for Community Development, the Combined European Bureau for Social Development and the Hungarian Association for Community Development under the patronage of the President of Hungary. The 130 delegates from 33 countries across the European Union stand behind the Budapest Declaration.

98   Craig, Gorman, and Vercseg 2004.

99   McFadden and Downie 2018.

ces in power and bring about change founded on social justice, equality and inclusion. The process enables people to organize and work together to:

- Identify their own needs and aspirations;
- Take action to exert influence on the decisions which affect their lives;
- Improve the quality of their own lives, the communities in which they live and societies of which they are a part of[100].

Core values for community development are concerned with greater social justice. This means working for a society where human rights are promoted and all forms of oppression, discrimination and exclusion are addressed. It is noted that while lots of very useful processes have individual outcomes, such as personal development and individual gain, the focus of community development interventions are **collective outcomes** that change the collective lives of the community or group as a whole.

"Collective analysis for collective action towards collective outcomes is a fundamental feature of how community development happens"[101].

Community development is a participative and dynamic process. According to the EuCDN framework it is built around the following **core values and processes**:

- Collective learning;
- Empowerment;
- Meaningful participation;
- Collective action for collective outcomes;
- Equality.

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100 LLUK n.d.

101 EuCDN 2014, 12.

When it comes to values, community development seeks to address poverty and inequality by working with people to challenge and change the attitudes of individuals as well as the practices and policies of institutions and structures that discriminate against people.

An important concept in relation to community development is **agency**, the capacity of people to order their world, create, reproduce, change, live according to their own meaning systems and have the power to define themselves as opposed to being defined by others[102]. Among others, solidarity and agency can be said to be the goals of community development.

The purpose of community development can also be to help create the conditions for a just, inclusive and sustainable society by supporting communities to engage in collective action for transformative change. In this regard, the CISCOS approach is in line with that of McFadden and Downie, who define community development as "the inclusion of under-represented groups, especially people with disabilities, in participatory governance—to empower these individuals in their self-determination and capacity to participate as equal partners in the decision-making process."[103]

2.1.3 Human Rights and Community Development

There are several arguments for why **a human rights framework** is needed for community development[104]. A community group, for example, may exclude people because they have a disability and they do not feel that they have the skills to be inclusive, or groups from different ethnic or religious backgrounds. In these cases, community development becomes a process for the denial of human rights.

Ife[105] argues that a human rights framework has to influence the practice of community development, and in effect, puts checks on how a community operates, so that the rights

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102 De Certeau 1986, vol. 17.

103 McFadden and Downie 2018.

104 Ife 2009.

105 Ibid.

of all people are considered and not just those of one particular community. The UN CRPD therefore, provides the context for community development work, and should inform community groups and organizations in their decision-making processes, taking actions, and ensuring that they are outward-looking.

Another question to consider is **context**. Interactions between local communities concerned with the 'principles of autonomy, change from below and self-direction' and local and national government structures located in the wider society with responsibilities for the wider society should be taken into account. Will the actions of one local community impact wider society? For example, if one community is successful in securing funding for local initiatives, does that mean that another community loses out on resources? Ife[106] poses the question "to what extent should a community's local needs be allowed to impact the wider society without some form of control or monitoring, and how much should higher-level authorities be able to intervene in community processes or decisions?"

This is linked with the issue of decentralization, and the relative power and autonomy of central government versus local government. While policy directions about the UN CRPD may be set at a national level, what happens at the local government level and local community level when it comes to implementation? What role do community organizations have in this context?

In considering what community development can bring to human rights, the notion of **participation** is identified as very important. Human rights must be actioned and this is where the notion of participation comes in. Ife argues that there is a sense that the human rights world has been dominated by high-level professionals, such as lawyers, law courts and the United Nations system and is distanced from the lived experiences of people with

106 Ibid.

disabilities. However, the UN CRPD might be understood differently as the drafting committee included people with disabilities' in its membership, and therefore more closely reflects the lived experiences of people with disabilities. Therefore, community development brings a grounded perspective, focused on the powerless, marginalized, and disadvantaged groups in communities. It is about supporting active citizenship in communities where the rights and obligations of citizens are recognized.

In thinking about the practice of human rights work, Ife[107] distinguishes between deductive practice and inductive practice. **Deductive practice** focuses on the definition of rights as articulated in Conventions and treaties and tries to find ways of turning these rights into reality for people. It is concerned with states' obligations and sees the practice as being concerned with implementing rights. **Inductive practice** has more in common with a community development approach. It focuses on the issue or problem that is emerging in the community, (e. g. where someone is discriminated against) and it supports members of the community to identify rights for themselves, and of ways of attaining them.

From a community development perspective, it is important that community members themselves can play a part in defining what human rights mean for them. In that way, they will have a greater sense of ownership of these rights. Community members should be able to look at the UN CRPD and apply the rights therein to their own political, social, cultural contexts. However, it is important to note, that in emphasizing the local community and identification of rights, we should not ignore the collective rights and responsibilities of all. Therefore, the notion of universal in the human rights framework is relevant here too.

According to Ife, community development must **be grounded in human rights** and ethics as it has the potential to violate rights. Community development can help to address the

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107 Ibid., 212.

class barriers that human rights highlight and assist people in identifying their needs and the needs of their community, to match them to existing rights. In his book Human Rights from Below[108], Ife stresses the importance of a bottom-up process, where local knowledge, wisdom, skills and understanding are valued. This contrasts the top-down perspective, where people higher up in the hierarchy are presumed to have more wisdom and expertise.

For Ife one of the important aspects of community development is engaging the entire community. All people engaged in community development from below are working for human rights. This applies whether or not people are paid or unpaid, activists or volunteers, citizens or engaged professionals.

Crickley[109], in her introductory remarks on the European Community Development Framework (EuCDN), discusses the intersection between human rights work and community development. She argues that the practice of community development needs to engage in the language and spaces of human rights (e.g. collective mobilization around single issues) including engagement with UN Treaty Bodies. She also points to a focus on **recognition and redistribution**. For Crickley, recognition mainly has to do with gender discrimination and racism. For our purposes, **recognition** refers to work that focuses on discrimination based on disability. According to Crickley, the focus on discrimination is a starting point and not an add-on to community development work.

Community Development and the UN CRPD

While the UN CRPD[110] does not directly address community development, it does provide guidance on many related issues. These include poverty, social inclusion, personal empowerment, anti-discrimination, political participation and active citizenship. The five main articles in these areas are Articles 5, 12, 19, 28, and 29.

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108   Ife 2009.

109   Crickley 2014.

110   United Nations 2006.

Article 5 addresses equality and non-discrimination. It includes a requirement for reasonable accommodation to achieve equality, and notes that programmes to promote equality are not a form of discrimination. This could include community development programmes.

Article 12 is about equal recognition before the law. It includes the idea of legal capacity, that a person's decisions should be respected and recognized before the law, and that all people should be presumed to have the capacity to make decisions. This is important in enabling the individual to take part in community development programmes.

Article 19 is partly focused on the importance of social inclusion and mentions the importance of community services in achieving this (see more below).

Article 28 focuses on the need for an adequate standard of living with a note that living standards should be subject to continuous improvement. This is an important goal of many community development programmes.

Article 29 addresses participation in political and public life. This includes the right to vote, the right to be elected, the right to effectively take part in public life and the right to join and form political organizations. Of all of the articles outlined here, Article 29 may be the most relevant when it comes to people with disabilities and community development.

According to Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), „States Parties to the Convention recognize the right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate the full enjoyment of this right [...] and **their full inclusion and participation in the community**, including by ensuring that:

- Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others. Furthermore, they are not obliged to live according to a particular system of life.

- Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support life and inclusion in the community, thus avoiding isolation or segregation from the community.

- Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs."

Following Article 19 of the UN CRPD, the idea of community development will be outlined in the next section. Human rights-based community development has a series of benefits:

- It strengthens the capacities and autonomy of individuals and communities;

- It promotes respect for rights and the accountability of local structures;

- It underpins diversity mainstreaming;

- It improves the quality and effectiveness of the process;

- It provides a basis for sustainable responses and durable solutions.

The UN Committee on Rights of Persons with Disabilities regularly writes **General Comments**[111] to articles in the UN CRPD. General Comment No. 5 is particularly relevant for community development since it is about living independently and being included in the community, and is meant to help with the implementation of Article 19.

Equality of Outcomes and Opportunities

Persons with disabilities encounter different forms of discrimination that prevent full inclusion including attitudinal, environmental and institutional discrimination[112]. In accordance with the social model of disability, the entities that put up those barriers are both society itself, and non-disabled members of society. But just as ethnic minorities, women and older people have the right to equal access to opportunity and services, so do people with disa-

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111 OHCHR n.d.

112 Harris and Enfield 2003.

bilities. One way to try to achieve this is disability equality training, where disabled persons are encouraged to claim their full and equal rights as citizens.

Human rights-based community development implies analyzing the different realities existing within the community. This of course relates to the **diversity of disabilities**, but also to **ethnicity, religion**, and **sexual orientation**, among other factors. **Age** is a key aspect of diversity analysis as children and elderly people with disabilities have completely different needs. Failure to consider each community's particular circumstances may lead to actions that, unintentionally, result in further exclusion and discrimination.

Self-Determination

To be self-determined is to believe oneself to be capable and effective[113]. If professionals in rehabilitation want to empower people with disabilities, the route to achieve this, according to Wehmeyer, is through providing opportunities and supports that promote and enhance their self-determination. **Self-determination** refers to the right and the capacity of individuals to exert control over and direct their lives. The concept is related to political rights and self-governance. For people with disabilities, to become self-determined and exert control in one's life can be achieved through the development of **goal setting**, **problem-solving**, **decision-making** and **self-advocacy** skills.

Self-determination can be **measured**, something that Lachapelle and his colleagues[114] did in a study involving people with intellectual disabilities, in which they compared self-determination with quality of life within the same group. The components of self-determination that they measured included **behavioral autonomy**, **psychological empowerment**, **self-regulation** and **self-realization**.

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113 Wehmeyer 2004.

114 Lachapelle et al. 2005.

- To have autonomy means to be independent and base one's actions on personal beliefs, values, interests and abilities.

- Self-regulation involves interpersonal cognitive problem-solving and the ability to set goals and perform tasks to achieve them.

- When one feels empowered, one has positive perceptions of control.

- Self-realization involves self-awareness and self-knowledge.

Empowerment and Participation

The theory of community development proposed by Bhattacharyya[115] is consistent with the focus on **empowerment** and **participation** within the developmental disabilities field[116]. To support people with developmental disabilities to make decisions based on their own experiences and perspectives is an important shift in power from the common model where other people make all decisions for them. This focus on autonomy is related to what is called 'felt needs' in community development theory.

Wituk et al.[23] involved individuals with developmental disabilities and their families in a series of focus group or listening meetings to inform and enhance the development of disability service provision in Kansas. In that study, participants were invited to participate in the process and experience being listened to and have real influence on the process.

The current understanding of the word **empowerment** is linked to having control over one's life. But the word also means that **someone is granting authority to someone else**, suggesting that the person who is empowered is not the one with the most power. Within the disability rights movement, the word also means **to enable** in the sense that it gives people enhanced possibilities to control their lives[117].

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115 Bhattacharyya 2004.

116 Wituk et al. 2007.

117 Wehmeyer 2004.

From a community development perspective, power is the capacity to make informed choices and have the freedom to take action (that is, to make participation effective). Empowerment implies that individuals from a community take an active role (it is not something that is someone else does to or for them). It is the process by which they **analyze their situation, enhance their knowledge and resources, strengthen their capacity to claim their rights and take action to achieve their goals**. For empowerment to work, it requires changes both at the **individual and structural levels**. As members of the community empower, their capacities and skills are recognized by other sectors of the community.

Participation

Participation is a key element in community development. For participation to be meaningful it requires all members of the community to take an **active role** in the processes of decision-making that affects their lives with **full and equal involvement**. Participation:

- Is an essential right;
- Promotes protection and reduces feelings of powerlessness
- Enables being able to draw on the insight, knowledge, capacities, skills and resources of people with disabilities;
- Helps people with disabilities identify their own priorities and preferred outcomes;
- Empowers people with disabilities allowing them to rebuild self-confidence and self-esteem.

Advocacy and Self-Advocacy

Advocacy is the representation of the views, feelings and interests of one person or group of people by another individual or organization. Garner and Sandow[118] state that advocacy

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118 Garner and Sandow 2018, vol. 25.

lies in the recognition that a person's own skills may not include the ability to speak for him or herself, for intellectual, social, emotional developmental or physical reasons. The recognition of an individual's rights to a hearing despite any or all of these difficulties' places advocacy within the context of human rights as outlined in the UN CRPD.

- Self-advocacy has been seen as fashionable, not only amongst organizations of people with learning difficulties, but also with service providers and non-disabled individuals who have worked in traditional services[119]. The concerns are that self-advocacy has become a process of consulting with users about what they want from services which are usually designed and delivered by non-disabled people. This has given people with a disability the opportunity to have their voices heard in a way that they are now, for the first time. given a choice how they live their own adult lives.

- Despite the fact that accessible environments and access to assistive technology is crucial for people with disabilities to participate in society, and is at the core of UN CRPD, access is not always provided even in developed countries like Australia[120]. This also means that UN CRPD can be used as a tool in the advocacy work in these areas.

- In the US, Centers for Independent Living (CILs) serve as important advocates for change and involvement in community development for people with disabilities. In their work, they empower people with disabilities to become engaged in the organization at all levels. CILs works across different disabilities, and sees people with disabilities as consumers, rather than recipients of care. They are engaged in peer support, self-help and the promotion of community and policy change[121].

In Ireland, Disability Federation of Ireland (DFI) considers advocacy and self-advocacy as key for an individual to be independent. DFI saw an opportunity to host training to build

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119 Aspis 1997.

120 Watchorn and Layton 2011.

121 O'Day 2006.

the capacity of people with disabilities to enable them to advocate on their own behalf to achieve their goals, and secure their entitlements in their own lives. This was achieved by considering:

- Practical self-advocacy;
- Self-esteem and assertiveness;
- Communication styles;
- Rights and responsibilities;
- Inequality and information;
- Support and putting theory into practice.

The first section of this chapter conceptualizes the term 'community development' and links it to a human rights framework. Referring to the UN CRPD helps to ensure the perspective of persons with disabilities is taken into account in a given community development process. Having made these fundamental clarifications, the following sections of this chapter deal with the practice of community development.

2.2 Practice of Community Development

Community development can be practiced in many ways, and there are different views regarding how to define it. There are some parallels between community development and community organization, which is a speciality of social work. It is important to distinguish between the two.

Disability service providers are involved in different forms of social work and this often includes working with groups of people. However, social work often targets individual outcomes, for instance, so that individuals may become better at coping and making choices that affect their lives. Community development is aiming for collective outcomes, such as collective contributions to community or policy change[8].

2.2.1 Methods for Community Development

The framework proposed by EuCDN[122] states that the following methods are included in community development across Europe.

Bringing people together around their shared experiences and interests.

This could be done through community meetings, social events, festivals, and many other kinds of meetings.

Identifying and exploring the factors underpinning marginalization or exclusion.

This may be achieved through group work, conflict resolution, story-dialogue or other means.

Building and owning evidence and a future vision.

Here, community-led research, including community profiling and needs analyses might be conducted as well as focus groups and community meetings held.

Developing confidence, skills and understanding.

Community education, learning and support are key elements here, as are encouragement and evaluation.

Mobilizing, organizing, networking and strengthening visibility.

This could be done through strategic planning, forming and supporting community groups, alliance building and different kinds of communication.

Taking action.

This includes campaigning, lobbying, fundraising and engaging with public entities and political processes.

122 EuCDN 2014, 18.

2.2.2 Outcomes of Community Development

In community development, the desired outcomes involve changes that occur at various levels. The levels proposed by EuCDN include the community level, the policy level (also called the structural level), and a broader level that has to do with ideology and culture. The framework proposed by EuCDN[123] gives examples of outcomes at different levels.

Outcomes at the Community Level

At the community level, the EuCDN framework states the following outcomes of community development processes:

- Better quality of life. The increased quality of life for people in the community might be the result of new community services, better access to employment or improved access to services, places or activities.

- Increased community leadership. This could be the result of more people becoming involved in community activity. It could also be related to people becoming more confident and critically conscious. Stronger skills, greater knowledge, better organization, and more activity and participation in decision-making arenas might also result in this outcome.

- Strengthened community capacity. Strong communities are active and resilient. They are able to negotiate and engage with power. They may also challenge and contest or create action plans that lead to development in the community.

- Changes in overall community experience. When communities come together to solve common problems and set up goals, this leads to a strengthened sense of belonging and ownership amongst the people in the community.

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123 Ibid., 19–23.

Outcomes at the Policy, Structural and Governance Level

At policy, structural and governance level, the EuCDN framework states the following outcomes of community development processes:

- Strengthened alliances within the community. Collective common interests are reflected in **strengthened alliances**, such as community networks and partnerships.

- Awareness for community issues. The **decision-makers** have **community issues** on their agenda.

- Participation in decision-making processes. Communities **influence decision making** through their assertive participation. This may be true at many levels; both local, national and European. Communities are supported so they can **design their own solutions, and also control them**.

- Attention for marginalized communities. **Policy, practices and legislation** is changed in ways that benefit **marginalized** communities.

Outcomes in Common Mind-Sets, Ideology and Thinking

Outcomes at this level reflect policy and legislation. The EuCDN framework states the following outcomes of community development processes in this context:

- Awareness for marginalized and minority groups. Marginalized and minority groups are well known by decision-makers and public institution staff. This **well-informed understanding** of these groups is reflected in their approach to them.

- Transparency and efficiency of decision-making processes. The way decisions are made is **transparent**. The needs of communities, including those of minorities and the marginalized, are **responded to effectively** by the services and structures. There is a **genuine sharing of power** with marginalized and minority groups when it comes to decision-making in the participatory spaces.

2.2.3 Real and Lasting Change

In order for community development to result in real and lasting change in lived experiences, certain requirements must be met, according to EuCDN:

- Communities need to be at the **heart of the process** of planning and action for change;

- The analysis and action needs to be centred around the **experiences**, **concerns** and interests of the communities;

- Social injustice and inequality must be addressed;

- The approach needs to be **participative**, with a **shared vision** of what the community wants to achieve;

- The forces and interests that could help or hinder need to be **analyzed**;

- In order to reach the outcome in the most effective way, a **strategy** needs to be employed. In this strategy, various ways to reach the outcome need to be considered.

- There needs to be **clarity** and **accountability**, and a willingness to work towards **continuous improvement**, through learning, action and reflection.

2.2.4 Involving Persons with Disabilities in Community Development

Something missing in the EuCDN framework, is guidelines on how to include persons with disabilities in the community development processes. This is very important, since persons with disabilities are often overlooked or only given token representation in development efforts. To facilitate the involvement of people with disabilities, organizers are advised to[124]:

- Use different ways to invite people to participate (e. g. mail, phone calls, emails);

- Use clear and simple language in written information;

- Use meeting venues that are wheelchair accessible and have comfortable sound and lighting features;

- Always use a microphone in meetings, and if possible, also a hearing loop;

124 This advice is a combination of general accessibility standards and examples from McFadden and Downie 2018.

- Provide both oral and visual information, use subtitles for videos and describe all visual information so that it is accessible for persons with visual impairments;

- Offer alternative formats to those who need them (sign language, braille etc.);

- Make the seating arrangements to signals equal partnership and facilitate communication;

- Be generous with pauses and think about adding individual consultation time to the agenda;

- Cultivate an atmosphere of respect and trust, that lets all participants know that their opinions matter.

Certain groups, such as persons with intellectual disabilities, might also require support outside the community development process in order to be able to participate fully. Of particular value is the development and strengthening of soft skills[125]. These include social skills, language and communication capabilities, the ability to work in a team, and also self-management skills like being on time and able to accomplish tasks in a timely manner.

2.2.5 Good Practices for Mixed Groups

When working with a mixed learning group, it may be valuable to clarify roles and responsibilities in a systematic way. The Hungarian Hand in Hand Foundation proposes the following structure.

Basic situation (needs/demands to be satisfied that the intervention is addressed):

- From the perspective of the (local) community;

- From the perspective of the professional.

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125 Cimatti 2016.

Objective (goals of the intervention):

- From the perspective of the (local) community;
- From the perspective of the professional.

Target group:

- Actors (participants) in the intervention;
- Initiator;
- Implementer (host organization);
- Partners involved (professional local partners, professional non-local partners, non-professional local partners, non-professional non-local partners).

Describe the activities performed during the planning/implementation/evaluation phases:

- Activities and methods (particularly the methods of involvement and empowerment);
- Roles and tasks (professionals and locals as well as target group);
- Resources needed (competences, time requirement, material and financial resources).

Achievements (measurable and non-measurable results of the intervention):

- At the personal level (among the members of the target group, with special regard to results in the area of the empowerment);
- At the level of the (local) community;
- At the level of the implementing organizations and partner organizations.

Before embarking on any kind of community work that is inclusive for persons with disabilities, it is important to build up an accurate picture of how a community operates, what internal strengths, resources and problems it has, how the community sees itself and what

external forces are affecting people in that area or with its identity[126]. In this context, it is necessary to map and assess a given community's structures, living conditions and needs.

2.3 Mapping and Assessment of Community Structures, Living Conditions and Needs

A community worker is based in their community either in a local authority, a local government agency, a voluntary disability organization, or a community and voluntary organization. The worker needs to know and understand the community they are working in to be able to effectively work in that community.

2.3.1 Community Profiles

The term 'community profile' is typically used "to refer to a range of projects undertaken or initiated by different organizations including communities themselves, statutory agencies and voluntary organizations"[127]. It is broader than a needs assessment, community consultation, or a social audit, covering both **needs** and **resources** and the whole range of issues that may be affecting communities. A community profile should have active community involvement, as well as be aligned with key community development principles.

Hawtin and Percy-Smith (2007) define a community profile as follows:

> *"A comprehensive description of the needs of a population that is defined, or defines itself, as a community, and the resources that exist within that community, carried out with the active involvement of the community itself, for the purpose of developing an action plan or other means of improving the quality of life of the community"[128].*

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126   Harris and Federation for Community Development Learning 2009.

127   Hawtin and Percy-Smith 2007.

128   Ibid., 10.

A community profile should be **comprehensive in coverage**. There are a number of issues that can affect an individual's life (e.g. housing, health, isolation) and these issues interact with each other such that "the whole is greater than the sum of the constituent parts". Hawtin and Percy-Smith (2007) point out that:

> *"The totality of individuals' and communities' lives do not conform to departmental, agency, service or policy boundaries"[129].*

The authors note that while service providers might be aware of the relationships between housing and health, practice has been slow to take on board this reality. This is why policies that are designed to tackle housing, health issues, or disability issues, are still often implemented in isolation from each other. They therefore propose that community profiles should be comprehensive in what they cover. In this way, they can help challenge:

> *"bureaucratic departmentalism as well as more accurately reflect the reality of people's lives"[130].*

2.3.2 Aspects of a Community Profile

Christakopoulou et al. suggest that a comprehensive community profile ought to address the following aspects of people's lives[131]:

- **The area as a place to live** including the quality of the physical environment and people's attitudes to living there, the extent to which needs are matched with resources and the extent to which local facilities meet people's goals and aspirations;
- **The area as a social community** including residents' involvement in the social life of the community, the extent to which the community is supportive and formal and informal networks;

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129 Hawtin and Percy-Smith 2007.

130 Ibid.

131 Christakopoulou, Dawson, and Gari 2001.

- **The area as an economic community** including income levels and employment prospects of local residents, prosperity and viability of local shops;

- **The area as a political community** including systems and structures of political representation and local area management, the extent to which local people can influence decisions that affect them, the degree of involvement in local decision making and participation in community organizations;

- **The area as a personal space** including the degree of attachment that people have to the local area and the memories and life experiences of local people;

- **The area as part of its city** including infrastructural, economic and social linkages between the local area and the city or district of which it is a part and the specific local identity that differentiates the community from the rest of the area or district.

In addition to this, the following aspects are important:

- An understanding of some of the issues within the community;

- A view of what services and resources (and lack of) are available in the community;

- Knowledge of what active community groups there are.

2.3.3 Types of Resources

Types of resources are the assets held in the area and put to use for the benefit of the community. Many of these can be referred to as social capital. They could include:

- Housing stock, parks, hospitals, clinics, community centres, places of worship and schools;

- People's time and expertise that is made available to others;

- Employment opportunities within an area;

- Potential resources such as derelict buildings or vacant land;

- Informal skills of members of the community and networks of informal support such as families, households and neighbors;

- Formal supports such as self-help and community organizations;

- Qualities and characteristics that exist within the community such as resilience, determination, trust, community-mindedness and the extent of volunteering or active citizenship.

Money can often be seen as the only resource and means of addressing unmet needs. Hawtin and Percy-Smith argue that this might not always be the most effective approach and that there may be different ways of using existing resources or delivering existing services[132].

Needs

Data on needs should inform decision-making on resource allocation.

Active Community Involvement

Active community involvement is important in terms of following a community development approach. It is important that at every stage members of the community are involved in gathering and organizing information and are fully consulted about priorities and strategies for an action plan.

Action Plan

To ensure an output from the community profiling exercise, an action plan can be produced. It should include issues that have arisen, priorities, strategies, setting of goals and targets.

2.3.4 Reasons for Undertaking a Community Profile

A voluntary disability organization may undertake a community profile to demonstrate the existence of unmet needs or inadequate resources, or as a part of a community campaign. Community profiles are undertaken as part of a broader community development approach, and support communities' capacity, skills and confidence to take action for themselves.

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132   Hawtin and Percy-Smith 2007.

A local authority might use a community profile as a way of gathering accurate information for policy planning, implementation, monitoring and evaluation.

In addition to demonstrating the existence of unmet needs and other issues in the community, a community profile may suggest ways to solve community issues. It can do this by helping to highlight overlooked resources, or showing previously unseen possible connections between resources or people. Other reasons for doing a community profile are presented below[133].

Research carried out by a community group can help to:

- Assess the particular needs and wants of a group of people or a local community;
- Find out if people's needs are being met;
- Identify trends in services;
- Map existing local services and organizations and find out what others are doing;
- Monitor and evaluate a service or project.

It can also help to:

- Provide information for fundraising, lobbying or campaigning;
- Deliver services and activities in a way that is best for people;
- Prioritize and make best use of limited resources;
- Create a good relationship with those who use services;
- Encourage people to be involved in their group or organization;
- Promote groups and organizations as open and accountable to users.

133 Ibid., 13.

2.3.5 An approach to Conducting a Community Profile

The following steps can serve as an orientation when conducting a community profile.

Step 1. Identify the purpose and objectives of profile

There will be a number of objectives to be identified, that will be addressed by carrying out the community profile. The list should not be too long, otherwise the project may become too large and difficult to manage. Once the objectives are agreed, you need to think about the types of questions that will provide the information to meet the specific objectives. These research questions will then dictate the methods to use.

Step 2. Consider Values and Ethics

In any research exercise, it is important to consider the following:

- Respect for the community being profiled and the involvement of members of the community in the process;
- Members of the community should gain something from their participation, for example, increased confidence at the individual and community level and increased skills;
- Ensuring that members of the community are listened to and that their views are taken on board and influence the design of the exercise;
- Ensuring the confidentiality of members during the information-gathering phase.

Step 3. Identify Appropriate Methods

The diversity in communities has implications on the choice of methods to use. We under-stand community to mean "people who share a common neighbourhood as well as those with a common identity or interest"[134]. People with disabilities may share some common interests, but disagree on other issues, for example, those relating to gender, race, poverty.

So it is useful to be conscious of "communities within communities"[38]. This may also be true of communities based on place.

Step 4: Develop an Information Checklist

To successfully carry out a community profile it is important to know what information needs to be collected. Gilchrist and Green propose the following checklist[135].

Information based in your own agency or project

- Start from where you are, your workplace.
- Can you get any information from discussion with other workers (e.g. their impressions, factual details and experiences)?
- Do an analysis of what services or resources your agency or project currently offers to the community?
- Talk and listen to existing users of your agency or projects services. Gather their views on the community.

Getting your own view of the community

- The aim is to get a feel or impression of the community.
- Get out and walk around the community you are working in.
- Visit the local shops or shopping centre, pubs, launderettes, libraries, parks etc..
- Buy a map of the local area.
- Talk and listen to local people.
- Conduct more structured interviews with key people and officials.
- Look at the local papers, listen to the local radio station if there is one.

This method may give you a biased or fragmented view of the community depending on

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135   Harris and Federation for Community Development Learning 2009.

who you have talked to and where you have visited. However, it does give you an image of a community that you can build on.

Factual data and information about the community

This method can give you concrete information on the community that can be obtained from local libraries, council offices and locally-based government departments.

Politics

- What political party controls the local council?
- Who are the local councillors or political representatives?
- What political parties and organizations are active in the community?

Housing

- What types of housing are there and where are they located (e.g. council housing, estates, owner-occupied, housing cooperatives and housing associations, privately rented, empty properties, multi-occupied properties)?

Employment and unemployment

- What type of industries, businesses and companies exist and where are they located?
- How many people do they employ?
- What is the local unemployment rate? How is this broken down (e.g. male or female, disability, age, race)?
- What trade union branches are there?

Public transport

- How is the community served by transport (e.g. rail options, buses, community transport, taxis and minicabs)?
- What is the frequency of service?
- How accessible are these transport options?

Leisure and recreational facilities

- What facilities exist locally (e.g. leisure centres, sports and social clubs, church halls, community buildings)?

Land use

- How is land used in the community (e.g. shopping areas, residential, industrial, housing, railways, wasteland)?

Population

- What is the population of the community and how is it made up and distributed (e.g. class, age, disability, gender, ethnic groups, religion, culture)?

Council departments and other agencies

- What are they, where are they located and what services do they provide (e.g. housing, social services, education including schools, youth clubs, adult education, colleges, local health services, police and local government departments with responsibility for communities)?

Voluntary sector agencies and community groups

- What voluntary sector agencies, projects, and community groups are there?
- Where are they located?
- What is their role in the community? Who do they work with?
- How active are they?
- What services and resources do they offer?
- What informal networks exist?

History of the community

- Read up on the history of the community (e.g. how it has developed and its social history).
- Read official reports and community newsletters.

- Conduct statistical analyses of census data for the community.

- Visit other organizations that are involved in the community and read through their files or annual reports.

Methods for collecting factual data

- Analysis of census data and other secondary data reports to find out about the composition of the community, demographics and employment situation.

- Conducting a survey and focus group discussions to find out what local services people are currently using.

- Carry out walking observations to find out about what services are currently available.

- Check with local authorities, the local government directory of services and lists of services to find out who provides services.

- Conduct one to one interviews and focus group discussions with service managers to find out who uses local services and who is excluded from them.

- Carry out a survey and focus group discussions to compare information from the analysis of demographics with an audit of services to find out about gaps in services.

2.3.6 Example of a Community Profile in Baltinglass, Wicklow, Ireland

In 2005, a community profile for the town of Baltinglass was put together. This profile captured its demographics, various features, and residents' feelings about the town. At the time of the profile, Baltinglass was at the beginning of a period of change. It was turning from a small town of less than 2000 to a commuter town of the nearby city of Dublin. One aspect that the community profile captured was residents' feelings about this change.

Information obtained in the community profile of Baltinglass can be split into two categories. The first is the objective information about the town. This includes demographics, businesses, historical buildings, and a brief history. The second contains information about how residents feel about the town, what issues residents identified, and their feelings about the changes that were taking place.

Information about residents' feelings about issues the town faced was collected from the Baltinglass Women's Group, The Parent and Toddler Group, the Park Committee, and other individuals. These groups were able to identify a number of issues. The community profile examined three of these in greater detail: the lack of access to public transport, the lack of a community centre or recreation facilities for youth, and the lack of public parks and play areas. In addition to these issues, the community profile also identified conflicts in the town. These included conflicts between new arrivals and long term residents, conflicts between the travelling community and settled residents, and a lack of communication between different groups in town. With this community profile, a much clearer picture of the town, it's goals, and the obstacles it was facing emerged.

In community development processes for implementing the UN CRPD, disability service providers play an important role. It is therefore necessary to reflect their roles and responsibilities.

2.4 Roles and Responsibilities of Disability Service Providers in Community Development Processes

There are differences between European countries on how the public service is organized. In some countries, it is the public sector that both orders and performs the services, in other countries, it is mainly private companies and/or actors in the nonprofit sector that deliver the services.

Regardless of who carries out the services, all service providers should know how to fulfil the responsibilities to follow the UN CRPD. This goes for services that are designed exclusively for persons with disabilities and for services aimed at all citizens. The range of different services offered by the public sector to its citizens is wide and relates to different perspectives and situations of life (e.g health care, personal assistance, employment, education and housing). These services should be designed for all and be able to be used by any citizen regardless of functional capabilities, age, health conditions or other personal characteristics.

2.4.1 Service Providers and the UN CRPD

According to Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), „States Parties to the Convention recognize the right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate the full enjoyment of this right [...] and their full inclusion and participation in the community, including by ensuring that it is so:

- Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others. Furthermore, they are not obliged to live according to a particular system of life.

- Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support life and inclusion in the community, thus avoiding isolation or segregation from the community.

- Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs."

It is a shared responsibility of the public sector and any service provider to make sure that persons with disabilities have the same possibilities as any other citizen to make individual choices, participate in society and have access to services on an equal basis.

2.4.2 The Paradigm Shift

The UN CRPD marks a paradigm shift in the understanding of disability. Disability is no longer seen as inherent to the person. Instead, disability is related to environmental factors and the disadvantages that occur when a person interacts in the environment[136].

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136 See Element 1 of the CISCOS manual.

Rights-based approach

Only states ratify international human rights treaties, but in practice, human rights obligations mean shared responsibilities between all authorities. The rights of citizens correspond to competences, which are increasingly delegated from the state to local and regional authorities that carry them out under the principle of self-governance[137].

One of the fourteen steps that the Committee on the Rights of Persons with Disabilities commented on in 2017 is that the State Parties should "enact and enforce laws, standards and other measures with the purpose of making local communities and the environment, as well as information and communication, accessible to all persons with disabilities"[138].

What does the UN CRPD mean for a given community?

There are many policy areas at the local level that directly concern human rights including housing, health care, education, social care and urban planning. People with disabilities might face discrimination in these areas. For example, in practice, the right to housing would mean providing access to homes for all members of the community[139].

What impact does a service have on persons with disabilities?

The process of disability impact assessment can be used to disability proof a service. This means to examine the impacts of the proposed service. The analysis should consider all potential impacts, both positive and negative. A disability impact assessment is the process of identifying, analyzing and assessing the impacts of existing or proposed services in relation to their consequences for the equality of persons with a disability[140].

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137   Council of Europe 2016, 19.

138   Committee on the Rights of Persons with Disabilities 2017.

139   Council of Europe 2016, 20.

140   Irish Department of Justice and Equality 2012.

Public procurement

The States Parties should design tendering processes for providing support services for persons with disabilities living independently in the community that take into account the normative content of UN CRPD Article 19[141].

- What happens if the local level does not comply with the convention?
- What is the legal science on the implementation on social conventions on the local level?
- Are there any theories on the responsibility for private social service providers in the procurement process?

Rights-based approach vs needs-based approach

A rights-based approach is a conceptual framework that integrates the norms, standards and principles of the international human rights system into the policies, programmes and processes of development and humanitarian actors. It therefore focuses on both procedures and outcomes and is founded on the principles of participation and empowering individuals and communities to promote change that enables them to exercise their rights and comply with their duties. It identifies rights-holders (women, girls, boys and men of concern) and duty-bearers (principally the state and its agents) and seeks to strengthen their capacities to make their claims and of duty-bearers to satisfy those claims. This requires an attitudinal shift in how to work with and for persons of concern. They are no longer viewed as beneficiaries of aid, but as rights-holders with legal entitlements.

141   Committee on the Rights of Persons with Disabilities 2017.

Needs-based approach	Rights-based approach
Deserving	Claim and entitlement
No one has definite obligations	Clear obligations
Receiving (beneficiaries)	Active participation (partners)
Some are left out	Equal rights for all
Charitable and voluntary	Mandatory with legal obligations and accountability
Addresses symptoms	Addresses causes

Table 1. Needs-based vs. rights-based approach

Thus, a community-based approach is integral to a rights-based approach as they are founded on common principles and goals. A dual approach requires that policies, programmes and activities are based on international legal standards and that members and leaders of the community consider their roles as both rights-holders and duty-bearers. It is important to analyze, with all actors, the obstacles to exercising these responsibilities and ways to overcome them.

Meaning for service providers

In 2017, the Committee on the Rights of Persons with Disabilities commented that implementation of Article 19 on independent living and inclusion in the community at the national level requires that States Parties should "ensure the participation of persons with disabilities, personally and through their representative organizations, in transforming support services and communities and in the design and implementation of deinstitutionalization strategies"[142]. Personnel must be trained in independent living within the community[143] and take part in awareness-raising activities. They should also take extra care to include women and children with disabilities in their services[144]. Providers could ask:

- How do we understand differences?
- What mechanisms are needed to prevent unequal treatment?

142 Ibid.

143 Ibid.

144 Ibid.

2.4.3 Roles in Practical Community Development

Community development may be the sole focus for some organizations. Other organizations may be involved in service provision and have community worker type roles that involve communities in this work. Other organizations may include community work as an element of their main work.

These variations in focus and approach can lead to different interpretations of the role of a community worker and therefore different expectations of the work that a person will engage in. Community workers are employed at all levels as project workers and managers, initiating, leading, facilitating and developing new and innovative ways of working with, and advocating on behalf of, marginalized communities.

In the disability sector, we see more and more examples of community worker roles being undertaken. Examples include community connectors, community transition workers, link workers and family support workers. They may not be described as community development workers, or community workers, but they use aspects of community development approaches in their practice. They work with people with disabilities to support their access to mainstream or generic community services and supports, as well as supporting their access to and experience of specialist disability services.

It is useful here to provide some descriptions of these types of roles in disability organizations, as well as in local government organizations. The following are examples of roles in disability organizations that have elements of community development principles and approaches.

Community Development Worker

- Works with key stakeholders to support the disability interest at the local level and to ensure the inclusion of people with disabilities in local decision making and in the development and delivery of services.

- Develops good working relationships with people with disabilities, disability organizations, health service executives, local government, statutory services providing employment and education supports, local development companies, community and voluntary organizations and other key agencies at the local level.

- Works with other social inclusion and community and voluntary groups to identify local needs in terms of disability and access issues.

- Builds the capacity of people with disabilities to represent, both in terms of self-advocacy and group advocacy.

- Sources supports, and/or training to support people's capacity.

- Builds contacts and relationships with local disability organizations, community and voluntary organizations and a range of statutory agencies to ensure that the interests of people with disabilities are included in the planning and delivery of local services and supports.

Community Connectors

Increasingly, community connectors are employed in disability organizations to provide services and supports for people with intellectual disabilities, brain injuries and other disabilities. Key aspects of this role include:

- Connecting or re-connecting people with disabilities to activities previously enjoyed;

- Supporting people to take part in social, leisure, recreational and vocational activities in their own community;

- Securing places for people with disabilities in existing community initiatives (e.g. art clubs, social clubs, dance, choir, walking clubs, shopping, community garden, community allotment, golf clubs);

- Focusing on the strengths of individuals and matching these to different interests and activities in mainstream community life;

- Developing and maintaining links with key community organizations over time and enabling them to become more knowledgeable and confident in supporting people with disabilities.

Family Support Workers

Family support workers are employed both in disability service providers, as well as in local statutory organizations providing services for people with and without disabilities. The following are elements of this role that incorporate community development principles and approaches:

- Liaising with health care professionals, teachers, social welfare or social security offices when required, to help members access services;
- Organizing support meetings to enable members to come together and share their experiences;
- Supporting a person who wants to change their career following the onset of disability;
- Accessing services in their communities in general.

Community Resource Workers

Epilepsy Ireland has ten community resource workers working across the country in different health administrative regions, i.e. Health Service Executive (HSE) regions. They link people who have epilepsy with different public services and community organizations and supports (e.g. housing).

2.4.4 Elements of Community Development in Local Governments

In Ireland, there is an organization called Pobal that supports community development approaches with marginalized groups including people with disabilities.

Pobal is a statutory body that works on behalf of the government to support communities and local agencies towards achieving social inclusion and development. It takes a community development approach and in particular supports this through measures such as the Social Inclusion and Community Activation Programme (SICAP).

The SICAP 2018 – 2022[145] provides funding to tackle poverty and social exclusion through local engagement and partnerships between disadvantaged individuals, community organizations and public sector agencies. SICAP addresses high and persistent levels of deprivation through targeted and innovative, locally-led approaches. It supports disadvantaged communities and individuals including people living in deprived areas, people with disabilities, single-parent families, people on low incomes and other disadvantaged groups.

The programme is managed at the local level by 33 Local Community Development Committees (LCDCs), with support from local authorities. Actions are delivered by Programme Implementers (PIs).

Examples of SICAP that support people with disabilities

Social farming

- Social farming offers people who are socially, physically, mentally or intellectually disadvantaged the opportunity to spend time on a family farm in a healthy, supportive and inclusive environment.
- Social farming activities take place in a safe and supportive environment taking into account an individual's abilities, desires and interests. Focus remains on encouraging participants to socialize, gain confidence and build relationships.
- While those participating in social farming activities may derive therapeutic benefits from such activities, this is not the main purpose or aim and the farmers are not playing the role of therapists. Social farming supports people in living ordinary lives, interacting with their community and environment and developing their potential.

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145 Administered by Pobal and funded by the Irish Government through the Department of Rural and Community Development, SICAP also receives funding from the European Social Fund under the Programme for Employability, Inclusion and Learning (PEIL) 2014-2020.

Practical self-advocacy courses

- Courses provide training opportunities in the area of self-advocacy as a practical step towards identifying people at risk, creating networks of support and giving disabled people the confidence to become more active participants in their own communities.

- The objective of the course is to develop participants' skills in the area of advocacy, to enable them to become more effective communicators and help them to identify when to advocate for themselves.

- The course highlights where learners can go for support if they feel their own self-advocacy efforts are not achieving the desired outcomes.

- The aim is to build confidence and leadership skills and encourage learners to think for themselves and challenge their beliefs.

- Self-advocacy courses present opportunities for some learners to use the skills they acquire from the training to advocate on behalf of others in the future.

North Kerry Partnership[146] who manage SICAP:

- The Partnership supported a range of initiatives aimed at supporting people with disabilities. These included a Youth Café in Listowel, Co. Kerry, that aims to give people access to supports and spaces in the community. The Disability Sports Project enables both young people and adults to engage in suitable sports activities and offers staff supports that seek to remove barriers.

- The partnership also provided Outsmart Stress, a workshop for teachers, parents and students with Autism Spectrum Disorder (ASD) provided by Smart Psychology, a psychology and well-being service. The aim of the workshop was to identify anxiety and distress in students with ASD, develop prevention strategies, and support students who become distressed. These workshops were very beneficial for parents as anxiety levels were high and self-care was not deemed a priority.

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146 Partnership companies are local development companies in Ireland, that use bottom up approaches to address economic and social issue and community development as a process to build strong, sustainable communities. North Kerry Partnership is governed by a voluntary board.

Sports Inclusion Disability Officer

The sports inclusion disability officer (SIDO), through working in partnership with all stake-holders, works to increase the participation of people with a disability by introducing them to sport and active recreation. This aim is achieved by:

- Establishing new and sustainable clubs;
- Collaborating with local disability organizations on the assessment of needs and the provision of opportunities for people with disabilities;
- Promoting the participation of people with disabilities in sport and physical activity;
- Communicating with all relevant disability sports organizations to enhance participation at local, regional and national levels;
- Creating effective working partnerships with sports bodies to encourage greater opportunities for persons with disabilities to participate in physical activity.

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2.6 Examples and Exercises

Examples of disability activism on housing conforms to community development principles. Changes to the built environment through disability activism is a form of community development. Work programmes inclusive of persons with disabilities benefit the broader community while addressing employment barriers[147]. The following are examples of ap-

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147 Seekins 2006.

proaches applying community development principles and practices with people with disabilities.

Example 1. Community Coalitions and Community Connections

Guillory et al. discuss the implementation of an approach that applies community development principles and practices with people with disabilities[148].

Key concepts

The project's goal was to implement a community development process in four communities that would use community coalitions to enhance community connections for all stakeholders.

The following question was posed:

> *"What type of approach could successfully apply community development principles and practices with citizens with disabilities, while adequately attending to process and outcomes?"[149]*

The authors decided to develop a project that deals with traditional approaches to supporting people with disabilities such as projects targeted only at people with disabilities, or projects that mainly focus on including people with disabilities in mainstream or generic community services.

In contrast, this project was designed to **help communities identify and build their social capital to enable all relevant members of the community to become more engaged in civil society**, and thus **become more engaged in their communities and connected to other citizens**.

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148 Guillory, Everson, and Ivester 2006.

149 Ibid.

A key principle of the project was to acknowledge that all communities and the people in those communities have **both needs and capacities**. Every stakeholder in a community has the capacity to give to the community, as well as a need for services and supports.

When all stakeholders in the community work together to deal with people's needs for services and supports, it is of benefit to all members of the community.

The authors highlight the importance of providing good quality of life indicators and outcomes for all members of the community, including people with disabilities and their families.

Quality of Life Indicators and Outcomes

The following quality of life outcomes were identified to support all individuals living in the community:

- **Civic engagement.** Stakeholders feel part of their community and can expect an entitlement to services, as well as having responsibilities in terms of giving back to their communities.

- **Community connections.** The extent to which different community stakeholders interact with each other and appreciate each other's backgrounds, values, talents, expectations and needs.

- **Social capital.** The formal and informal network of organisations within a community, aiming to reach desired goals through coordination and cooperation.

The focus is on a community's strengths, the resources it has, and how to support self-determination and leadership amongst its members. It is also on community development's role in empowering communities to tackle their own needs for services. The emphasis is on **involving diverse stakeholders including those with disabilities**, thus promoting a more active participation and a give-and-take between the stakeholders and their communities. The authors identify coalition building as a tool for achieving the concepts discussed above.

Methods

Project staff worked with four communities in Louisiana and South Carolina in the US and supported them to use a case study approach to focus on the goals for each coalition. Three of the coalitions were already in place, and one new coalition was formed, where there were already established connections to professionals in the community. The needs in each community were for expanded housing options for citizens on low incomes (including people with disabilities), reliable transport opportunities for all people who do not drive and expanded leisure and recreation opportunities for young people.

Assistance provided to coalitions

The four coalitions were provided with systematic and intensive assistance over a 33-month period. Skilled facilitators worked with the coalitions to develop an **individual community development plan**. Examples of assistance provided included:

- Helping the communities to identify and recruit members with disabilities;
- Helping to develop and implement strategies for including people with disabilities in the work (e.g. supporting people in carrying out needs assessment and planning and implementation activities);
- Fostering the development of leadership roles within coalitions.

The authors understanding of community development was that there was an expectation that all stakeholders, including people with disabilities, can contribute and benefit from a community's investment in social capital.

Quality Indicators Framework

The project staff drew on community development practices and community coalitions literature, supporting the four coalitions to reflect on their present and future pers-

pectives in order to develop unique indicators for each coalition across the following 3 areas[150]:

1. Community experiences
2. Community behaviours
3. Community values

The indicators they identified were included in their individual community development plans. A case study approach was recognised as a useful approach to assist the coalitions to focus not only on the **process** they engaged in, but also on the **outcomes** that they achieved.

Stages of Coalition Building

Four stages of coalition building are identified:

- **Establishing the coalition** involving dedicating resources to becoming a coalition and gathering contributions from stakeholders;
- **Identifying the value and mission** statement of the coalition;
- **Affecting systems change** involving equipping members to track their work and develop interagency relationships;
- **Performing the functions** of the coalition and once the objective has been achieved disbanding.

Example of Case Study: St Jude Parish County, Louisiana

Need: dependable transportation opportunities for all citizens who do not drive.

Forming Stage

When the project began, the transportation system was limited, both in terms of affordability and accessibility. While several options were available for residents who do not drive,

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150   They used a five step process to assist the coalitions in this work as explained by Everson, Guillory, and Ivester 2005.

many stakeholders, including those with disabilities, felt that their transportation needs were not being adequately met. For some services, people were not sure if they were eligible to use them or not, some were poorly advertised and some were restricted to transport for medical or employment needs.

An existing 'Interagency High School to Adult Life Transition Team' had been operating for 15 years before the project began. It included members from the local school, several adult services agencies and support groups including family and service user groups that mainly represented stakeholders with disabilities.

Support from the project staff enabled the Interagency Team to prioritise the setting up of a transportation subcommittee. The membership of this twelve-member subcommittee was expanded to include public agencies, community organisations, local government representatives, public and private transportation providers, individuals with disabilities and advocacy organisations. Thus, its membership was more directly representative of transportation users.

Within the first three months, two meetings were held and a process for planning and structuring meetings was agreed. Work focused on drafting goals and exploring initiatives and opportunities for funding to support the proposed activities.

Storming Stage

St. Jude conducted a **needs assessment** that included dedicating three to five meetings to learning about transportation options. The needs assessment process proved to be a meaningful way for stakeholders with disabilities to contribute by providing first-hand feedback on both the pros and cons of existing transportation services.

The result of the assessment was **a matrix** with summaries of the existing options.

Stakeholders with disabilities played a key role in influencing the mission statement of the coalition.

Goals were prioritised and members of two subcommittees included people with disabilities. Funding was sought to support activities.

St. Jude's coalition met monthly during this stage. Written agendas and action plans were developed and disseminated. The coalition adopted ground rules to structure meeting behaviours.

Several events seriously affected the coalition's progress, which the authors note is not unexpected during the storming stage. Local elections as well as changes in staff meant that changes were required in coalition leadership and member roles. However, no coalition member emerged as a leader to whom project staff could transition responsibilities. Members became frustrated and discouraged. Neither the coalition nor the subcommittees met for a seven month- period and all activities were put on hold.

The **persistent self-advocacy** of coalition members who had a disability and continued to communicate about the transport issue among themselves ultimately led to the reconvening of the coalition. Due to the efforts of these stakeholders, the other coalition members agreed to commit, once again, to the coalition's goals and activities.

Norming Stage

Funding to support the targeted activities of the coalition was eventually secured. Stakeholders with disabilities played a key role in the design of a resource guide used in an outreach campaign to promote increased usage of existing transportation services. Stakeholders with disabilities contributed to the development of the questionnaire that was the basis for the needs assessment carried out in the parish to identify gaps in transport options.

One of the goals related to the expansion of at least one existing transportation service for St. Jude Parish residents. The actual result was that existing transportation services were expanded in four areas, two relating to the population-at-large and two specific to individuals with disabilities.

Performing Stage

Of the four coalitions that participated in this project, the St. Jude Parish Transportation Coalition was the only one that was well on its way to actually attaining the performing stage, the highest level of team functioning.

Lessons Learned

How were people with disabilities centrally involved in the project?

The main focus of this project was the participation and contribution of people with disabilities. Participating coalitions were encouraged and supported to explore and **define roles for stakeholders with disabilities** in:

- Developing needs assessments that articulated the needs of all stakeholders;
- Defining roles that stakeholders could play in collecting and interpreting needs assessment data;
- Defining leadership roles in the coalitions for people with disabilities as well as strategies for developing leadership skills and behaviours.

Three lessons were outlined:

- Each coalition-building stage offered coalitions and stakeholders distinct opportunities and challenges and some stages worked better than others in terms of being inclusive of people with disabilities and supporting their participation;
- The opportunities for people with disabilities to participate in and contribute to community development activities could take many forms and vary considerably;
- Creative strategies and enhanced supports may be needed, across the stages, and the activities.

Example 2: Community Centred Strategies for Supporting People with Disabilities: The Littleton Model Community Project, New Hampshire, US

Key Concepts

Nisbet and colleagues[151] point out that even though there are more and more community-based services and supports available that are inclusive of people with disabilities, a formal services structure that does not incorporate community decision-making structures is still in operation. They argue that this partly explains why people with disabilities are still relatively excluded from ordinary life and the opportunities that are available to other citizens relating to community life, integrated employment and political engagement.

The authors consider that research and practice in community development, public health, social capital, grass-roots organising, universal design and service user-directed supports can provide a useful basis for moving beyond the existing services and supports infrastructure.

In terms of social policy approaches the authors refer to Ryan (1972) who identified **two types of social policies**: "exceptionalistic and universalistic".

- **Exceptionalistic policies** are considered to be "exclusive, backwards-acting or curative, stigmatizing".
- **Universalistic policies** are instead described as "inclusive, forward-acting or preventative, and non-stigmatizing".

To demonstrate the difference between the two, Nisbet et al give the example of an exceptionalistic policy as one that provides a button outside a business that when pressed rings for a member of staff who will come to the front of the building and assist a wheelchair

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151 Nisbet et al. 2006.

user to open the door and negotiate the step up into the building if needed. A universalistic policy would involve providing a level entrance and an automatically opening door for all customers.

Another example they give is assigning a job coach to a workplace rather than putting in place a supervisory training programme to ensure that supervisors have the knowledge and skills to train and supervise employees with and without disabilities[152].

An example of a universalistic policy is visitability, that is how to design single-family housing that is both affordable, sustainable and accessible. This concept of visitability has also been explored by Maisel[153].

Move towards a community development approach to services and supports

Recognising that there has been progress in terms of de-congregation, smaller and more individualised housing and employment options and family support and respite care for people with disabilities, the authors[154] argue that exceptionalistic policies still underpin the development and organisation of services and supports.

They point to areas of innovation in response to demands for more inclusive practices at the community level including the employment of community connecters engaging citizens as advocates, and individualised budgeting as members of the disability community continue to advocate for more control over their resources and broader community support and participation.

Initiatives that support individualised budgets, self-determination and user-directed services acknowledge the ability of people with disabilities and their families to control resour-

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152 Ibid.

153 Maisel 2006.

154 Nisbet et al. 2006.

ces and secure for themselves supports such as personal assistance outside of the formal disability service system. However, it is worth pointing out that this has been achieved to varying degrees across countries.

The authors argue that the inability of the services infrastructure to adequately respond to disabled people's needs is part of the reason that innovative practices and approaches have been developed such as individualised budgets.

They consider that such practices are not part of a community development strategy but are responses focused on the individual, rather than collectively determined.

There is a distinction between micro-level interventions, such as individualised budgets, and macro-level responses. The latter are necessary for complex issues, such as transportation, and require several communities to come together to solve problems and allocate resources. Services for people with disabilities have operated in a separate world, in which service providers and service recipients are distinct groups. The recipients of the services usually don't have any control over them.

Project: The Littleton Model Community Project

In the town of Littleton, a community of about 5,800 people in New Hampshire, representatives from the disability, business, education, public service, and health communities attempted to address disability and ageing issues from a community planning perspective. Their vision was not just to create another program for people with disabilities, but instead create a new and different way to support them in the community. This included ways to break down both physical and attitudinal barriers and they sought a special form of flexibility to make the project work.

The project received a state grant and its **mission** was to "encourage persons who are ageing, and those with disabilities, to participate fully in community life by creating and

maintaining a municipal infrastructure free of physical, social, policy, and attitudinal barriers"[155].

A full-time project coordinator was employed who provided support to the development of the Littleton Model Community Advisory Council. This group included leaders from local businesses and local services, public government officials, and citizens with and without disabilities. Much of the work on research, employment and transportation was carried out through subcommittees.

Nine factors relating to the process were identified as critical to achieving the project goals.

1. **An empowerment evaluation methodology**

    Members of the Advisory Council helped to guide the direction and interpretation of project data. This meant that the project evaluation addressed the questions they had about how to build a better and inclusive community.

2. **Cross-disability representation**

    The involvement of people with disabilities in the group's work on an on-going basis was identified as very important.

3. **A focus on community**

4. **A focus on issues that crossed agency territorial boundaries**

    As the community project was not a service provision project, but rather focused on community organising and capacity building, the Advisory Council members could bring together representatives from the school, large disability service providers and the office of employment security to develop a plan to provide training and employment opportunities for all young people.

    The group therefore worked in a way that crossed traditional agency boundaries.

155 Ibid., 76.

5. **Support of town leadership**

   It was critical to have the local administration directly involved in the project. This provided credibility and acceptance of the project and a facilitative infrastructure.

   An example of the benefits of this approach arose when new accessibility standards for voting stations were introduced. Whereas in some towns there was a lot of criticism of the cost of these standards and difficulties in introducing them, in Littleton because of the existing working partnership with the town manager, solutions could be found quickly in stations that were non-compliant.

6. **Media coverage**

   The media coverage resulted in the community members feeling proud that they were recognised for their efforts. It also led to an awareness in the community of what the project was about and how important the community is for the elderly and people with disabilities.

7. **Celebration of small successes**

   It was discovered through the project that community building is not easy work. Therefore, it was important to recognise small successes, especially when the stakeholders' efforts may not always be apparent in the short-term.

8. **Identification and development of indigenous leaders**

   The council was able to identify leaders throughout the community, including families and persons with disabilities. Their leadership was further fostered through training as well as informal and formal mentoring activities with assistance from the University of New Hampshire's Institute on Disability.

9. **Flexibility to respond to opportunities**

   This involved the council being able to respond in a flexible way when new opportunities arose. This was done by drawing on existing relationships in new ways.

Project Achievements

In the first three years, the focus was on four key areas:

Needs assessment. Community leaders sought to gain a greater understanding of the needs of the community. This was done through a series of in-depth interviews exploring stakeholder perceptions of the elderly and people with disabilities, a survey of transportation use and availability and a door-to-door survey of accessibility among businesses in the area.

Community-based solutions. Increasing the emphasis on community-based solutions to address issues brought to the attention of the council. As an example, a parent of a child with a disability found it difficult to find recreation opportunities for her child. She joined the advisory council and worked with the social service providers, the school, the town manager's office and the recreation department to initiate new accessible recreational programs that supported the needs of all children in the community.

Accessibility. One example was the re-design of the community website to ensure universal access for the town's citizens. Another example was guidance and limited financial support provided for businesses to improve access. Those that improved physical access received free advertising on the town's website.

Time-based exchange system. This system is based on an exchange of services. For example, when a person volunteers to do an hour of work that gives them a credit that can be redeemed for an hour of service from another volunteer. This project had a Time-Dollars program which provided a member-based website that enabled residents to exchange their strengths and skills. Each person's time was recognised as having equal value, thus the resources of all participating residents could be shared and each person's contribution to the community was valued on an equal level. This program also helped promote social connectedness among members.

In conclusion, the effectiveness of formal services was actually improved by the role that communities had in tackling systemic barriers to inclusion. Critical to this process was the involvement of people with disabilities themselves.

Independent Living and Community Development

Centres for Independent Living (CILs) differ from more traditional disability service organisations in two important ways. Firstly, they encourage disabled people to take collective action to promote access to communities. Secondly, they are directed by disabled people, with the majority of staff and board of directors comprised of individuals who themselves are eligible for services.

In the US, the legislation underpinning CILs requires them to engage in individual and systems advocacy to promote community integration[27].

O'Day draws parallels between the concepts underpinning independent living, as well as the structure of CILs with Bhattacharyya's conceptualisation of community development. Independent living concepts include self-help, peer support, consumer direction, and collective action, corresponding to Bhattacharyya's conceptualisation of community development as the "promotion of solidarity and agency through self-help, felt-needs, and participation"[4]. Solidarity is understood as being based on shared interests and circumstances.

Therefore, CILs can provide important resources to community development agencies due to their disability expertise and the leadership roles that disabled people assume in CILs, providing a level of legitimacy that is not always found in disability service providers.

As agendas for advocacy come from people with disabilities at the local level, assurance is provided to community development staff that these issues are genuine and relevant. CILs provide a high level of expertise on disability issues and work with community planners on areas such as accessible housing units, parks and recreation facilities.

2.7 Further Reading

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Curriculum Element 3:

Adoption of Inclusive Models in Service Providing Organisations for Persons with Disabilities

Curriculum Element 3: Adoption of Inclusive Models in Service Providing Organisations for Persons with Disabilities

Chapter 6 is the third part of the CISCOS curriculum. The first part of the Curriculum (CE1) is dedicated to planning approaches on the implementation of the UN CRPD and subsequent implications for service providers. The issues presented were focused on local governance and planning towards disability-inclusive local development. The second part of the Curriculum (CE2) is devoted to community development and subsequent implications for service providers. Topics include the role of social communities and community development for implementing provisions made by the UN CRPD.

This third part (CE3) will complete the CISCOS approach by adding the perspective of social services. The main goal of this chapter is to discuss the implementation of inclusive models of service provision for persons with disabilities at the local level. Two elements of this task are particularly important. Firstly, the understanding of inclusive social services. Pro-inclusion social services must be characterised by equal accessibility to all population groups, including people with disabilities. Providing residents with disabilities with the same access to mainstream social services as other people can have a decisive impact on the success of inclusion activities.

3.1 Introduction

Among the factors increasing the importance of inclusive social services, special attention should be paid to deinstitutionalisation. Unfortunately, this process is often reduced to a change in the organisation of the support system and possibly the place of residence of the disabled person. Its most important dimensions are social and political. The former

aims to ensure that dependent persons have full social rights, the power of self-determination and are able to take decisions on matters concerning them. The political dimension concerns not only the full range of political rights, but namely the right of persons with disabilities to be recognised as persons before the law by society and the local community with the ensuing consequences for national and local policies.

While we agree with the concept of deinstitutionalisation, it should be stressed that the effectiveness of this process depends on ensuring broad access to inclusive social services and their high quality. Hence the need to communicate a growing market for such services to service providers.

The market itself requires regulation and supervision. Reserved markets provide opportunities to ensure stable and continuous funding, which becomes particularly important during economic crises. In the near future, savings in social spending are to be expected. Thus, providing opportunities for the stable development of the social services market is important not only for people with disabilities, but also for the local economy. Fiscal austerity may hamper inclusive activities and solutions should therefore be sought, in which expenditure on these services would be treated as an investment in human and social capital.

The manual consists of two parts. The first part discusses issues related to inclusion as an important objective of social services, their quality and financing. However, the presented financing models should be treated as proposals. The actual solutions depend not only on individual countries and the local situation, but also on economic factors. The latter may change very significantly in the near future. However, the task of local communities will still be to support dependent persons in their quest for independent living. This should be encouraged not only through the aforementioned deinstitutionalisation, but also through the development of personal assistance. This is not only an opportunity for the people with disabilities, but also for local labour markets.

The second part of the manual contains examples of good practices that reflect what we consider to be particularly important principles: individualisation, localisation, cooperation, accessibility and safety. The examples and good practices should serve as an invitation to the discussion and inspire us to search for our own solutions, adapted to specific local conditions.

Our aim is to show applied solutions in relation to different groups while indicating how basic, universal objectives of inclusive social services can be implemented. We are convinced that the second part of the manual will be helpful not only in staff training, but also in organising the services themselves.

We would like to thank everyone who contributed to the collection of practices and the creation of this manual. We wish you a pleasant read.

3.2 Social Services: Inclusion, Quality and Funding

As mentioned in the introduction, the main purpose of this manual is to discuss the implementation of inclusive models for providing services for persons with disabilities at the local level. This requires determining what inclusive social services are, clarifying the scope of services involved and an indication of how these services can be financed and what the consequences are of adopting individual financial and organisational solutions. The division of tasks and responsibilities between a person with disabilities and possibly their family, local government and central authorities is particularly important. It is much easier to agree on a general course of action than to design and implement specific solutions and determine the method of financing them. Considerations of how to finance services is the issue that begins and ends the discussion about the introduction of new services or changes in existing organizations. It is also worth taking a broader look at what the locally built support system for people with disabilities should lead to and how to build a local community ensuring the possibility of independent living for people with disabilities and their inclusion in social life. It is impossible to achieve these goals without paying attention

to issues related to accessibility and universal design. In addition, it seems interesting to discuss selected examples of public policies aimed at adapting the social services system to the needs of implementing the UN CRPD and those attempting to put into practice what results from UN CRPD. The first part of the publication is written in line with this logic. It ends with a short summary of reflections and transitions to the second part, in which we discuss in detail the case studies on the implementation of individual services in different EU countries.

3.2.1 The UN CRPD and Social Services

There is no definition of social services in the UN CRPD. However, we can find clear indications on how social services should be shaped to ensure that people with disabilities can enjoy the full rights guaranteed by the Convention.

Services should first and foremost enable persons with disabilities to live independently. This applies to every person with a disability, and the scale of adjustments and forms of support changes should be considered. Such services should respect the dignity and subjectivity of a person with a disability, who should be able to use all services available to the general public.

Thus, services available to the general public should be planned and implemented in cooperation with the organizations of people with disabilities. If there is such a need, persons with disabilities should also be able to use complementary specialist services enabling full social inclusion.

That is why one of the main tasks in adapting services to the requirements of the Convention is deinstitutionalization and allowing persons with disabilities to live and lead everyday life in the local community.

Further on in the chapter, the individual elements that can help inclusive social services to be more in line with the UN CRPD are considered and described.

3.2.2 A Twin-Track Approach Towards Inclusive Service Provision

The starting point for the discussion about inclusive social services for people with disabilities is understanding the concept of a twin-track approach. This is when all services available to the general public (mainstream services) are simultaneously available to people with disabilities (inclusive services). At the same time, there are a number of services dedicated exclusively to people with disabilities that meet their specific needs (disability-specific services). Services dedicated to persons with disabilities must not contribute to their segregation, they should facilitate social inclusion and independent living regardless of type and degree of disability. This is in line with the universal design approach from Article 2 of UN CRPD. Universal design means designing products, environments, programs and services to be usable by all people, to the greatest extent possible and without the need for adaptation or specialised design. **Universal design should not exclude assistive devices for particular groups of persons with disabilities where this is needed**. This approach is fundamental for the inclusion of people with disabilities in the life of the local community and assuring equality of rights. It is also one of the foundations of the UN CRPD.
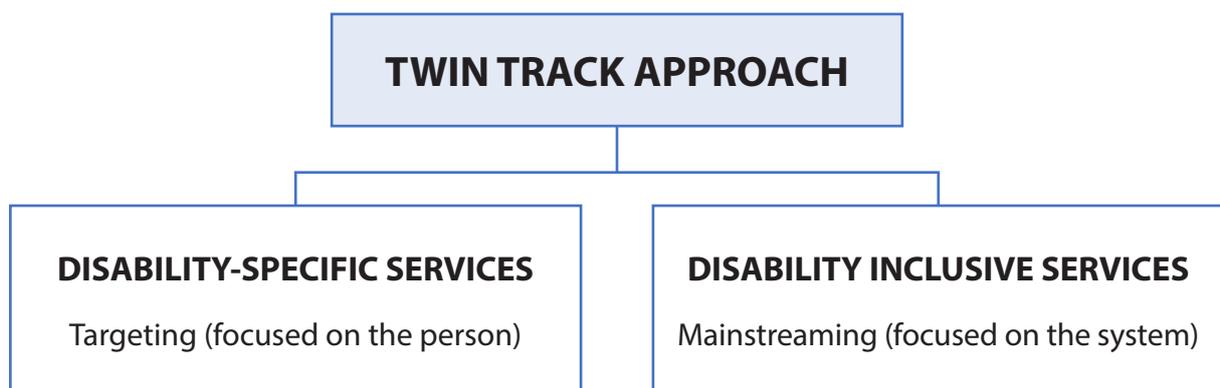

Figure 1. Twin-track approach

The twin-track approach to inclusion can only lead to successful outcomes for people with disabilities if the emphasis is put on both tracks as they complement each other. If the

focus is only placed on one of the two (disability-specific services or mainstream services) it cannot be called a twin-track approach and there is likely to be an imbalance[156]. Lack of a twin-track approach can lead to a situation in which persons with disabilities have access to services that respond to their specific needs (e.g. personal assistance) but it is not possible for them to actually use the services available to all residents of the community (e.g. health care services, public transport services and cultural and recreational activities). Consequently, full participation is impossible. A reverse situation is also possible, in which local authorities focus on the availability of services for everyone and neglect services specifically targeted at people with disabilities. The consequence of both situations is the exclusion of people with disabilities from the local communities and the inability to implement the right to independent living, which is crucial for UN CRPD implementation at the local level.

The twin-track approach does not mean implementing and sustaining already existing segregating services. There is a clear difference between a specialised service (e.g. personal assistance, job coach) and segregation (e.g. sheltered workplace, institutional living arrangements). The goal of specialised services is to enable fuller social inclusion and independent living also for people with severe disabilities. This distinction is illustrated by examples in the table below:

Special services	Segregation
• Job coach or supported employment • Teaching assistant • Supported housing • Personal assistance	• Sheltered workplaces for workers with disabilities • Special schools for all the children with disabilities • Institutional living arrangements

156 CBM n. d.

The application of the twin-track approach also has very practical and financial dimensions. Organizing and financing services for more clients is easier and cheaper. From the perspective of service providers, this means that each one, regardless of the type of service it provides, should take into account the perspectives of people with disabilities in service planning and implementation. However, there are also service providers that focus only on services specifically targeted at people with disabilities (e.g. professional activation services for people with disabilities and respite care services for careers of people with disabilities). The practical application of the twin-track approach is shown below (Example 1).

Example 1: Twin-track approach in public transport services

Public transport is a service available to all residents. The principles of universal design or at least reasonable accommodation were taken into account when planning and implementing the service locally. Buses, trams and trains are available for people with different disabilities and stops and timetables take the principles of universal design into account. Drivers are trained in supporting passengers with disabilities.

Specialised transport operates as a parallel solution to accessible public transport. It should be available at an affordable price and at the times of choice for people who, despite the availability of public transport, are unable to use it because of their disability.

3.2.3 Quality Social Services

Using the twin-track approach alone will not ensure that the service is inclusive. According to the guidelines proposed by EASPD, for a service to be considered inclusive a number of factors must be met. Their list is presented in Infobox 1.

Infobox 1: Quality Social Services[157]

What does planning and implementing quality social services mean?

- To facilitate full participation, inclusion and equal citizenship;
- To build the service around people with disabilities and their changing needs (tailor made and person centred);
- To be community-based and rooted in society;
- To be set-up in, and in close cooperation with, mainstream stakeholders;
- Transitioning from a holistic approach to a multi-faceted approach;
- To be provided by sufficient, well trained and managed staff;
- To allow the social network (family, etc.) to stay together;
- To be based on stakeholder cooperation;
- To ensure security to all users;
- To allow real and informed choices.

Not all of these criteria can be met only as a result of measures regulating the service market or the efforts of service providers themselves. Therefore, the best solution is to create this type of service in a local community focused on implementation of the UN CRPD (see CE1) and implement community development activities (see CE2). The adoption of inclusive models in service providing organizations for persons with disabilities is the culmination of the whole process (see CE3). It is possible to act in every local government to improve services and service providers themselves can be the initiator of the change process.

It is also worth mentioning that high-quality social services are an important tool for implementing EU policy, including the objectives of the European Pillar of Social Rights (EPSR).

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157 EASPD 2019b.

Infobox 2: Quality Social Services and EPSR[158]

Quality social services are fundamental to ensure the implementation of at least ten principles of the EPSR:

- Principle 1. Social services assist in achieving inclusive education, training and life-long learning by supporting all people to have access to such opportunities.
- Principle 2. Social services support gender equality by providing care and support to enable parents or family members, often women, to choose to work if they wish to.
- Principle 3. Social services support equal opportunities by helping all people access employment, social protection, education and goods and services.
- Principle 4. Social services assist in active support of employment by providing personalised, continuous and consistent assistance to help disadvantaged persons enter the labour market.
- Principle 9. Social services support work-life balance by providing care services to those who need it.
- Principle 11. Social services provide childcare services and support to children who need it, as well as additional support for disadvantaged children and families.
- Principle 17. Social services support the inclusion of people with disabilities by providing services that enable people with disabilities to participate in society and the labour market.
- Principle 18. Social services support the provision of long-term care by providing quality, community-based long-term care services to people who need them.
- Principle 19. Social services assist the provision of housing and help for the homeless by providing support services for homeless people.
- Principle 20. Social services help increase access to essential services by helping disadvantaged people access such services.

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158 Ibid.

In the CISCOS curriculum, we focus on five areas of service provision, distinguished by the life course of people with disabilities:

- Service provision for children (early childhood- and-pre-school);
- Education in school following a life-course approach;
- Vocational training and employment;
- Housing and residential support services;
- Support for elderly people with disabilities.

Of course, some of the services are provided in more than one area, so the division above is mostly organisational. We also assume that the services provided should be as universal as possible and not limited by the specific disability or financial capability of a person.

3.2.4 Inclusive Social Services Values

In the CISCOS curriculum, we state that inclusive social services are based on the following values.

| Values	Description
Person-centred	Building on personal needs and strengths as a basis for developing further skills.
Locality-based	Based on locality means recognising the relevant community resources in the target area and mobilising community resources as capital in service providing[159].
Collaborative	Collaboration requires a system change, a high level of trust, extensive dialogue and strong and interdependent relationships between the diverse partners[160].
Accessible	High quality and accessible, available, adaptable and affordable for all.
Safeguarding	The safeguarding procedure helps to clarify how to support people with disabilities to live free from abuse, harm and neglect.
Addresses symptoms	Addresses causes

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159 Natural, cultural, human, social, built, political, financial; Emery, Fey, and Flora 2006.

160 Australian Research Alliance for Children and Youth 2013.

These values describe high-quality social services focused on inclusion and human rights. The European Association of Service Providers for Persons with Disabilities (EASPD) indicates that persons with disabilities have a right to support services that are **adequate, accessible, adaptable, affordable and tailored to the individual needs and wishes of users**[161].

However, practice repeatedly differs from these assumptions and one of the elements that significantly affects reality is the mechanisms for financing services. It is not about systemic negation of the UN CRPD goals or financing services contrary to the Convention (although such situations have arisen) but more about the fact that the method of financing social services significantly affects their quality. Similarly, the costs and conditions for the adaptation of service providers to changes (e.g. in the field of deinstitutionalization) affect the availability of new solutions and the engagement of stakeholders in achieving more inclusive communities. The next section will further discuss the impact of financing models on social services for people with disabilities.

161 EASPD 2015.
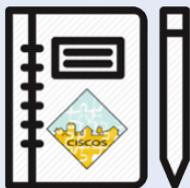
To discuss:

- Why is it important to have both mainstream and specialist services?

- What is the difference between special services and segregation? Is this distinction always easy? What are the challenges?

- Why is making mainstream services inclusive and accessible not enough for the inclusion of persons with disabilities in local communities? Can you think of any examples in your region or community where services are accessible but people with disabilities are still not included in the community? Why?

- What do you think of the inclusive social services values? Do you think they are easy to implement? What are the challenges?

- In your opinion, what does a person-centred service mean? Can you give any examples of services that are and are not in line with this value?

Facilitation tips:

- **Case study.** Using the example of a specific person with a disability (e.g. a young man with autism requiring intensive support, an elderly deaf-blind woman, an elderly man with Alzheimer's, a young women with mild intellectual disability) analyze what support this person could count on in the current system in your community. Think about what using a twin-track approach for these people means practically.

- Choose one service from those existing in your local community and analyze whether this service is compatible with **inclusive social services values**. If it is not, think about what changes are necessary.

- Choose one area (e.g. education, housing) and discuss whether services in this **area** can be considered inclusive and of high quality. If so, what decides this? If not, why? What changes are necessary?

3.3 Funding Models

In the most general terms, ways of supporting people with disabilities can be divided into cash benefits in the form of financial transfers and social services. In practice, we usually deal with some form of mixed financial and service benefits. In the CISCOS curriculum, we are only interested in services or financial resources, for example, in the form of a personal budget, with the direct purpose to finance services.

The second criterion for the distribution of support is the universality or selectivity of entitlements to a specific benefit. Selectivity can be associated with both the previous actions of the entitled person (e.g. payment of contributions, being in a specific situation like poverty or having a properly documented form of disability like a severe disability certificate in Poland).

More and more often we can speak of "restricted universalism"[162], where the right to benefit does not guarantee that it will be received adequately or within a short time. This is associated with another issue of who the main party responsible for the organization and financing of a given form of support is: a person with a disability, his or her family, local government or national authorities.

As mentioned above, this responsibility may apply to both financing and organizing all of the support (e.g. as part of the activities of the state that organizes and finances public infrastructure) and separating organisational and financial issues. In practice, it is a complicated network of links between individual institutional actors.

According to the classification proposed by the EASPD, four main models for financing social services for people with disabilities can be identified[163]:

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162 Ranci and Pavolini 2015.

163 EASPD 2019a.

1) **Reserved markets**, meaning a system where authorities can reserve access to specific public markets for organisations responding to certain characteristics (e.g. not-for-profit entities). This is a common model for the funding of not-for-profit social services and is organised differently across Europe.

2) **Public Procurement** is the way public authorities purchase goods, works and services, including the provision of social care and support services. This model has grown in influence in the last decade as public authorities have looked at ways to better manage more limited budgets, as well as due to the influence of EU legislation in this field.

3) **Personal budgets**, meaning an amount of funding that is allocated to an individual by a state body so that the individual can make their own arrangements to meet specified support needs. This innovative model is growing in popularity as it allows persons with support needs to have more control over how they wish to receive their support.

4) **Private investment** is the investment made by players other than conventional public sector bodies in social services. Although not used to fund day-to-day service provision, private investment (especially loans) is playing an increasingly larger role in financing social infrastructure investments, as well as to exploring new ways to finance innovative social projects.

The same report also indicates the strengths and weaknesses of each solution in the context of providing services to people with disabilities and achieving the objectives of the UN CRPD. Below, we present the pros and cons of each model.

Reserved markets

- Reserved markets can be a positive model for enabling social care and supporting providers to implement the UN CRPD. If well developed through a partnership approach, including with representatives of end-beneficiaries, the model guarantees funding continuity and reliability for providers to develop more person-centred services and ensure they have well-trained staff.

- Reserved markets are, however, perhaps not the ideal model if the policy objective is to ensure that persons with support needs have choice and control over the services they wish to receive, an element at the very heart of the paradigm shift that the UN CRPD requires of social service provision. This being said, co-production is a very powerful instrument to enable services to be in line with the UN CRPD and should be encouraged and applied in all funding models, including reserved markets.

- Many contracts in the reserved market model are often limited in transparency, as it is often up to the public authority to decide who gets the contract. The calculation of the costs of each service is also generally confidential to the public authority and the service provider. If poorly managed and organized, there is a risk of misuse of public funding or corruption. Other challenges include a lack of licensing mechanisms in some countries (especially in central and eastern Europe), the predominance of short-term contracts and the fact that some reserved market contracts include funding costs that are below the collective agreements between the sector's employers and trade unions. As is the case in public procurement, the terminology and mind-set used is often problematic. This is particularly the case for the use of market-oriented terminology which aims to reduce social services to any other product or service, despite the very specific nature of social service provision.

Public procurement

- If used appropriately, public procurement is an effective instrument to boost employment for persons with disabilities. Contracting authorities should be strongly encouraged to use social considerations that oblige applicants to either directly or indirectly employ persons with disabilities and other persons with support needs who are excluded from the labor market.

- Public procurement through competitive bidding is not a suitable, effective, or efficient instrument to fund the transition to community-based care services that are in line with the principles of the UN CRPD. Public authorities should consider other options, such as personal budgets and reserved markets, to fund such services.

Personal budgets

- The personal budgets concept, by giving more control to persons with support needs, is the future for the funding of social services across Europe, at least in the field of social care and support for persons with disabilities.

- The success of personal budgets relies on strong commitments, including financial, to the development of monitoring and enforcement mechanisms to ensure quality and a willingness for all stakeholders to engage creatively with one another and respect the roles and responsibilities within the new system.

- However, personal budgets are not a holy grail and it will require time and effort to find the right balance and build the right mechanisms. The development of support, advisory and capacity-building systems for persons with disabilities, social service providers and public authorities are crucial. It is also important to take into account the diversity of social services systems in Europe.

Private investment

- There is increasing and unmet demand for private investment in social services, due in part to the impact of austerity and the increase in demand for services. This is particularly the case for loans for community-based social infrastructure projects in line with the UN CRPD.

- Private investment in social services is dependent on stable and adequate levels of public funding of social services. In the significant majority of cases, boosting private investment in social services will not be effective without also ensuring sufficient public spending on social services.

- Boosting private investment in social services will require a proactive approach from public authorities and all relevant stakeholders in order to build up the capacity of those involved, develop the right partnerships at the local level and create financial instruments that meet the needs and realities of the social services sector. Structured partnerships between public authorities, investors and social service providers is crucial in order to build well-targeted financial instruments for the sector.

It is also worth emphasizing that the pros and cons described above are as universal as possible, but in practice the same methods of financing the same services can give different effects, depending on the existing infrastructure and social context. Personal budgets can support the market of formal services or promote further familiarization of care and transfer of even greater or full responsibility for a person with a disability to family carers.

Different effects may occur between individual countries introducing similar solutions, as well as within one country, for example between urban and rural communities or those with better infrastructure and those without. In countries where long-term care policy was less developed and care alone was primarily the domain of the immediate family, such benefits were treated as the backbone of the new system and aimed at supporting informal care (as in the case of Germany and Austria) or supporting a new segment in the labor market (as in the case of France). In the Netherlands, the introduction of a cash benefit took place in the context of a highly developed service sector and aimed to make the existing supply of services more flexible, increasing the empowerment of dependent persons and reducing the cost of services. In Italy, the currently operating cash benefit has evolved from an earlier income support system for people with disabilities[164].

It is also worth remembering that without local community activity and the involvement of local stakeholders in matching solutions to local conditions, it is difficult to find good social services. The good practices and discussion materials proposed in the next chapter are the starting point for introducing changes rather than ready-made solutions that will work in all circumstances. Policy transfer is not easy and sometimes is simply not possible.

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164   Bakalarcyzk et al. 2019; Da Roit and Gori 2019.

To discuss:

- What are the consequences of specific funding models for people with disabilities?
- How can financing models affect the quality and inclusiveness of social services?

Facilitation tips:

- **Case study.** Choose one social service available in your community and indicate how it is financed and what the consequences of this model of financing are for different actors including person with disabilities, families and carers, local government and service providers. Discuss in the group the consequences of changing the financing method to a different model.

- **Personal budgets.** Choose one social service available in your community and discuss in small groups what the consequences are of changing the financing model to personal budget. How will it affect the possibility of independent living for persons with disabilities?

- **List of services.** Choose one of the five areas (e.g. early intervention, education, employment etc.) and list all the services that are available in your community. What is the funding model for this service? What are the consequences?

3.4 Inclusive Community-Based Services and the Right to Independent Living

Independent living means that a person with a disability, thanks to the available support system, has the ability control his or her life and make decisions regarding all areas life including where and with whom he or she lives. As the European Network of Independent Living indicates, "independent living requires that the built environment, transport and informati-

on are accessible, that there is availability of technical aids and access to personal assistance and/or community-based services. It is crucial to point out that independent living is for all disabled persons, regardless of the gender, age and the level of their support needs"[165].

Article 19 of the UN CRPD establishes the equal right of all persons with disabilities to live in the community, with choices equal to others, stating that:

- Persons with disabilities have the opportunity to choose their place of residence and with whom they live with on an equal basis with others;
- Persons with disabilities have access to a range of in-home residential and community services, including personal assistance necessary to support living and inclusion in the community rather than isolation or segregation;
- Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

The role of Article 19 to understand why the local level is important for the implementation of KPON is discussed in detail in CE1. In this part, however, it is worth focusing on translating the content of the article and the accompanying General Comment (UN CRPD/C /18/1) into specific services for people with disabilities that support independent living in local communities.

3.4.1 Deinstitutionalisation

Ensuring the right to independent living in local communities is associated with the deinstitutionalization process, which means a shift from institutional to community based living arrangements. In the Convention or General Comments there is no definition indicating how many people living together constitutes an institution. The key is other indicators such as:

- Obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from;

- Isolation and segregation from independent life within the community;

- Lack of control over day-to-day decisions;

- Lack of choice over whom to live with, rigidity of routine irrespective of personal will and preferences;

- Identical activities in the same place for a group of persons under a certain authority, and a paternalistic approach in service provision;

- Supervision of living arrangements and usually also a disproportion in the number of persons with disabilities living in the same environment.

Research shows that in all European countries there are still people living in residential care. Although exact numbers are not known, it is estimated that in Europe alone over a million people live in various types of institutions[166]. Living in an institution is associated with limited impact on your daily choices as well as greater exposure to situations of violence and violations of fundamental rights[167].

Infobox 3: Deinstitutionalisation definition

Deinstitutionalisation is a political and a social process that enables the shift from institutional care and other isolating and segregating settings to independent living. Effective deinstitutionalization occurs when a person placed in an institution is given the opportunity to become a full citizen and to take control of his or her life (if necessary, with support). Essential to the process of deinstitutionalization is the provision of affordable and accessible housing in the community, access to public services, personal assistance and peer support. Deinstitutionalization is also about preventing institutionalization in the future and ensuring that children are able to grow up with their families and alongside neighbors and friends in the community instead of being segregated in institutional care.

Source: *European Network of Independent Living*

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166 Šiška and Beadle-Brown 2020.

167 European Union Agency for Fundamental Rights 2018.

causes resistance and objections (FRA, 2018). The implementation of DI is associated with the need to provide a wide scope of support services, including personal assistance (PA). Sometimes, actions aimed at ensuring the possibility of independent living are perceived by persons with disabilities and their families as threatening and assumed to involve living without actual financial support or other forms of services. The concept of independent living itself is treated as excluding people with severe impairment or challenging behavior. However, it appears that the negative attitude towards the idea of independent living derives not so much from the drawbacks of the concept itself but rather from the troublesome implementation of its premises.

This is partly due to a lack of suitable community-based services for people with complex needs[168]. Therefore, the deinstitutionalization process itself must be combined with the development of inclusive social services, including but not limited to specialist services.

3.4.2 Personal Assistance

The key service to ensuring the possibility of independent living is personal assistance, the scope and organization of which has been described in the General Comment to Article 19 of the UN CRPD.

Infobox 4: The definition of personal assistance from General Comment no. 5 to Article 19[169]

Personal assistance refers to person-directed or user-led human support available to persons with disabilities and is a tool for independent living. Although modes of personal assistance may vary, there are certain elements that distinguish it from other types of personal assistance, namely:

168 Ibid.
169 United Nations 2006, art. 19.

(i) Funding for personal assistance must be provided on the basis of personalized criteria and take into account human rights standards for decent employment. The funding is to be controlled by and allocated to the person with a disability with the purpose of paying for any assistance required. It is based on an individual needs assessment and upon individual life circumstances. Individualized services must not result in reduced budget or higher personal payment.

(ii) The service is controlled by the person with a disability, meaning that he or she can either contract the service from a variety of providers or act as an employer. Persons with disabilities have the option to custom-design his or her own service, including deciding by whom, how, when, where and in what way the service is delivered and instructing and directing service providers.

(iii) Personal assistance is a one-to-one relationship. Personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants should not be shared without full and free consent by the person granted personal assistance. The sharing of personal assistants will potentially limit and hinder self-determined and spontaneous participation in the community.

(iv) Self-management of service delivery. Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences. Even if the responsibilities of the employer are contracted out, the person with disability always remains at the centre of the decisions concerning the assistance and their individual preferences must be respected. The control of personal assistance can be through supported decision-making.

Although personal assistance services already exist in various forms in most European countries, they rarely meet the criteria set out in the general commentary[170]. It is worth emphasizing that the provision of personal assistance is a necessary condition, but not sufficient to enable people with disabilities to live independently in local communities. It is also necessary to ensure that all services targeted at the general population are designed to be inclusive and accessible to all persons regardless of their ability (see point one of the twin-track approach). Ensuring the implementation of the right to independent living should therefore be a starting point and a signpost for both the planning and implementation of inclusive social services.

To discuss:

- Why do you think that the deinstitutionalization process may cause resistance and fear? What kind of fear or concerns of DI might different actors have (e.g. persons with disabilities, their families, local authorities, management staff)? How can these concerns be addressed?
- What does the personal assistance service look like in your region? Is this service in line with UN CRPD? If not, why? What changes could make it compatible with the UN CRPD?

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170 Šiška and Beadle-Brown 2020.
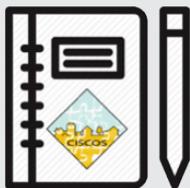
Facilitation tips:

- **Deinstitutionalization**. There is a plan to close an institution for persons with disabilities in your region. Plan the transition for specific people with disabilities living in this institution (examples of such people can be worked out in a group). What support should be provided in the community? What are the risks associated with the deinstitutionalization process? How can they be reduced? Work in small groups and then compare answers.

- **Independent living**. Think about what the right to independent living means in practice for people with various disabilities (e.g. a young woman with intellectual disabilities, an elderly man with Alzheimer's, a deafblind person at the age of professional activity). What does independent living mean for these people? What support should be available in the local community? Work in small groups and then compare answers.

3.5 Policy Successes and Failures

3.5.1 Policy Change: Challenges and Chances

The transition from a segregated system of services based on a medical approach to disability with institutional living arrangements to the system based on human rights and inclusive social services is associated with many challenges and barriers.

These barriers could be different in different countries and depend on cultural, economic and political factors as well as how the system has traditionally functioned up until now. There are also differences in the strength of civil society organizations and influence of DPO's on disability policy on local and national levels.

From a top-down perspective, one of the main factors is the central government's approach and legal regulations that set a certain time frame and the necessity to make changes, for example, the existence of a nationwide deinstitutionalization strategy and adequate funds to support the change. From the bottom-up perspective, the extent of self-government and the power held by local government units is important, as well as the activity of local DPOs.

The cooperation of all entities and the compliance of the direction of activities facilitate the deinstitutionalization process, when the lack of top-down regulations and the weakness of bottom-up activities slows it down or makes it impossible. If the only entity offering services is a traditional segregating facility this creates a greater challenge.

3.5.2 Differences Between Countries

It is also important to consider the historical perspective. In countries like the UK, initiatives intended to alter perceptions of disability are dated as early as the 1970s (UPIAS 1976). Poland and other post-soviet countries, took some 20 years to join the countries of the West in a very gradual and often difficult process of shifting from the medical model of disability towards the social model. These different starting points and the rapid acceleration of the process after 1989 also result in a completely different power distribution of the key actors involved in a potential deinstitutionalization process. In many cases, it is not only a matter of organizing the process of transforming a large segregating institution, but also convincing the entire local community, especially people with disabilities, that such changes make sense and would be beneficial for all.

As was mentioned in the section about various models of financing social services, similar and even identical solutions can have different impacts in different countries, regions and communities, depending on local conditions (see Infobox 5).

Cross-cutting issues include different definitions of disability and people with disabilities, and key legal regulations indicating the rights of people with disabilities, including the

role and importance of the UN CRPD itself. Another important factor is the different level of organization and impacts of disability rights movement advocacy on the national level, as well as the different levels of decentralization, and thus the decision-making of local governments. From a local perspective, the decisive role is played by local stakeholders and their mutual relations and thus impacts to what extent issues related to disability in general and social services in particular are a priority for the local community.

Infobox 5: Factors affecting the implementation of inclusive social services

- Different levels of UN CRPD understanding and implementation.
- Different levels of strength of the disability rights movement (DPO's, non-formal networks).
- Different levels of actual power of local authorities to plan and provide inclusive services.
- Different levels of social services systems and social service development, especially according to special services for persons with disabilities.
- Different level of actors or stakeholders' involvement in policy planning and different levels of social involvement in community development.

Below are examples of conditions for conducting disability policy - both from the level of changes in national policy and the impact at the local level. These examples show how social and cultural context must be taken into consideration in planning and implementing inclusive social services.

Poland. An Example of Transformations in a Post-Communist Country[171]

The situation of people with disabilities in Poland is a result of historic factors relating to the country's socialist past[172] and the economic and systemic transformation of 1989, with

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171 Kubicki, Bakalarcyzk, and Mackiewicz-Ziccardi 2019.

172 Rasell and Jarskaya-Smirnova 2013.

the neoliberal reforms that it offset. Mladenov's 2015 "Post-socialist disability matrix 2017b" is relevant here. However, we are adding the analytical dimensions of state socialist legacy and post socialist neo-liberalization to Mladenov's matrix. Namely, the growing influence of ratifying the UN CRPD in 2012. This ratification affected public discourse and regulations as well as the ways in which the upholding of the rights of people with disabilities is monitored. Reports on the implementation of the UN CRPD form one example of such monitoring[173].

Another useful analytical framework is that of three-dimensional social justice (Fraser 2013.) This refers to the economic, cultural and political dimensions of participation in public life. In this context, the trajectory of disability could also be seen as the trajectory of social exclusion, understood as a threefold deprivation of assets, rights and participation. Deprivation significantly leads to decreased availability of rights and participation[174]. In turn, fulfilling one's needs to the greatest possible extent in all of these three aspects would allow for both attaining social justice and breaking the trajectory of social exclusion relating to disability.

The main aspect of the state socialist legacy (see also Table 1) is the domination of institutional care, which segregates and thus separates people with disabilities from the non-disabled majority. Notably, many non-disabled experts and professionals, as well as politicians making decisions about supportive measures available to people with disabilities, tend to equate supporting this group with segregated institutionalization and thus consider it the most appropriate way of containing the issue of disability. That is not to say that the process of deinstitutionalization and supporting independent living has not started, but it is very gradual, meaning that the main conclusions of the 2011 report are still relevant. The problem with the current provisions is very complex. Firstly, the government does not imple-

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173 Zadrożny 2015; Biuro Rzecznika Praw Obywatelskich 2015; Kubicki 2017, 120–125; McRae and Szarota 2018.

174 Karwacki 2014, 233–234.

ment "(…)modern solutions like personal budgets, direct payments, individual budgets, respite services"[175], to name but a few. Secondly, it is often argued that the provisions already in place lack synergy. Thirdly, while there are NGOs that endeavor to support people with disabilities, they are few and far between. This, in turn, means that whether a person with a disability gets the support they need will depend on where they live. Consequently, many people with disabilities in Poland have no viable alternatives to living in an institution.

In relation to economic distribution, the effect of the UN CRPD is still largely declarative and has had little if any impact on the everyday life of people with disabilities. Yet, one can see a slow move away from both segregation and neoliberal attitudes. Retrenchment policy has never been as robustly implemented in Poland as in other countries. It appears, however, that the main obstacle to applying the principles of the UN CRPD is not the state socialist legacy, or the liberal economic transformation, but the familialism of Polish social policy[176]. Such an approach proposes that the family is the main unit responsible for the welfare of its members and it should be the primary provider of care. This is at odds with the values of the convention, that emphasize the individual rights of people with disabilities. Thus, a gap in the support system can be observed between the family and the segregating institutions providing round-the-clock care.

The medical model of disability is especially prevalent in the disability adjudication system. The main purpose of this system is to deem people unfit for work and, in some cases, independent functioning[177]. It is worth noting that the adjudication system was set to undergo changes in the last quarter of 2018. As of December 2019, its final form still remains unknown. The aspect of the experience of having a disability that has been most influenced by the new attitudes based on human rights and the social model of disability is cultural recognition.

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175 Wapiennik 2009, 2.

176 Szelewa 2017.

177 Radlińska, Bażydło, and Karakiewicz 2014.

	State socialist legacy	Post-socialist neo-liberalization	UN CRPD effect
Economic redistribution	Segregated service provision: • Sheltered work-shops • Residential institu-tions	Restructuring and re-ducing social support: • Decentralisation • Benefit cuts • Workfare	Pointing out subjec-tivity and the right to choose; emphasis on employment in the open market and also support for indepen-dent living
Cultural recognition	• Medical, producti-vist understanding of disability (co-dified in disability assessment systems) • Denial of disability (at the everyday level)	• Stigmatisation of social assistance and 'dependency', accompanied by the promotion of self-sufficiency • Responsibilisation	Social model of disa-bility; pointing out the barriers that peo-ple with disabilities face in everyday life as the disabling factors
Political representation	Weak civil society, suppression of coun-ter publics and counter-discour-ses	De-politicization through: • Restriction of civil society to service provision • Token (quasi-corpo-ratist) participation	Presence of people with disabilities in the public debate; "nothing about us without us" attitude; attempts to influence legislation

Table 1. Post-socialist disability matrix[178]

The long Road to Deinstitutionalisation. Example from Poland

In Poland, over 67 000 people with disabilities live in various types of institutional living arrangements. Despite a call for action from disability rights movement in Poland, UE and worldwide a deinstitutionalization strategy has not yet been created at any level. The UN CRPD Committee in concluding observations on the initial report of Poland in 2018[179] is concerned that there is "critical stagnation in and absence of determination in the process of deinstitutionalization of persons with disabilities and their transition to independent living in the community ensuring the right of such persons to choose where, with whom

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178 Mladenov 2017a, with the addition of CRPD effect by the authors.

179 Committee on the Rights of Persons with Disabilities 2018a.

and how to live outside institutions and group homes, including the absence of a strategy and action plan and targeted funding for the deinstitutionalization process after the termination of European Union funds allocated to this purpose".

There are known cases of EU funds for deinstitutionalization used to build new institutions. Despite the effort of some DPOs and experts in this field, there was never a policy window of opportunity for the deinstitutionalization process.

There are many actors with varying strengths and impact in this process. Among them are persons with disabilities, families and carers of persons with disabilities, local authorities, management staff, professional staff, service providers, DPOs and also the church (the Catholic church runs some of the institutions in Poland). The voice of persons with disabilities and DPOs is usually the weakest and institutions are rooted not only in tradition but are also often important employers in the local labor market. At the same time, institutional living arrangements are not only out of line with the UN CRPD but are against even the most basic human rights. There is no doubt that a DI process should be conducted.

Key barriers in the DI process in Poland are:
- Common assumptions amongst persons with disabilities, their families and carers and local and national authorities that the process cannot succeed (expected policy failure);
- Lack of inclusive services supporting independent living in local communities, including personal assistance;
- Lack of determination at every level from local authorities to national government;
- Weak, divided and underfunded disability rights movements;
- Low trust in state capacity of providing social services;
- Many project-based solutions (for example supported housing solutions) funded only as a project, not as a systemic solution;
- Medical approach to disability in policy planning and implementation, lack of understanding of the need for a human rights approach at every level.

It is worth mentioning that even with such adverse conditions, the deinstitutionalization movement is getting stronger every year. There are more grass-roots initiatives, but also DI projects funded by local governments. By the end of 2020, Poland will also adopt its own deinstitutionalization strategy. The example of Poland shows that although changes are difficult and slow, the determination of individuals at the head of NGOs, companies and local governments is important. The key to success is the cooperation of all actors.

3.6 Summary

Ratification of the UN CRPD and all the documents specifying how its individual articles should be interpreted show the direction of changes in public policies implementing the objective of UN CRPD. Article 1 states the: „full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." The key element of these changes is undoubtedly social services, and thus the activities of service providers in line with the twin-track approach and allowing the independent living of people with disabilities in the local environment. Despite the awareness of what to do and even attempts to change, the practice and everyday life of many people with disabilities deviates from theoretical assumptions. The effectiveness of reforms depends on many factors, starting with the relative autonomy of local government units, regulations regarding disability adjudication rules, entitlements regarding support or principles of (co) financing of social services, the activity of disability rights movements, and finally on existing in a given area with the appropriate service providers. It also seems that the key moment is not the selection of a new policy, but its subsequent implementation and consistent development of further services in cooperation with individual political actors. In order to address the practical challenges facing those who want to implement inclusive models in service providing organizations for persons with disabilities, in the next chapter we will focus on discussing specific examples of activities divided into five areas corresponding to particular stages of life, from early intervention and support for children to services for the elderly.

3.7 Action Plan Towards Inclusion: Conceptual Basics and Action Steps for the Organisational Development Process of the Institution Blue Rider

3.7.1 Introduction to the Blue Rider Scenario

Blue Rider is a traditional organisation for persons with disabilities that has been working actively in the Newland district for many decades providing traditional in-patient and some out-patient services for people with disabilities of various age groups. Blue Rider is a complex facility for 120 people with so-called mental and/or multiple disabilities of various degrees of severity. The core facility has about 250 part-time and full-time employees in care and administration and the facility is divided into six areas, each of which has area managers and in some cases group managers. In addition to the general residential group area with six groups, there is a group for young adults, two closed groups and one group for people with Prader-Willi Syndrome. In addition, there are transport services, kitchen, housekeeping and building services. Although Blue Rider is a provider of traditional in-patient facilities, it has been considering new ways of supporting people with mental and multiple disabilities for some years now as a result of the inclusion discourse intensified by the UN CRPD. Up until now, however, this has only led to the creation of a few new inclusion-oriented services for housing-related assistance. The institutional care model has remained mostly unchanged.

A care scandal where violence against some service users became public, leading to financial difficulties for Blue Rider facilities due to declining user rates. Subsequently there was a change in management in 2015. Considering the precarious situation, the new management team decided to initiate a consistent inclusion-oriented development process. It quickly became clear that this process would entail significant changes for the organisation as a whole, especially for the people with disabilities and their relatives or legal guardians as well as the employees.

The management of Blue Rider has now drawn up a first concept for the planned organisational development process, which is to be discussed at a staff meeting, to which the residents' councils and relatives or legal guardians are also invited. According to the ideas of the management team, the change processes should be carried out consistently, but also closely coordinated with the other actors involved.

3.7.2 The Management's Ideas on 'Blue Rider on the way to inclusion'

Goals and principles of the change process:

- The aim of the development process is to transform the services offered by the core facility into decentralised, district or community-oriented services. For this purpose, a social space-oriented service organisation is to be developed, which will be effectively linked to other offers at the forefront and in the environment of service provision.

- The thinking and actions of all those involved should be based on the central idea of individualised support in an inclusive community and developed from this conceptual perspective. The development process should implement an urgently needed conceptual modernisation, that can greatly improve the chances of economic stabilisation and thus contribute to the overall stability of the organisation and job security.

- The technically demanding and innovative approach is intended to promote the identification of employees and increase job satisfaction. In view of the already noticeable lack of qualified support staff, this will be of considerable importance in the future when it comes to retaining or recruiting qualified employees for Blue Rider.

- In order to do justice to the responsibility associated with the change process, it is necessary to consciously justify and plan change steps conceptually. A careful implementation of change steps is all the more possible the more the participants actively participate and know what they are doing. Against this background, a differentiated action concept in which tasks and goals are formulated for different areas is of great importance.

- The concept of action deals with the transition process, and on the other hand, it contains statements on how the new service model in Newland district is to be designed. It is intended to provide orientation for all those involved in the implementation process and at the same time leave room for development potential and creative solutions.

- This reorientation is associated with new and, in some cases, additional tasks that require adequate financing by the responsible cost units.

In the following, the philosophy of the development process, i.e. the reasons why these far-reaching changes are considered necessary and what opportunities they offer Blue Rider are described in more detail.

3.7.3 Why? The Philosophy of the Organisational Development Process

Enabling more participation, self-determination and quality of life instead of care

Blue Rider has developed a structure with comprehensive, multi-layered services for adults with mental and/or multiple disabilities, with numerous central services, assignments and routines that are difficult to understand from the inside and outside. In this context, Blue Rider is a complex facility. An essential characteristic of the organization is the provision of care for people in the fields of living, work, education, leisure and often also therapy as well as medical and nursing care. As a rule, this care takes place on the premises of the facility, located outside the town of Rotburg and is only connected to it by a poorly developed bus connection. The people cared for live separated from their environment, in a world of their own, created especially for them.

The service operation is characterized by the effective supply process, maintained 24 hours a day, 7 days a week, ensuring the supply for all, preferably in groups. The care structures at Blue Rider are not oriented towards the individual needs of the clients due to the logic of the institution. The possibilities for social participation and self-determination, which are already hampered by their impairments, are thus further restricted.

Blue Rider agrees with the broad professional consensus that new forms of professio-
nal support for people with disabilities outside of institutions can achieve better results
in many situations than in-patient help (see also the General Recommendation No. 5 to
Article 19 of the UN CRPD on self-determined lifestyle). However, a prerequisite for this is
that professionally recognized quality standards are observed. A conceptual orientation of
housing-related assistance towards the model of private housing with flexible, reliable and
needs-based support is helpful. The development process for Blue Rider is thus linked to
new professional concepts and aims to make them usable in order to enable clients to par-
ticipate more socially, determine their own lives and improve their quality of life. The aim is
to modernize the range of services offered by Blue Rider in a responsible manner.

Respecting, protecting and asserting the rights of people with disabilities

As a result of the UN CRPD, the community of states recognise general human rights from
the special perspective of persons with disabilities or mental illness in a binding manner.
The declared aim of the Convention is equal opportunities for people with disabilities and
their full participation in society. Thus, it is a remarkable milestone in disability policy even
for a highly developed country like Germany. Since 26 March 2009, the Convention has
been a binding legal requirement in Germany for all levels of government (see Article 4
BRK).

Article 19 of the Disability Rights Convention contains precise provisions for the implemen-
tation of the right to a self-determined life and inclusion in the community for people with
disabilities. Specifically, by ratifying Article 19 BRK, the States Parties recognise „the equal
right of all persons with disabilities to live in the community with equal opportunities for
choice as other people and take effective and appropriate measures to enable persons
with disabilities to fully enjoy this right and to be fully included in the community". To
ensure the realisation of this right, the state shall ensure that persons with disabilities have
equal opportunities to choose where they reside and decide where and with whom they
live. It should be stressed that there is no obligation for people with disabilities to live in a

particular form of housing. Article 19 is guided by the principle of inclusion and therefore calls for special facilities to be overcome in favour of equal living in the community. The development process of Blue Rider is based on these human and civil rights guidelines for making community-integrated, small-scale and self-determined forms of life possible for all clients with so-called mental and/or multiple disabilities. This paper serves as an action plan.

In the development process, it must be ensured that the rights set out in Article 19 are, of course, also applied to people with severe disabilities and thus with a high or complex need for support. It is precisely this group of people that puts the validity of human rights to the test for all those involved and demands a high degree of willingness to develop creative arrangements and open up new avenues. It will always be necessary to show a willingness to deal with conflict, not only with the funding agency, but also with the public and one's own organisation in order to enforce the guaranteed rights of clients appropriately. In this respect, the development process of Blue Rider is also a process of local human rights education that focuses on community learning.

Promoting personal development of people with disabilities and strengthening their self-esteem

The development and learning of people always goes hand-in-hand with new experiences in extended and sometimes little-known situations. Development and learning takes place when these challenges can be successfully met. Considering this, it can be said that access to new requirements and risks is an essential prerequisite for the personal development of people.

The widespread idea that assistance for people with disabilities must create a protective space does not take this context fully into account. In well-intentioned care, there is a danger that the opportunities for learning to deal with the everyday risks of life will be denied to people with mental or multiple disabilities. The 'dignity of risk' must not be subordinated

to the idea of protection. If people with disabilities are denied the opportunity to face new, difficult demands or to deal with risks, as is largely the case in the sanctuary of institutions, the results of such institutional socialization often consist of depressive disorders, low self-confidence, or can lead to infantile adults.

Nevertheless, it would be wrong and pedagogically questionable not to seriously address possible difficulties and risks in the development process, which may include more indivi-dualized forms of housing for people with pronounced learning difficulties. In the develop-ment process of Blue Rider in the region of 'Farbenland', this should be done in a way that supports the process of independence so it can be mastered by the clients and strengthen their personal development. Among other things, reliable support, learning opportunities for individuals and groups that accompany everyday life, and individual participation plans that also use new electronic media are important in this context.

Understanding and shaping the development process as a learning process

The development process is associated with the need for change, that affects not only the people with disabilities in care and the staff, but also the parents or relatives of people with disabilities, legal guardians, politically responsible persons, staff in administrations and pu-blic institutions and the community as a whole. Learning processes are therefore necessary for all those involved. A responsible and careful conversion strategy requires appropriate consideration of the perspectives of all those involved. Different aspects of these changed conditions and the associated learning tasks will be discussed below.

People with disabilities face many new challenges when they are no longer home re-sidents, but apartment owners or tenants. The use of assistance in inpatient facilities is strongly predetermined by the rules of the facilities, care services and the daily structure determined by home routines, which simultaneously limit individual wishes and assist the home residents with many activities.

The new practical and social requirements for people with disabilities in their own homes or in a supported residential community should be understood primarily as opportunities. However, this presupposes that appropriate framework conditions are in place with regard to the scope and quality of the necessary support. For clients living in their own home, this means the possibility of acquiring more independence, self-confidence and control over their own life. But in the sense of activating support, this must be combined with offers to acquire skills in self-care, housekeeping, personal life planning and also in the area of social and civic life. It is important that the people concerned acquire certain competencies in dealing with professional help, which allow them the highest possible degree of control and self-determination.

People with disabilities should also be able to articulate their own interests and needs in the community. Formal forms of involvement in advisory and decision-making bodies are often already available. However, to actually make use of opportunities for participation, knowledge of democratic rules and other competencies are required, that must be acquired and practiced through experience and suitable forms of learning.

For parents, relatives and legal guardians as well as people with disabilities themselves, a move towards person-oriented assistance means entering new territory. This is often connected to concerns about the adequate care of their children or the people in their care. They often find it difficult to develop a positive image of an everyday life based on flexible person-oriented help due to the dominant help system. Here, it is important to initiate rethinking processes and create trust through targeted information and reports about positive experiences. This can help increase the chances of a successful separation from the parental home or a fully supportive inpatient environment. Staff members who have so far primarily provided inpatient help must adapt to the changed self-image of their users and are called upon to change their working methods from care to support. This concerns both support in everyday life and support in personal future planning for people with disabilities. This also means offering support in using a personal budget, giving people with disabilities the opportunity to purchase specific support services.

The forms of financing for new service concepts also pose new challenges for Blue Rider as a service provider. While assistance services have so far been refinanced on a flat-rate basis or broken down according to care keys, new forms of financing, such as specialist service hours in the context of outpatient care as well as personal budgets, require new and more flexible working methods. It should be noted that the form of assistance provided by AHVs cannot stand in isolation. The areas of work or daily structure and leisure must also be included in the planning of assistance. In addition, it may be challenging to find a way to use property that is still subject to earmarked liabilities in the longer term.

Policymakers are called upon to develop the necessary public infrastructure on the basis of equality requirements in such a way that it enables people with disabilities to carry out their everyday lives with support in the same way as everyone else.

Employees in administrations and public institutions are faced with the task of creating the conditions for people with disabilities to use their services and of raising awareness of possible barriers and discrimination. Intensified sensitization of administrative staff should make it easier to find individual and appropriate solutions to inquiries and problems in individual cases.

Social service providers at the local and supra-local level are called upon to make their contribution to the implementation of the provisions of the UN CRPD, in particular Article 19, by effectively supporting the conversion efforts of Blue Rider. This refers both to the question of what incentives can be developed to make new, open support concepts more attractive and flexible and the willingness to review individual support planning practice and current financing systems.

In summary, the desired changes must be supported by a variety of information and learning opportunities.

Ensuring effective participation of clients and their families in the development process

The participation of the residents in the development processes of Blue Rider is necessary and useful in many respects. It is of central importance for all people to have control over their lives. This includes experiencing that their own interests, needs and wishes and rights as citizens are respected in everyday life. Routines and traditional structures make it difficult for many residents in large institutions for the disabled to experience having a real influence on their daily life. As a result, they often develop feelings of resignation, depressive shame and a loss of confidence in their own self-efficacy. The experience of being seriously involved in important decisions affecting one's own life circumstances helps to strengthen people's self-confidence. This applies at the individual level, but also with regard to organized representation of the interests of the residents of institutions for the disabled.

By broadly involving the home advisory board or other forms of representation of the residents, it is also possible to benefit from their everyday practical experience and to include their resulting wishes, suggestions and interests in the process. Not considering activating involvement and participation of the residents would greatly impair the quality of the development process.

The necessity of participation also results from the corresponding legal regulations for the operation of homes. In the Region of 'Farbenland', a new act on housing and participation has recently been adopted. Its purpose is to protect the interests and needs of residents in homes and to safeguard and promote their independence, self-determination and personal responsibility.

The new act states that the residents are entitled to participate in matters that directly affect their lives in the home (e.g. house rules) through an advisory board. Despite restrictions regarding their explicit right of co-determination, the residents' representatives should be sufficiently and timely involved in the formation of opinions on the development process of Blue Rider.

Broad participation of the residents in the planning and design of the development process of Blue Rider is conceptually indispensable. However, the challenge remains to find suitable ways to enable this that take into account the sometimes limited articulation abilities of many residents.

Realising the human rights mandate in the development process

The above-mentioned contexts make it clear that the development process of Blue Rider is founded on a human rights-based understanding of disability. The current and upcoming challenges regarding the transformation of the large institution will require effort, but for a committed disability service provider are essential to overcome.

3.7.4 Developing and Implementing a New Service Model

The following describes the components of the new service model that the development process should lead to. In addition, concrete implementation steps and accompanying measures of various kinds are described. In principle, the relocation of residents from the care facility must go hand in hand with the establishment of social-space-oriented support structures, particularly in the fictive city of 'Rotburg'.

a) Target structure of the development process

In order to implement the conceptual ideas described above, a service model is required that differs from the previous stationary model. New working structures should prevent old institutional practices from being adopted in the new forms of assistance. The following elements and processes should determine the service model in the future:

- Assistance teams in districts and communities;
- Meeting and counselling services;
- Individual participation in planning and overall planning;
- Housing, leisure and partner exchange;
- Cooperation with other providers and public bodies;
- Complaints office.

b) Draw up and implement an action plan for inclusive housing

With differentiated housing offers in the social environment, residents with various types of disabilities should be offered support oriented to their individual needs. Alternatives to the current forms of care are should be made possible. Appropriate housing offers for people with particularly challenging behavioral patterns should also be included.

By creating attractive forms of housing outside the central area of the institution, the right of choice and the right to participation of all Blue Rider members will be fulfilled. For the development of housing ideas and concepts, the instrument of 'personal future planning' should be made available and integrated into the overall planning process.

Particular attention should be paid to the cooperation with those responsible in the municipalities and districts when creating new housing offers in Rotburg and the surrounding area. Existing contacts in the social environments should be further developed. In addition, the people in the neighbourhood, persons of the local trades and crafts and members of local associations should be included. In order to offer residents, the opportunity to use the planned cross-provider network of formal and informal support, various forms of accessible information, communication and advice are necessary, some of which must be created.

The guiding principles of a person-centred orientation towards social spaces explicitly include all areas of life (e.g. daily concerns, work, daily structure, education, leisure). This means, for example, creating small, decentralised housing communities integrated into the direct living environment of the municipalities and neighborhoods or other offers of housing-related support. In addition, all clients of working age should also be given the opportunity to work temporarily or permanently outside of a sheltered workshop and be able to take advantage of other employment opportunities that meet their needs.

Concrete measures

Over the next five years, a total of about 90 per cent of the housing at the central location of Blue Rider will be dismantled and relocated to the town of Rotburg and the surrounding areas. The aim is to achieve a balanced spread of the newly created housing offers throughout the area with a mix of new buildings, the acquisition of existing buildings and their conversion, and various rented apartments. The creation of housing units of various sizes is intended to better meet the choices and decisions of the residents. At the same time, additional capacities should be created within the framework of outpatient assisted living.

In order to address the dangers of client isolation, at least two meeting and counselling centres for people in need of assistance are to be set up in the town of Rotburg with the involvement of other institutions and citizens of the municipality. These new offers should be accepted as a comprehensive place for cultural and leisure activities and can also be used for educational projects. In this context, the competences and possibilities of cooperation with other local actors should also be considered.

Various social counselling services are to be located in the meeting and counselling centres. The main topics will be: work, housing, leisure, education, coping with everyday life, social law, personal budget and AAC. These counselling services will also be there to provide support for residents, their relatives and caregivers considering future housing alternatives.

The development process must have a concrete action plan, carefully thought through and rapidly implemented. The aim is to ensure that all clients, especially those with a greater need for support, the relatives and caregivers, the employees, the residents of the municipality and the institution as a whole have the chance to benefit from the overall process.

c) Redesign action routines and train staff

In order to implement new concepts, qualified and motivated employees are needed who are able to cope with the work demands of the new service model. These demands

are both technical and organisational in nature and cannot be handled in the daily routines practised so far. The professional requirements include the expansion of pedagogical knowledge in the areas of social space orientation, networking, personal assistance, participation and future planning. This makes systematic personnel development an indispensable instrument for qualifying employees in the development process.

Training and development needs must therefore be determined and further training courses adapted and made available. A reliable flow of information must be guaranteed. Participation in networks and workshops with external experts is indispensable in order to achieve continuous improvement of the employees' skills. The basis of the organisational requirements are flexibility, commitment and reliability requiring a professional duty rostering system that allows for effective planning of personnel deployment and optimal use of personnel resources.

In order to translate the above-mentioned steps into concrete terms, all employees should take part in several further training courses. These events should be completed within two years. As multipliers, the participants are obliged to systematically pass on their knowledge to their colleagues. By work shadowing and on-site discussions in new housing offers, employees can expand their practical skills for working in inclusive shared flats and apartments. Regular specialist days for Blue Rider should complement this offer. Supervision and coaching of employees should be available on a regular basis and as required. These training measures can be used to develop a module to document the further training of employees (also externally). For this purpose, management must make the necessary time quotas and financial resources available. Up-to-date information on the subject of inclusion and action plans should be accessible on the start page of the intranet.

d) Take the financial challenges seriously and use their economic potential

Restructuring in the field of home-related assistance for people with disabilities also has financial implications for Blue Rider. The conversion of inpatient places also means that

previously stable income is now partly linked to other forms of benefits and therefore varies. With regards to expenditure, regular personnel costs must be financed. If necessary, existing employment models and contracts should be changed, and socially acceptable, flexible and cost-relevant solutions developed. Building costs are incurred in full for downsizing measures, even if facilities have reduced the number of places available. There are also costs for building measures to construct or adapt childcare facilities.

Since residential homes are subsidised with public funds, their use is sometimes subject to a time limit. Possible repayment obligations must therefore be clarified if the buildings are to be used for new or modified purposes. Here, the social welfare authorities are also obliged to develop viable and acceptable solutions together with Blue Rider.

The financing of planned projects and changes is of central importance to continue the development process of Blue Rider. The distinction between outpatient and inpatient assistance has been abandoned by the new law in favour of flexible assistance arrangements and permeability and flexibility should be reflected in the forms of assistance.

e) Securing social and political support through cooperation and communication
The approval and support of government authorities is needed to realise the concept. The plan for the conversion of the complex facility should therefore be presented and discussed with the politically responsible local authorities (the district of Newland and the town of Rotburg). This will ensure that the plans for Blue Rider are integrated as far as possible into public planning. In addition, the possibilities and interests of the local authorities can be included in the solutions to important upcoming problems (e.g. financing of transitions, dealing with existing real estate, process consulting, etc.)

Active participation in the Disability Advisory Board of the local government, other municipal bodies and relevant contact and advice centres is a good way of entering into dialogue with politicians and articulating interests. An active and influential advisory board

for people with disabilities, a lively culture of communication and cooperation between service providers and an active lobby in the municipal political environment are of great importance for the success of the inclusion-oriented development process. The focus of such participation should always be on strengthening the self-help positions of people with disabilities and promoting public acceptance of the development process.

f) Initiate and participate in local participation planning

The aim of Blue Rider is to influence local conditions so that people with disabilities can participate in social life without discrimination. In connection with the implementation of the UN CRPD, many municipalities in the region have begun to systematically survey where barriers for children, young people and adults with disabilities make it difficult for them to participate equally in community life and how these barriers can be dismantled. For this purpose, the concept of local participation planning was developed as a form of municipal social planning. According to this concept, the planning process should take place under the leadership of the city and the district and be participative and learning-oriented. Blue Rider supports the district to start such planning processes and design them with the goal of an inclusive community. Blue Rider will participate constructively.

Local participation planning means Blue Rider should actively reach out to communities in order to get in contact with the local neighborhoods, actors, associations, sponsors and institutions, to explore the social space and make it even more accessible for people with disabilities.

Networking and network building in order to gain cooperation and alliance partners should contribute to the creation of public forums for change, where important questions of participation and inclusion of people with disabilities can be discussed publicly. Planning instruments can only be effective if communication and cooperation between politicians, administration and the other actors is achieved and consistently developed.

3.7.5 Concepts for Practical Work of Blue Rider

The contents of the action plan for the further development of Blue Rider in the Newland region are to be further specified in a catalogue of various specialist concepts. The specialist concepts refer to activities for clients, parents and relatives and employees, actions in the social space, actions of cooperation in municipal planning and coordination, and actions for the qualification of the management level and executive management. These specialist concepts make it possible to design the development process systematically and purposefully:

- Concept to support the involvement and qualification of clients;
- Concept for the involvement and qualification of parents and guardians;
- Concept for the qualification of employees;
- Concept for the development and implementation of inclusion-promoting measures in the social sphere;
- Concept for cooperation in municipal planning and coordination;
- Concept for the qualification of the management level and executive management.

CISCOS Workbook
See Worksheet 6.7
Conceptual basics and action steps for the
organizational development process of the
institution "Blue Rider"

3.8 Examples and Exercises

There are many important principles underlying the objective of socially inclusive service delivery that could be included in the description of good practices. However, we would like to emphasise five approaches: person-centred, community-based, collaborative, accessible and safeguarding. Inclusive social services as a person-centred approach is one of the main approaches that is widely adopted in human services (de Akker 2019). Community-based policies are based on the UN CRPD, mainly on Article 19, and there are a number of General Comments and several studies to guide and assist their implementation. Social inclusion as a collaborative approach requires a complex, network-based working method,

resulting in the ability of service providers to develop innovative solutions (Keast 2019). Accessibility is perhaps the most relevant principle of all, the full implementation of which is still a problem in many countries across Europe. Finally, the principle of safeguarding provides a safe environment and its relevant measurement for people with disabilities. Before describing the details of these principles through good practice examples, the five main service areas and related good practices are summarised below.

By using these principals, this chapter aims to examine five types of social services:

1. **Services for children (early childhood and pre-school).** The UN CRPD highlights the need of early childhood development as an important part of the education system. The process of early childhood intervention provides an essential opportunity for children (from the prenatal stage to age eight) to have the chance for "physical, cognitive, linguistic, and socio-emotional development" in a variety of settings (World Bank, 2010).

2. **Education in school following a life course approach.** The right of persons with disabilities to education is emphasised in Article 24 of the UN CRPD, by raising the awareness of equal opportunity. Regarding education, we use the life course perspective (Elder et al. 2003). This educational approach refers to the "time, context, process and meaning" of human life as a complex system that needs to be reflected in education (Bengtson and Allen 1993).

3. **Vocational training and employment.** Article 27 of the UN CRPD provides a right and equal basis for the importance of open, inclusive and accessible vocational training and employment for people with disabilities. Here, too, the UN CRPD highlights a decades-long ambition of policymakers. If it is possible, people with disabilities should have the same training and employment opportunities (Recommendation concerning Vocational Rehabilitation of the Disabled, No. 99, 1955).

4. **Housing and residential support services.** "Adequate standard of living and social protection" as defined by Article 28 of the UN CRPD includes satisfactory housing facilities that are indispensable to a full, inclusive life. A community-based supportive

housing system is a synthesis of housing and services. Our curriculum is based on the Common European Guidelines on the Transition from Institutional to Community-Based Care.[180]

5. **Supporting elderly people with disabilities.** The Special Rapporteur on the Rights of Persons with Disabilities created a report (2017, 2019) on the rights of older persons with disabilities, that emphasises the needs of people with disabilities who are ageing and older persons. These include the need for available community-based support services and arrangements, assistive technologies and devices and supporting autonomy and independence. These demands highlight the importance of independent living, which guarantees dignity and autonomy and a "life outside of residential institutions for older persons with disabilities" (UN, 2019 p. 7).

3.8.1 Description of the Chosen Principles

The CISCOS curriculum states that inclusive social services are based on the values of person-centred active support, a locality-based collaborative way of working, accessibility and safeguarding.

Person-centred active support

A person-centred approach is one of the main standards of the UN CRPD. However, the way this is implemented can be very diverse. An implementation gap (a of failure between plan and practice) can be created through the adaptation process[181]. The person-centred approach or individualised planning has been used since the beginning of deinstitutionalisation[182].

180 https://deinstitutionalisation.com/

181 Mansell and Beadle-Brown 2004, 5.

182 Beadle-Brown 2006.

Infobox 1: Person-centred active support[183]

"Person-centred support requires an understanding of what is important to each individual, what their positive qualities are and what they want for their future.

Person-centred active support is a way of supporting people so they are engaged in meaningful activity and relationships as active participants, exercising more control over their lives and experiencing greater levels of inclusion, independence and choice." (Tizard Centre)

Main elements:

- Choice to empower people to make their own choices;
- Creative solutions to find new solutions based on the unique circumstances and needs;
- Family, partners and friends to be open to work together with peoples' natural support network;
- Personal growth to help people own their futures and to take control of their lives;
- Personalised technology to use technology to change peoples' lives;
- Specialist skills to support complex, multiple needs requiring special skills and knowledge;
- Total communication to connect with people including verbal and non-verbal communication.

The person-centred approach might include the following aspects:

1. Individualised service providing that follows the unique circumstances of the person, by emphasising the personal voice (and choice) of the service user[184].

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183   Hft n. d.

184   Mansell and Beadle-Brown 2004.

Example 1. Good practice of education at the Association for Farm-based Education, Hungary

Farm-based education allows children to improve at their natural pace. Maturation or maturing is not only a determining phenomenon in nature, but is also a crucial element in the growth of children with its own unique dynamics. This methodology allows us to respect these dynamics and provides the pedagogical environment in which the child can grow and mature at his or her own pace.

The learning development focusing on the individual can be realised because one teacher teaches around five children. However, if it is needed, there is the possibility to provide one teacher for one child. On average, 16 children are guided by three to four professionals simultaneously during the learning developing process.

- Instead of knowledge, the emphasis is on developing skills that later can be built upon.
- Activity-based learning is the primary goal to enable the children to gather experience about their own physical abilities and develop the control to utilise their physical skills to the fullest (improving big and small movements and motor coordination). They gather experiences about themselves through social relations, learning how they can become part of a smaller or bigger community and how to relate to each other within a group and develop basic relationship qualities (see further below).

2. An empowerment process that enables people with disabilities to l**ead a dignified life in the community** while recognising their **strengths** and improving their **quality and level of choice and control**. Such a process also contributes to support **full participation** and **citizenship** in society.

Example 2. Good practice of vocational training and employment at the Never Give Up Foundation in Hungary

The Never Give Up social cooperative was established and is operated with the equal involvement of people with disabilities. This is rooted in the foundation's past, when people with disabilities were involved in designing its programs as partners, with their interests and capabilities fully considered. When selecting colleagues for a coffee place, a similar methodology was applied in order to support the employees to find their place in the system. The aim is that they work in areas that match their personalities and are preferred by them.

The philosophy of the foundation is to consider the interests and capabilities of persons with disabilities to the fullest and help them focus on their strengths and skills.

The foundation believes that partnership and enabling is better than one-way support or treatment. Capital was raised by people with disabilities with the help of the music they made. This model is applicable to the coffee place as well (see further below).

3. The involvement of natural support network (families, friends, neighbours, etc) as a circle of support[185] and the **mobilisation of the resources of the individual's natural social network**[186]. The focus should be on **developing positive communication and building strong relationships** between children, their families, and their natural support network, including other families, neighbours and friends who can provide valuable support.

185 Beadle-Brown 2006.

186 Mansell and Beadle-Brown 2004.

> **Example 3. Good practice of housing and residential support services at the Polish Association of Persons with Intellectual Disabilities in Poland**
>
> The **'Circle of Support Safe Future'** model is a comprehensive concept of environmental support for people with intellectual disabilities and their families at their place of residence in a specific local community, focusing on social inclusion by creating support circles around them. The model includes the implementation of permanent solutions, leading to social change, including the creation of conditions enabling the functioning of a person with intellectual disability in their living environment also after the death of their guardians, parents or other relatives. Together they work to develop the skills and passions of people with disabilities, creating opportunities for active participation in the local community, caring for them and safeguarding their future independent functioning (see further below).

4. A focus on the required support as a process. By focusing on the required support as a process, we can avoid limiting the goals to what services can provide[187].

> **Example 4. Good practice of the Center Draga in Slovenia**
>
> On the stage, various expressive components are intertwined with the different difficulty levels of presentation and adapted specifically to the individual. **The experience of each performer has been shaped through the process of making the performance**. All the participants gained **self-confidence and self-esteem**, some of them have changed drastically and achieved tremendous, unexpected progress (see further below).

187 Beadle-Brown 2006.

Locality-Based[188]

The locality-based approach means **recognising the relevant local community resources** in the target area and **mobilising community resources**[189] in service providing. Through the locality-based framework of social planning and providing, we are able to "capture the multi-dimensional nature of community life"[190]. (Beaulieu, 2014:1)

Infobox 2: What is community?[191]

Community is taken to mean people who share a common neighbourhood as well as those with a common identity or interest.

In this Curriculum, we use the term location-based community.

Location-based communities range from the local neighbourhood, suburb, village, town or city, region, nation to even the planet as a whole. These are also called communities of place.

Source: *EuCDN, 2014, p 15, CISCOS C2*

Infobox 3: What are assets?[192]

Assets are what we want to keep, build upon and sustain for future generations. They can be physical things like a building, a local swimming pool or a 150-year-old tree in the town square. Assets can also be intangible, like the work volunteer groups do to beautify the main street or raise funds for the food bank.

How can we involve the local resources in the process of service providing? The following types of resources can be considered in service provision.

Natural resources. The use of natural, in other words environmental, resources such as landscape, air, water, oil and the biodiversity of both plants and animals[193] provide an oppor-

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188 See also the CISCOS materials of Chapter 5 on inclusive community development as well as materials on the importance of the local level to be found in Chapter 4.

189 Emery, Fey, and Flora 2006.

190 Beaulieu 2014, 1.

191 See Element 2 of this manual.

192 Emery, Fey, and Flora 2006, 2.

193 Flora and Flora 2008; Beaulieu 2014.

tunity to be connected to the given, natural resources of our planet. "A healthy and functioning environment provides valuable ecosystem services, such as food, timber, wildlife habitat, flood control, and recreational opportunities, which are essential for human life"[194].

Example 5: Good practice of education at the Association for Farm-Based Education in Hungary

The educational method used in accordance with **farm-based** (activity-based) **pedagogical principles** was inspired by foreign examples and developed to include Hungarian specificities by the **Association for Farm-Based Education**, primarily targeting pre-schoolers and primary school children. **Tiny Nice Farm has been active since 2015** in **Hungary, where improvement and learning adapts to the annual cycle of nature**. It is organised around farm-based activities, during which the pace of transferring knowledge and improving skills are adjusted to the individual and collective pace of the children. **They provide a large space for the child to learn both in terms of physical surroundings and mentally.**

Specific methods:

- Less sitting and a lot more physical activity (in a natural environment);
- More attention, more teachers for less children (multi-teacher system);
- Providing a suitable physical environment for physical activities. On both locations they rent an area with a house and land. Most of the learning-development takes place outside;
- Opportunities for individual development and improvement in a natural environment through activity-based pedagogy.

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194 Beaulieu 2014, 2.

Activity-based development built on knowledge with the available tools learned in controlled and supervised workshops that still involve free creativity including:

• Woodwork and timber processing. For example, the benches in the building were made by the children based on their own needs;

• Gardening using small and large tools, taking care of flowerbeds;

• Animal care. Looking after rabbits and chickens together (grinding and pre-paring food, cleaning the kennels and feeding);

• Knitting and weaving to develop fine motor coordination;

• Bush pruning and tree climbing in the courtyard;

• Learning kitchen jobs (see further below).

Cultural resources based on "common language, symbols, gestures, beliefs, values, rituals, stories and world-view" of the locals and also events, materials (e.g. paintings, books), festivals, museums, and other activities occurring in communities (Beaulieu 2014, Flora & Flora 2008)[195].

Example 6: Good practice of employment at Center Draga in Slovenia
Theatre Director Matjaž Pograjc used an individualised approach to adapt the stage presence of performers to cognitive and other disabilities to fit their strengths and skills. He offers the stage as a space where everyone can enjoy creating or expressing something individual and unique. As singers, musicians, actors, raconteurs and dancers the performers enchant the audience with their authenticity and sincerity rather than a learned skill.

195   Beaulieu 2014; Flora and Flora 2008.

The body (and the voice) are not used as tools of representation and evocation of appropriate effects, as these eschew the control of the director's mind and the formulation of a legible meaning. The unexpected stammers, enthusiastic cries and compulsive movements reveal the fragility and pureness of the performance and at the same time give a sense of belonging to the (theatre) community here and now. Drama and music are proven to enable quality and activity-oriented activity for individuals, as well as intense inclusive integration into the modern social environment (see further below).

Human resources regarding the personal investments that "people make in their education, on-the-job training, or health"[196].

Example 7. Good practice of supporting elderly people with disabilities at the Hungarian Association for Community Development in Hungary
Solidarity Neighbourhood is a **community development program** launched in 2014. The program is based in Budapest District 12, and was established with the objective of activating elderly neighbours and involving people with disabilities.

The **community mentors** of the Solidarity Neighbourhood program are local professionals, engaged in local initiatives. They act as a bridge between the organisational system and the neighbourhood volunteers, activating locals and involving them in the community development program. The group of neighbourhood volunteers and community mentors was established (Hegyvidék Neighbours) with two to three-hour long meetings every second week.

196 Flora and Flora 2008.

This group provides a regular structure for the operating, planning, organising, evaluating, sharing information, acknowledging and supporting each other with regards to events or communities individually organised by neighbourhood volunteers or by the group. The meetings are moderated by a community developer (the professional manager) and provide the possibility for ongoing learning and training. The neighbourhood volunteers with disabilities are equal members of the community and access the workshops with the help of their neighbours.

Social resources "consist of bonding and bridging activities that occur within the local community setting, as well as linkages that tie community members to organisations and resources located outside the community (what is sometimes referred to as vertical connections)"[197].

Example 8. Good practice of housing and residential support services at Helpific in Hungary

Helpific aims **to innovate the traditional welfare system evolving peer-to-peer elements into long term care** and complementing existing welfare and market-oriented models. The organisation aims to do this by mobilising existing community resources, relying more on the concept of participation and social integration with the help of modern ICT tools.

Helpific works as an impact-oriented enterprise promoting social innovation based on a modern sharing economy model.

197   Beaulieu 2014, 3.

> The platform creates person-to-person encounters in local communities between vulnerable people and fellow citizens based on neighbourhood, mutual interest and informal connections instead of formalised professional or clinical relationships.

Political resources. "The ability to affect the distribution of both public and private resources within the community"[198].

> **Example 9: Good practice of supporting elderly people with disabilities at INVEMA in Germany**
>
> INVEMA e.V. has made a name for itself in the Siegen-Wittgenstein district by working in accordance with the UN CRPD and declaring unconditional participation in all areas of life for people living with disabilities. INVEMA e.V. has thus contributed to the gradual change of local support services and public infrastructure towards inclusion (see further below).

Financial resources. "Financial capital represents resources needed to fund the provision, construction, and implementation of a variety of programs, projects, and assets that advance the community's economic, social, and infrastructure development"[199].

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198 Flora and Flora 2008, 145.

199 Beaulieu 2014, 4.

> **Example 10. Good practice of education at the Association for Farm-based Education in Hungary**
>
> Financing the pedagogical work of the Association for Farm-based Education is subject to constant change (e.g. changes in government regulations), but generally, two-thirds of the finances necessary to maintain the centre is paid by the families and the rest is financed by the reduced salary of the teachers, donations and tenders. The farm-school is in touch with the local institutions (e.g. preschool, school), with whom they share events and activities. Moreover, the farm provides the opportunity for them to organise community programs, such as camps and birthdays. The parental circle is responsible for coordinating the donation process, and which special occasions they organise (e.g. charity events). Besides the pedagogical work, the association publishes material related to farm-based education and organises international conferences and training in the subject (see further below).

Built resources. "Built capital (also referred to as the built environment) is the man-made infrastructure that supports human society – our roads, bridges, airports, water treatment facilities, buildings (factories, schools, offices, stores), communication technologies, and public places" as well as existing public services[200].

> **Example 11: Good practice of housing and support of inclusion at Draga Centre in Slovenia**
>
> The planning of health and social care services in Slovenia over the last 20 years has been accompanied by problems of coordination between sectors and a lack of joint planning at the political level. However, this is slowly improving with changes in the current legislation. In local settings and within existing services networking between professionals is generally more coordinated and without major complications, such as between the health and social care centres, social work centres and NGOs in the field of treatment for service users. Good cooperation practices thus exist (see further below).

Collaborative Ways of Working

Collaboration requires a system-change, high levels of trust, extensive dialogue and strong and interdependent relationships between the diverse partners. Specific attributes of the collaborative method include:

- High trust and stable relations;
- Thick communication flows;
- Tactical information sharing;
- Systems change;
- Dense interdependent relations and goals;
- Shared power;
- Pooled, collective resources;
- Commitment and accountability to the network;
- Long-term relational time frame requirement (three to five years).

Example 12: Good practice of vocational training and employment at CUDV Draga in Slovenia

CUDV Draga has been creatively active in the field of music, theatre and dance for many years. Through the theatre concert Slovenian Songs pupils got the opportunity to cooperate with the professional actors and musicians that work at the Slovenian Youth Theater.

In addition to eight professional actors, there are twelve persons with cognitive disabilities singing and dancing on stage. A performance was created that shows that the world lives in a symbiosis. Through music, poetry and dance, it evoked the sensitivity towards people who are different, and also the strong expressiveness that art can awaken in people. Gregor Strniša's poetry got a new sound from the members of Silence, who have consciously distanced themselves from the pop genre and shifted towards electronic music […] Slovenian Songs from another world blurred the borders between different and normal. There was genuine joy in creating, and the final product is a performance that also marks a huge step forward in securing equal opportunities for persons with special needs, or as one of the actors said, "it's a little weird that we handicapped perform in a real theatre performance. But perhaps once there will be a time when this is no longer weird."

Accessibility

Of high quality and **accessible, available, adaptable and affordable** for all. An available, barrier-free environment must be provided based on the user's accessibility needs.

> **Example 13. Good practice of employment at Never Give Up Foundation in Hungary**
>
> The coffee shop Nem Adom Fel is located in the 8th district of Budapest, which is generally accessible for people with disabilities. When choosing the location, it was a priority that it is accessible by public transport (bus, tram), located in the city centre, and could be purchased at a relatively low price. The headquarters of the foundation is located next to the coffee shop, making it a central area strongly linked to the daily operations of the foundation.

Safeguarding

Article 12 of the UN CRPD highlights the relevance of a safeguarding process during service providing regarding the "equal recognition before the law". Generally, the safeguarding procedure helps to clarify how to support people with disabilities to live **free from abuse, harm and neglect**.

> **Example 13: Good practice of housing support at Helpific, Hungary**
>
> When building an online community, continuous efforts are needed to answer messages, respond to inquiries and solve problems. Responsiveness is vital at Helpific, as they promise an easy-to-handle tool for registered members and must make sure that in case of any difficulties the user can rely on them. Helpific also analyses user behaviour and follows visitor statistics in order to optimise the platform to the user's needs. Safety and security and creating an atmosphere of trust is very important. An emphasis on consumer communication helps solve most of these issues.

3.8.2 Examples from Organisational practice

Example 1: Early intervention. The "Gezenguz" Model

Contributor: Dr. Judit Schultheisz (Gezenguz Foundation)

Gezenguz Foundation, established in 1990 by paediatrician Dr. Judit Schultheisz, facilitates the diagnosis and early development of premature children with nervous system injuries, motor development issues and different development or developmental risks, within the frames of complex and family-oriented care. The foundation has developed early intervention therapies, rehabilitation methods and tools (e.g. Huple®) that can be learnt through training and are globally accessible.

Location

The children and families are received at five locations in Hungary (Budakalász, Óbuda, Budafok, Győr, and Salgótarján) with nationwide treatment profiles.

Each location builds a network of cooperating partners at the local level, a team of professionals and services with whom joining forces can efficiently facilitate the intervention of the children and their families.

Important actors

In the spirit of the organisational attitude of the foundation, it establishes cooperation with every partner involved in the developmental process around each institution (the local team).

Every location builds strong cooperation with the hospitals (for example the developmental neurology, and genetics department) and with already existing local public services (for example pedagogical services, post-natal consultant network, paediatrician, family and child-welfare services and centres) and the municipality. If necessary, each location provides a physiotherapist (working in accordance with the Gezenguz model), a remedial

teacher and a psychotherapist or they build up further cooperation with the local professionals (who learn the therapy concept and methods of the Gezenguz model).

This means at each location to foundation attempts to create a local professional team, with the goal that families do not have to leave their living quarters, and are provided with help close to where they live. This need emerging among families created the grounds for the foundation to establish more locations throughout the country. The framework within the complex rehabilitation program that the cooperating network and the professional team provide is completely specific to each region. However, the professional directives of the Gezenguz model and the care protocol applied in the quality management system is commonly agreed.

Willing to become the member of the local professional round table, the Foundation undertakes important professional lobbying activity in order to make the early intervention child therapy as widely accessible as possible, and to have it realised by a competent local team.

The model's effect on child development is continuously monitored by researches in co-operation with universities.

Example: the objective examination of balance with the Huple® device (centralising the centrum, postural control, proprioceptive and vestibular stimulus processing, examining feedback mechanism).

Applied methodology

The most complex early childhood intervention system has been developed in Hungary that includes a variety of diagnostic methods, intervention therapies, developments, coordination of family care and family support tailored to parent or relative cooperation.

The basic characteristic of the model is that the therapy involves the complete family, and is individual in nature in all cases. The need-based rehabilitation development plan is developed according to the individual needs of the child and his or her family. During this process, trust in the parents' competencies is of key importance. In order to unpack these competencies, a coaching style cooperation is applied. Not only the families are involved in the process of the development, but also those people who have an impact on the life of the family within the natural support environment (e.g. grandparents, friends, etc.) thus the natural network and support environment of the family is strengthened.

The specifics of the Gezenguz-model are built on the family house model that contributes to the creation of a homely atmosphere in which the support is provided in a safe and natural environment. The house in addition to being homely, utilises the method of reversed integration. The family, friends and in some cases the peers of the children participate in the practices of the development team (e.g. they join the process of the neuro-hydrotherapy treatment).

Methodology principles:
- Realisation of local service providing;
- Pursuit of complexity (systems theory);
- Need recognition, pursuit of punctuality;
- Flexibility that is supported by frequent supervision and control;
- Establishing patient support that is adjusted to the rhythm of the child and the child's family;
- Step-by-step improvement (steps cannot be skipped during the development process);
- Open communication with the parents in order to make them feel safe.

Special methods developed by the Gezenguz Foundation:

Huple®, a therapeutic medical device (motor skills and coordination development device)

The device contributes to the diagnosis and treatment of the developmental disorders of the central nervous system in a playful manner.

Dynamic development. While static motor skills therapy response reactions may be absent, Huple®'s dynamic therapy generates constant reactions by stimulating the vestibular system. This has a very positive effect of the development of motor skills (fine and gross motor skills and cognitive development), thus helping the maturing process of the neuro system.

It is primarily advised to be used with children between the age of 0 and 6 years, but can be used with older children as well.

Neuro-hydrotherapy /NHT1-2./:

By developing the vestibular system, the formation and development of correct movement patterns is facilitated by special correctional techniques used in the water. The device influences the maturing process of the nervous system, improves the child's muscle tone, breathing control, thermal control, mobility and coordination.

The Huple® device is also used to create a playful developmental process.

The process of realisation

Using the services of the Gezenguz Foundation:
Typically, parents with a young child access the foundation with the prescription of a specialist doctor. This process is facilitated by the fact that the organisation is known in the hospitals throughout the country, hence the doctors' recommendations can cover a wide territory.

A fellow parent network was established that provides help as a social information supplier (available throughout the country).

The process of providing the service

Following getting in touch with the family and in accordance with the care protocol of the Gezenguz model, the necessary diagnostic examinations are conducted. Each family has an individual treatment process, therefore, already from the first consultation, the goal is to be flexible throughout the cooperation and adjust the plan to the needs of the family and the rhythm of the child's development. Following the diagnostic and analysis processes, the consultations the therapeutic treatment recommended for the family are created (generally each child receives four or five therapeutic treatments).

Families receive outpatient treatments at the foundation's facilities multiple times per week. Weekly Intensive Therapy is also an available option and if needed they can be treated at home.

Control and monitoring

The control process is strictly monitored, resulting in monthly supervision.

Financing of the service
- The therapy is supported by the government (public funding, budget support);
- Private funding via family members and financial support paid by the parents;
- Support from the municipality;
- Collecting 1% of personal income tax;
- Private donations (e.g. enterprises);
- Participation in international projects (e.g. Erasmus+).

Challenges

There are many cases where collaboration and effective cooperation between professionals does not take place in early intervention therapies and developments. Hence, the foundation strives towards making this more common on an institutional level.

Incorporating the very early treatment program (between 0 and 16 weeks) in the hospital care system. For example, creating a Gezenguz Room next to NICU in Kecskemét and Kaposvár.

Achievements: The Huple® program created by the Gezenguz Foundation has become a world-class development methodology acknowledged both in Hungary and internationally in Austria, Belgium, the United Kingdom and France.

Findings

In the spirit of continuous learning, authenticity and staying true to the identity, ongoing trainings contribute to providing more and more professional and complex help to the families concerned. In this process, the interests of the child and the family is of primary importance. Establishing a locally available professional team plays a key role, as the foundation realised the efficient cooperation of professionals greatly contributes to creating a suitable development environment for the child and family. High quality care is also guaranteed by the quality control system established decades ago (ISO).

Contact: Dr. Judit Schultheisz

https://gezenguz.hu/gezenguz-foundation/#1461915132779-8fd3d461-c7a3 https://www.facebook.com/gezenguz/

https://www.youtube.com/channel/UCrjsxoh6x7Yc4vl5ECiW96A

https://huple.hu/

Example 2: Education in School Following a Life-Course Approach: Inclusive, Farm-Based Education

Contributor: Andrea Szendrei, Association for Farm-Based Education

The educational method used in accordance with farm-based **(activity-based) pedagogical principles** was inspired by foreign examples and developed specifically for Hungary by the Association for Farm-Based Education, primarily targeting pre-schoolers and primary school children.

Tiny Nice Farm, where improvement and learning adapts to the annual cycle of nature, has been active since 2015. It is organised around farm-based activities, during which the transferring of knowledge and improving of skills is adjusted to the individual and collective pace of the children.

Location

The farm-based pedagogical development is available in Hungary in Pest County at two locations: Gödöllő and Pilisszentiván. When selecting the two locations, the homes of the children and families participating in the process were considered in order to make the locations easily accessible for them, so the children did not have to travel long distances.

Stakeholders

In the early methodology development phase, the professional team included a **development teacher** and an **art therapist** through whose networks **the children and families struggling in the current educational system** were addressed. Together they laid the foundation of the methodology and development was also supported by external professionals (e.g. Dr. Peter Guttenhöfer). The initial target group of the pedagogical method development was children who faced difficulties during schooling (e.g. were not accepted, rejected, or could not function properly within the given frames of school and weren't given sufficient help).

Following the methodology development period, practice began at the two locations and new families and children joined. At that moment, **in accordance with the inclusion principle, anyone could apply who was open to the farm-based pedagogical development** including children with disabilities, learning difficulties, learning disorders, psycho-social problems and children with average abilities. They all found their places in the farm-based educational method.

The grouping of team members at the two locations is based on professions: teacher, early childhood educator, art therapist, gardener, shop teacher and volunteer.

Managing change: how to build a methodology of inclusive teaching based on the best interest of the child

The need for developing a methodology and its possible direction was inspired by a few teachers, parents and their children and started in a student community of interested families. In the beginning, the families and colleagues-to-be only spent the holidays together. After learning together for a period of three to four years, the first real pedagogy work began and the methodology matured.

Since 2015, and later from 2018, the extended form of program developed into different forms: at Gödöllő pre and middle schoolers are together, while at the other location (Pilisszentiván) there are middle schoolers and slightly older children. 25 per cent of the children have disabilities.

Financing of the pedagogical work is subject to constant change (e.g. changes in government regulations), but generally two-thirds of the finances necessary to maintain the centre is paid by the families, and the rest by the reduced salary of the teachers, donations and tenders.

The farm school is in touch with the local institutions (e.g. preschool, school), with whom they have shared events and activities. Moreover, the farm provides the opportunity for them to organise community programs, such as camps or farm birthdays. The parental circle is responsible for coordinating the donation process, and what special occasions they organise (e.g., charity events). In addition to the pedagogical work, the association publishes material related to farm-based education, and organises international conferences and training in the subject.

Methodological approach

Tiny Nice Farm provides a large space for the child to learn both in terms of physical surroundings and mentally. The learning development focuses on the individual and can be realised because one teacher teaches around five children. However, if needed, there is the possibility to provide one teacher for one child. On average, there are 16 children guided by three to four professionals during the learning and development process.

Specific methods:

- Less sitting and a lot more physical activities (in a natural environment);
- More attention and teachers for less children (multi-teacher system);
- Providing a suitable physical environment for physical activities. On both locations there is an area with a house and outside land where most of the learning development takes place;
- Opportunities for individual development and improvement in a natural environment through activity-based pedagogy;
- Extensive planning but also improvisation according to the children's daily needs;
- Involving the children and the parents as partners.

Tiny Nice Farm aims to address the problems reflected in the Hungarian pedagogical system, namely that there is a large gap between the preschool and the school period at an institutional level. The period between pre-schooler age and the age of 10 is handled

together. **The children attending this school thus have the possibility to experience the transformation in harmony.**

Applied methodological elements

- The children take part in creative **free games** where the organised open garden space is full of possibilities that inspire children to play.
- **Activity-based development** built on knowledge with the available tools learned in controlled and supervised workshops that allow free creativity. The required learning material is related to each activity, for example, calculating during woodwork. Activities include:
  - Woodwork and timber processing. For example, the benches in the building were made by the children based on their own needs;
  - Gardening using small and large tools to take care of flowerbeds;
  - Animal care. Looking after rabbits and chickens together (grinding and preparing food, cleaning the kennels, feeding);
  - Knitting and weaving to develop fine motor coordination;
  - Bush pruning and tree climbing in the courtyard;
  - Learning kitchen jobs.
- **Physical activity** including free running and walking together.
- Currently necessary content written into stories.

Other options that can be chosen by the children include extra lessons, massage therapy and craft lessons. Instead of knowledge, the emphasis is on developing skills that later can be built on.

The primary goal of activity-based learning is to help the children gather experience about their own physical abilities and develop the control to utilise their physical skills to the fullest (e.g. improving big and small movements and the fine motor coordination.

The children gather experiences about themselves in the context of social interactions and learn how to become part of smaller or bigger communities and how to relate to each other within a group, and build relationships.

Challenges

The changing legal environment that provides the background for the functioning of Tiny Nice Farm is challenging. The professionals conducting research into the efficiency of the applied methodology also face challenges.

Results of the practice and lessons learned

Developing the abilities of the children, in accordance with the given field of development.

Farm-based education allows children to improve at their natural pace. Maturation or maturing is not only a determining phenomenon in nature, but is also a crucial element of child development with its own unique dynamics. This methodology respects these dynamics and provides a pedagogical environment in which the child can grow and mature at his or her own pace.

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https://farmiskola.hu/

https://www.facebook.com/Farm-alap%C3%BA-Nevel%C3%A9s%C3%A9rt-Egyes%C3%BClet-511273592324591/

Example 3: Vocational Training and Employment

Contributors: CUDV Draga and Theatre Mladinsko Ljubljana (Matjaž Pograjc)

> *"It's a little weird that we handicapped perform in a real theatre performance. But perhaps once there will be a time when this is no longer weird."*

Centre Draga is an institution for the education, training, work, health care and rehabilitation of children, adolescents and adults with moderate, severe and profound intellectual disabilities and impairments.

The Centre was established in 1984 by the Government of the Republic Slovenia. It is situated in the vicinity of Ljubljana, the capital of Slovenia. In addition to the main facilities located at the Centre's headquarters in Ig that consist of five residential homes, a school, several workshops, dispensaries and rooms for medical rehabilitation, various additional units have been set up.

Location

Osrednja Sloveija in širše

Stakeholders

As good practice, the creation of a joint project is **based on the cooperation of the Theatre Mladinsko Ljubljana and the Center Draga**. CUDV Draga has been creatively active in the field of music, theatre and dance for many years. By taking part in the theatre concert Slovenian Songs pupils got the opportunity to cooperate with the professional actors and musicians that work at the Slovenian Youth Theatre. The "Slovensko mladinsko gledališče" (literally translated to mean Slovenian Youth Theatre, The Mladinsko Theatre) carries its history in its name.

Theatre Mladinsko Ljubljana was established in 1955 as the first professional theatre for children and youth in Slovenia. In the first twenty-five years it created performances tackling topics including the Holocaust, coming of age and love in the times of revolution. In 1980, it took a new step and deliberately expanded its programme, linking political criticism and provocativeness with innovative performative procedures to attract audiences of all ages. The theatre's home, where they conceive, create, study and play, is in Ljubljana but they perform a significant number of their performances on tour. From its early days in

Slovenia and then Yugoslavia, and at least since the early 1980s Mladinsko has been firmly embedded in Europe's theatre landscape and since the 1990s also the landscape in South America and other continents. In over forty countries around the world, their ensemble, capable of extraordinary transformations, has left an indelible impression. The actors tackle music, choreography and psychological challenges working in a non-hierarchical way, supporting each other in a group. Mladinsko describes itself: "We are a theatre. But we expect more than just watching from our spectators, we try to engage them in a dialogue and make them active participants. We create performances, but not in a vacuum. We observe our society critically, comment on it and strive to shape it." For Mladinsko the public space becomes an equal space for performance.

Implementation

In addition to eight professional actors, there were twelve persons with cognitive disabilities singing and dancing on stage. A performance was created that shows that **the world lives in a symbiosis. Through music, poetry and dance, it evoked sensitivity towards people who are different, and also the strong expressiveness that art can awaken in people**. Gregor Strniša's poetry got a new sound from the members of Silence, who have consciously distanced themselves from the pop genre and shifted towards electronic music […] Slovenian Songs from another world blurred the borders between different and normal. There was a genuine joy in creating, and the final product was a performance that also marks a huge step forward in securing equal opportunities for persons with special needs, or as one of the actors said, "it's a little weird that we handicapped perform in a real theatre performance. But perhaps once there will be a time when this is no longer weird."

At the initiative of director Matjaž Pograjc, 12 people with special needs joined the project of the theatre's play Slovenska Popevka, ten of them from CUDV Draga with intellectual disabilities, Down syndrome, autistic disorders, post-traumatic brain injuries, as well as combined disorders and blindness. It is a play, designed as a theatre concert combining

drama, music and dance. The premiere performance was on 9 November 2017 and has been performed a further 20 times to date.

Methodological approach

As on the stage, various expressive components were intertwined with different difficulty levels of presentation and adapted specifically to the individual. The experience of each performer was shaped through the process of creating the performance. **All the participants gained self-confidence and self-esteem and some changed drastically, achieving tremendous, unexpected progress.**

During the search for the adequate solutions, we noticed **a dynamic fusion of special pedagogical and theatrical professions**. Overall, the public's response reflected a general acceptance of abnormality, in line with contemporary society. Music and theatre have proven not only to be excellent mediums that enable quality and usefully spent free time, but also supportive of inclusive integration into the social environment.

Professionals acting as a bridge

Support for theatre professionals and users was provided by six professionals from the centre. The main tasks were **to assist in establishing contact between users and theatres**, interpret the specific needs and requirements of participants on both sides and find professional and technical solutions to realise individual scenes and develop ideas of engagement. The centre also prepared the players for play, dance and musical performances with daily pedagogical work.

The decision of the centre's professional staff who participated in the project was to try **to be as involved as possible in all stages of the play's production**. The aim was to allow the director and the actors to get to know the users and their abilities on their own, giving them the opportunity to discover their potential on an ongoing basis. However, the professional staff were always available for consultation or assistance whenever it was needed.

Another aim was to give users the most authentic experience of the ordinary, unadapted world and the opportunity to actively and independently face the challenges of an un-adapted environment (e.g. agreements, expressing wishes, disagreements, suggestions, orientation, etc.).

The project had a good initial design. The basic ideas followed in the creative process were:

- To offer the user various forms of creativity to directly discover their interests;
- An individual approach, choosing appropriate strategies, procedures and content that opened the possibility for the user to successfully cooperate in the group;
- The user was able to choose the level of complexity of cooperation;
- The user was not restricted by creation rules (i.e. right or wrong).

The following are areas that needed special attention and required specific approaches.

Social competencies:

- Social field including relations with teammates, interdependence, ability to assess position, response to the non-verbal expressions of a teammate, personal adaptation and independence;
- Behavioural and responsive characteristics including activity, orderliness, confidence, mood, compliance, self-monitoring and judgment.

Artistic expression:

- Testing and integrating different fields of artistic genres including declamations, games, pantomimes, dance, music and spatial expression;
- Searching for expressive options that were closest to the user in terms of their interests, abilities and specifics;
- Synthesis of the different options of expression;
- Ensuring the conditions under which the user could test their own expression were safe, and developed their own creative potential.

Communication competencies:

- Overcoming difficulties in comprehension, vocabulary, articulation and specific disorders;

- Orientation to the fact that each individual can express his or herself, it is only necessary to find an appropriate way to test different forms of communication.

Pedagogical aspect:

- Understanding texts, understanding action, learning texts, learning to sing, learning to play instruments, learning to move, manipulating objects and space and co-creating with a partner.

Level of orientation:

- Individual search for expression levels that are in the sphere of the moderate superstructure of the field of mastering the existing state.

The opportunity given to users of participating in this project is a huge step and a unique breakthrough for the population of people with intellectual disabilities in the Slovenian social space. However, public reactions have shown that it is a bold initiative. While most supported and welcomed the project, there were individuals who still differ in their acceptance. But accepting otherness cannot happen in theory, and this is why any practice that brings convergence is all the more valuable.

Director Matjaž Pograjc used an **individualised approach to adapt the contents and the stage presence of the performers to cognitive and other disabilities to fit their strengths and skills**. He offers the stage as a space where everyone can enjoy creating or expressing something individual and unique. As singers, musicians, actors, raconteurs and dancers, the performers enchant the audience with their authenticity and sincerity rather than a learned skill. The body (and the voice) are not used as tools of representation and evocation of appropriate effects, as these eschew the control of the director's mind and the

formulation of a legible meaning. The unexpected stammers, enthusiastic cries and compulsive movements reveal the fragility and pureness of the performance and at the same time give a sense of belonging to the (theatre) community here and now.

Challenges

Mladinsko is not just a theatre. Matjaž Pograjc, who describes Strniša's work as "poetry for voice", aims to build a theatre monument to the man who proved that songs can be art and that pop can be good music. In the process, he aims to find beauty in unexpected places and venture into (in Slovenia still uncharted) territory of disabled theatre, bringing together Mladinsko actors with musicians, singers and dancers with cognitive disabilities.

"With a daring, innovative approach, the fusion of all participants helped to give birth to a powerful, dynamic energy, that created an unrepeatable theatrical ensemble that will astonish and enthral us anew with every performance. I am certain that Slovenian Songs will be an unforgettable performance, subtly mirroring the multifaceted wealth of our lives, a special relationship to creativity and individuals in synch with the world. From life to the stage and from the stage into life!" (One of the spectators, November 2017.)

Results and lessons learned

Theatre concert Slovenian Songs is an inclusive theatre project. Performances have been staged since 2017 throughout Slovenia. On the occasion of Slovenia's National Independence Day, December 23, 2019, the show was included as a central part of the program. The artistic part of the celebration, entitled 'Your Heart, My Homeland - A Story for a Different Celebration', directed by Matjaz Pograjc, followed the speech of the President of the Republic of Slovenia. The play was produced in cooperation with the Slovenian Theatre Mladinsko and Centre Draga and was broadcast live on the first program of TV Slovenia. A short promotional film Slovenska Popevka was made, as well as a film of the entire performance.

In the future, we wish to develop a network of modern services and programmes to meet the needs of individuals with moderate, severe and profound learning disabilities and their families as well as the standards set by the participating professional departments. The most important goal is to preserve a high degree of satisfaction for our current users and their relatives as well as the staff optimism.

In addition, there is a strong emphasis on raising awareness among the general public, both nationally and internationally, in terms of the talents and abilities of people with disabilities.

Contact:

center.draga.ig@center-db.si>

https://www.center-db.si

https://mladinsko.com

https://www.youtube.com/watch?v=4eQfTk09EY4

https://vimeo.com/243811809

https://4d.rtvslo.si/arhiv/proslave-in-slavnostne-seje/174252978

https://www.rtvslo.si/dostopno/napovedi/dan-samostojnosti-in-enotnosti-drzavna-proslava-s-tolmacem-v-szj/509764

Example 4: "Everybody can afford to help others" - A Social Enterprise Founded and Run by People with Disabilities

Contributor: Dely Géza, director of Never Give Up Foundation

Restaurant, coffee house and community space Nem Adom Fel (I'll Never Give Up) opened on January 2016 and was the first social enterprise to involve people with disabilities in its founding as well as in its daily operations. It is operated by Nem Adjuk Fel (We're Not Giving Up) Social Cooperative.

Location

Never Give Up is located in the 8th district of Budapest in Hungary, which is generally accessible for people with disabilities. When choosing the location, it was a priority that it is accessible by public transport (bus, tram), located in the city centre, and could be purchased at a relatively low price. The headquarters of the foundation is located next to the coffee house, in a central area strongly linked to the daily operations of the foundation.

Stakeholders

The partners that helped finalise the social enterprise were NESST Springboard program and COSTA Café (as a business partner in finalising of the operations of the coffee house). Mentors from the hospitality sector contributed to the building. For example, members of "Fröccs terasz", "Ízlelő étterem" and "Fészek klub" were consulted regarding the portfolio of the services and the design of the space. When starting the project no, one in the team had been involved in hospitality or even managing a business, hence all the necessary knowledge needed to be gathered ahead of the opening.

The cooperative was established and is operated with the involvement of people with disabilities. This stems from the foundation's past, when disabled people were involved in the designing of the foundation's programs as partners, with their interests and capabilities fully considered. When selecting colleagues for the coffee house a similar methodology was applied in order to support employees to find their place in the system and **work in areas that match their personalities and are preferred by them**. For example, the waiters and waitresses should be open-minded, have a positive vibe and enjoy communicating, while the baristas should be interested in the handling of machines. Both the cooperative society and the coffee house could partner with all the organisations and partners of Nem Adom Fel, so it was a great help to have their valuable contacts.

Implementation

The social corporative, which is independent of the foundation, was established to handle the operation of the coffee house. As the property is owned by the foundation, a complimentary rental contract was signed by the parties.

In the beginning, the employees took part in a three-month training, during which they learned all the basics of their jobs including waiting, coffee-making etc. The newcomers are now trained by their colleagues and the training is always customised to the needs and abilities of the individual. A restaurant in the 11th district helped a lot initially with regards to the operation design. Before opening, the current manager of the coffee house spent valuable time there as an intern.

The team of the coffee house includes several disabled people and consists of 30 employees (five to six people per shift), a shift manager and a management team of three people.

Methodological approach

The initial goal was to create a community space that could accommodate the members of the foundation as well as their activities, events and meetings. After the purchase, domestic tenders were used to renovate the property and it was decided to extend the original scope to form a social cooperative and accommodate hospitality functions with the help of the Springboard Program (to identify and develop social enterprises). This way the space could function not only as a community centre hosting cultural events but as a coffee house and a restaurant as well.

The philosophy of the foundation is to consider the interests and capabilities of the disabled to the fullest and help them focus on their strengths and skills. The foundation believes that partnership and enabling is better than one-way support or treatment. Capital was raised by disabled people with the music they made. This model is applicable to the coffee house as well, so those who work there can treat it as their own and feel like they add value to a cool, mainstream place.

Challenges

The coffee house is not well-embedded in the area and cooperation with local entities could be stronger. Joint efforts have so far been made with the Municipality, Vasas HQ (providing catering) and "Kesztyűgyár" Community House (event organisation). The intention to draw more locals to the restaurant for lunch and dinner has not yet been accomplished as they seem to prefer other places in the area. It is also a challenge to increase profit in ways that do not discredit the foundation's principles and moral values. Whenever a compromise had to be made in favour of money, it was proven that principles are more important than profit.

It was also challenging to harmonise the cooperation between disabled and not disabled employees. The main values (mutual respect, acceptance, partnership) must be accepted by all colleagues.

Results of the practice and lessons learned

The community dimension of the venue has grown stronger lately, that is well reflected by the cultural events taking place. Never Give Up built an audience that keeps returning to different events and is considered to have some of the best programmes in town, courtesy of a disabled program manager. The goal to provide quality has been achieved since the venue is well known for its cultural events.

Elements that contribute to sustainability:
- Daily income;
- Cultural and community events, happening at least three times per week, usually in a full house;
- Events management including catering and renting spaces.

Contributing to the employment costs, the venue is an accredited employer which enables Never Give Up to employ five to six people per shift.

How can the staff who have previously worked for a foundation become successful businessmen and businesswomen? **The road is full of challenges since the project requires totally different operation, but a gradual approach is one of the main factors here.**

Contact	Géza Dely, delygeza@gmail.com
URL of the practice	http://nemadomfelkavezo.hu
Related Web site(s)	https://www.facebook.com/nemadomfelkavezo/
Related resources that have been developed	https://www.youtube.com/watch?v=H8--t1EfdWI

Example 5: Job Crafting

Contributor: Foundation Activation

Job crafting is an innovative service supporting the professional activation of people with disabilities which, thanks to the simultaneous impact on the job seeker and the employer, achieves good results in terms of acquiring and maintaining employment of people with disabilities in the open labour market.

Location

The service is provided in the workplace environment throughout Poland.

Stakeholders and partners

Foundation Activation (Fundacja Aktywizacja) is the main polish service provider in the field of vocational activation of persons with disabilities. Other partners include:

- The people with disabilities (excluding intellectual disabilities), who want to work in the open labour market, i.e. users;
- Employers who want to hire persons with disabilities;
- Other employees;
- Methodological approach.

Implementation

The main problems addressed are the low rate of employment of persons with disabilities in Poland as well as law durability and quality of employment. The methodological approach used was originally designed in the US as a worker-driven practice focusing on the quality of employment. At the centre of this process is the job crafter and their client. In the Polish version of this service, the focus is not only on the persons with disabilities but also on employers and other employees in the workplace. The job crafter is not working alone but with a team of specialists.

Job crafting is a service that grew out of the 30 years of experience of the Activation Foundation (FA) in supporting persons with disabilities in the search for good quality employment. For many years, FA has been a leader in the professional activation of persons with disabilities and the largest non-governmental organisation in Poland operating in this area, permanently employing 150 employees in seven field offices across the country.

Their many years of experience have taught them that professional activation of persons with disabilities has a long-term effect on preparing persons with a disabilities to enter the labour market, as well as appropriately affecting the employer and preparing the employee team that the person with disabilities will join. In the search for the optimal solution, FA used the originally designed US job crafting method.

The original version of this method mainly emphasises working with the client on their development without considering the environment. Implementing it in the Polish context based on their experience, FA added the component of considering the future work environment. Recognising the potential of such a position in the process of professional activation, they also changed the structure of the team involved to include an appointed leader (job crafter), who became the manager of the professional activation of the person with disabilities. The leader is responsible for the process and the outcomes but must also cooperate with other specialists involved such as psychologists, vocational counsellors,

lawyers and other specialists according to individual needs. **An important task of the job crafter is the proper establishment of relations with the employer and a good understanding of the work environment and its active co-creation**. This task includes analysis of the job and the employer's organisational and legal conditions and recognition in the future employee team.

Financial background

The service received support six times in the form of a public grant (2017-2020) for a total amount of PLN 17,712,632.23.

Challenges

The service is project-based and according to FA management staff better outcomes could be achieved with permanent financing since it is expensive to properly train job crafters. There are different aspects to consider including how to involve with persons with disabilities in the professional activation process, how to work with employers and employees in different working environments, how to make workplaces accessible and how to use reasonable accommodation. This work requires a high level of coaching skills. With project-based financing, it is hard to achieve full-time permanent employment contracts.

Results and lessons learned

The main purpose of the job crafting service is to make persons with disabilities independent by **influencing the process from inactivity to professional activity**. Indicators measuring the success of the professional activation process include whether the employment lasts for over six months (durability of employment) and regularly examining whether the employment patterns found in this model for our clients meet these parameters. The results of systematic research (carried out on a monthly basis) conclude that 75.84 per cent of employment lasts for over six months (research from 19/12/2019 N = 563).

The foundation also asks persons with disabilities about the quality of employment. Questions include: How satisfied are you with your current job? Up to 79 per cent of all answers rated a 4 or 5 on a 5 point scale (data as at 19.12.2019. N = 563).

If service providers want to achieve better access to the open labour market for persons with disabilities, they should work in a partnership with people with disabilities and employers. Both are equally important in the process.

Contact details	Fundacja Aktywizacjaul. Narbutta 49/51, 02-529 Warszawa, sylwia.danilowska@aktywizacja.org.pl
URL	http://jobcrafting.org.pl/
Related Web site(s)	https://aktywizacja.org.pl/

Example 6: Housing and Supporting Inclusion

Contributor: Centre, CUDV Dolfke Boštjančič Draga, 1292 IG, Slovenia

Location

The central local community of Grosuplje in Slovenia

Centre Draga is an institution for the education, training, work, health care and rehabilitation of children, adolescents and adults with moderate, severe and profound intellectual disabilities and impairments and people with brain injuries (hereinafter referred to as users). In addition, it operates in accordance with the Standard Classification of Activities Regulation.

The centre was established by the Republic of Slovenia in 1984. In 2006, the centre approved the Statute and in 2011 the Ministry of Labour, Family and Social Affairs approved the amendments to the decision on the transformation of the centre into a public social wel-

fare institution. Centre Draga has units in different locations in Slovenia, and their program is implemented through day-to-day forms of schooling and employment, as well as the full-day residence of children and adults.

Stakeholders and partners

The planning of health and social care services in Slovenia over the last 20 years has been accompanied by problems of coordination between sectors and the lack of joint planning at the political level. However, this is slowly improving with changes in the current legislation. In local settings and within existing services, however, networking between professionals is generally more coordinated and without major complications, such as between the health and social care centres, social work centres and NGOs in the field of treatment for service users. Good cooperation practices thus exist.

In order to find possibilities for achieving inclusion, Centre Draga connects with the various organisations and associations in Slovenia and local communities in which the individual units of the centre are located. As a result of good cooperation with the local community and various organisations, the centre has been able to develop, through an idea project coordinator and an interdisciplinary team, an example of good practice, namely independent living for a couple with intellectual disabilities in the community.

Methodological approach

The centre's focus on housing and integrating individuals into the community is one of the primary goals to improve the quality of life for people in need. **This commits us to the constant search and exploration of new avenues, working methods, forms of assistance and adaptation, and supporting technologies that can achieve this goal**. The main premise of realising the social model in line with our vision is that all persons with developmental disabilities are given the opportunity to choose and take responsibility, even when it is not clear how they can do so, or the way in which they can is not in line with our expectations.

For the past three years, the centre has team-mapped the idea of two users living independently, namely a couple who previously lived in an institution and then a residential unit. They expressed the need for an independent life where they could make their own decisions and have more peace and privacy. The preliminary project coordinator, in collaboration with the CUDV Draga team, prepared the conceptual plan to find suitable housing based on prior written and oral discussions with representatives of the local community including the social work centre, the mayor and representatives of the local community, shops, organisations, inns and schools. After lengthy efforts and searching, the owner of a house was prepared to rent the apartment to the disabled couple.

Based on many meetings and mentoring, multiple risk assessments for various life activities such as shopping, transportation, site visits, apart-hotel handling, safety and health care, and a program and customer support plan, the couple moved and gradually began to live independently. There were many barriers to achieving this goal, especially created by individuals who thought that the attempt was too risky and that exaggerated control and checking the apartment was in order, as well as those who feared the responsibility and health peculiarities of the users. After some time, the owner of the house was no longer convinced to extend the rental contract of the apartment. With persistence, consistent planning, evaluation and elimination of weaknesses in the support plan and discussion, the couple is almost independent after three years of housing experience. Improving on the initial 80 per cent, the couple now receives about 20 per cent of the support services. After that time, it was possible to identify the areas they could handle on their own or with little support and those areas in which they require public services. In order to promote and raise public awareness, a movie was made with the help of national TV, which also premiered and is available online.

Quality of life monitoring and verification systems (of subjective and objective quality), quality analysis and research generally speak to the positive effects of community living, with the mandatory involvement of users, their families and representative

organisations. Good instrumentation for such country-specific verification is needed. Slovenia is only at the beginning of the implementation of systematic pilot projects of community integration in the area of obtaining dedicated European funds. Changing life in institutions with community living is not a sufficient condition in itself. It is necessary to start with pilot research and do a detailed analysis of the situation and the user needs. There should be more research into links between quality of life and quality of existing services. Only by understanding how the quality of service affects the quality of life of users can we offer a community service policy that will ensure the successful inclusion of excluded people.

The professional paradigm pursued by the Draga Centre places **the first priority on improving the quality of life for vulnerable people**. It does not matter if someone fails but rather to what extent help for him or her is possible. This commits us to the constant search and exploration of new avenues, working methods, forms of assistance and adaptation, and supporting technologies that can achieve this goal. The main premise of the implementation of the social model is that all persons with developmental disabilities are allowed to choose and take responsibility, even when it is not clear how they can do so or the way in which they can does not meet our expectations.

Challenges

One of the key issues in enforcing Art. The Convention also has a role to play in the leadership of representatives of local communities and the political sphere in promoting a different culture of life for different user groups. The presence of apathy in leadership and institutional rigidity may also hinder the introduction of new ideas in the field of DI. Without cultural change in the way individuals interact in leadership positions with workers, external stakeholders and systemic support, appropriate change cannot be achieved. Changes and cultural values, however, require such circumstances and conditions to take effect. We often think that the goal of success depends on the negotiating and rhetorical skills of individuals, including senior executives, but we cannot leave individuals to make

changes alone as an empirical follow-up to a new reality. Such conceptual designs must also be systematically supported.

Thus, it is necessary to determine what kind of housing we need in individual municipalities, since it is the municipality - the local community - that combines everything including health, education, social space, institutions, infrastructure, power, economy, road building permits, etc. This makes cooperation between departments easier, since they do everything to improve the lives of citizens. For nonprofit housing, municipalities should be more committed to social housing policy as there is a great need for affordable housing units.

Results of the practice and lessons learned

In the area of community integration or inclusive living, a good example is the practice of the independent living of a couple with intellectual disabilities. Prior to the relocation and monitoring of their life, a conceptual plan was created in addition to a project scenario, an evaluation and improvement support plan, records of agreements and tasks and a risk assessment involving different stakeholders for support organisations, contractors and their assistance tasks. As good practice, two films were also made, the first, the Second Violin, showing the life of the couple in a lounge and working and the second film, New Neighbours, showing their life in an independent apartment.

Some individuals may still think that the social model is threatened by the rejection of discussions and views regarding illness or deficits, thus preventing users from talking about their problems openly (not via their relatives) so they can be more honest. The experience shows the complex nature of the various deficits and barriers of individual groups of people, requiring psychosocial and emotional understanding, as well as the understanding, coordination and interconnection of different experts within different fields of expertise and politics. We emphasise the need to develop and integrate theory and practice with research modes that will be open to different experiences across the spectrum of different

populations of children and adults. With regard to the global space of the social model, it has undergone a considerable development of ideas in recent years from other models that address different vulnerable groups of people, including models of cultural character and models of social relations. We are aware that the ideas of these models not only bring new conceptual challenges and changes, but also different models of professional practice, available assistance and appropriate services and economic security for all users and their families. Our aim is to improve cooperation between European associations and organisations. The results of work and cooperation in the Slovenian area are reflected in the recognition of the individual and the institution.

The main purpose of deinstitutionalisation and efforts in the field of the independent living of persons with disabilities should be to encourage professionals, the lay public and those responsible in the country to think critically about the importance of different forms of residence for individuals in terms of benefits for them, their families and society as a whole as well as the state itself. Through changes in national policy as well as legislative framework, projects and our own work, we strive to develop new programs and plans for independent and community living. Housing policy, not-for-profit housing and subsidies from municipalities and the state also play a key role in this.

Contact details	center.draga.ig@center-db.si
Related Web site(s)	https://www.center-db.si
Related resources	https://4d.rtvslo.si/arhiv/dokumentarni-filmi-in-oddaje-izobrazevalni-program/174337408 https://4d.rtvslo.si/arhiv/new-neighbours-novi-sosed-je/174616264

Example 7: Circle of Support Safe Future Model

The Circle of Support Safe Future model is a comprehensive concept of environmental support for people with intellectual disabilities and their families at their place of residence, in

a specific local community, focused on the social inclusion of these people, including by creating support circles around them. The model is focused on the implementation of permanent solutions, leading to social change, including the creation of conditions enabling the functioning of a person with intellectual disability in their living environment also after the death of their guardians, parents or other relatives.

Location

- National level (model designing and evaluation).
- Eight communities at the local level (implementation).

For now this is a project-based pilot program.

Stakeholders

Circles are an environmental support system that is comprised of persons and agencies/authorities involved in the daily life of a person with disabilities and who have an impact on the quality of his or her present and future life. This includes:

- Family members and friends;
- Neighbours, friends and local volunteers;
- Doctors and nurses;
- Lawyers;
- Local service providers;
- Social welfare centres and staff;
- Religious groups;
- Other families in similar situations.

Together they work to develop the skills and passion of a person with a disability, create opportunities for active participation in the local community, care for them and safeguard their future independent functioning. Circles of Support Safe Future model is led by the Polish Association of Person with Intellectual Disabilities (created in 1963, 12 500 members, supporting 30 000 persons with disabilities on a daily basis).

Implementation

The Circle of Support Safe Future model is a comprehensive concept of support for adults with intellectual disabilities in the local community, where these people and their families can live with dignity and lead independent lives.

The aim is to develop solutions for:

1. The legal-financial, residential and social security of a person with intellectual disabilities at a time when, for natural reasons, they are already losing reliance on the family.
2. The preparation of community support enabling them to continue to function in their local community.

The key figure that the Safe Future model is organised around in environmental work is a person with intellectual disability. To create a circle of support for them, they must accept this idea. The most important aspect of working with a person with intellectual disability is focusing not on their deficiencies and deficits, but on their resources, strengths and interests. This means building circles of support that fully respect the dignity and autonomy of all persons with intellectual disabilities.

Circle of support:

- Enables a person with a disability to function properly in his or her existing community and improves their quality of life;
- Broadens the group of people involved in the support of a person with disabilities in their community;
- Provides the skills or education needed for a person with disabilities to function independently (as far as possible);
- Develops legal, housing, financial and health solutions;
- Maintains the quality of life of a person with disabilities after losing their closest relatives.

The support system developed in the Safe Future model is mainly based on environmental resources, understood as a set of talents and skills of individuals, social relationships, norms, trust, cooperation, and also organisational capabilities (e.g. local institutions). An effective combination of and the activation of these resources can create development capital that gives new opportunities for people with intellectual disabilities.

There are three elements of action to introduce and support the change:

1. Working with people with disabilities and their families (12 circles in 8 places, over 100 persons);
2. Organising the local community (coalition);
3. Education and support for the change process (central and local).

Methodological approach

The problem that needed to be addressed is the lack of support for families with a person with intellectual disability, especially adults. The Safe Future model is a social macro-innovation adapted to Polish conditions that also fills a significant gap in the support system for people with disabilities. It is compatible with the overall evolution of European assistance systems, focused on the development of social services, environmental appreciation forms of support and activation programs. In the axiological layer, the model refers to the principle of respecting the dignity of persons with disabilities by realising their right to self-determination and full participation in social life (empowerment approach).

Challenges

In Poland, some persons with intellectual disabilities do not have their legal capacity and all the legal power is in the hands of their carers. In such a situation it is a real challenge to put the person with a disability at the centre of their own lives.

The lack of preparation, anxiety on the part of families, fears, distrust, and worries about how to face the future all come into play. How should I start thinking about it? Can I allow

strangers to interact with my child? Can my child be supported adequately in the external social world?

Cooperation with family is a long-term process that can be extremely emotional. There is a need to support the family in a new situation without imposing. Small steps to create new solutions to support the autonomy of a person are needed (e.g. a training apartment) as well as the mutual support of families.

Results of the practice and lessons learned

What were the concrete results achieved with regard to outputs and outcomes? What has been the impact (positive or negative) of this good practice on the beneficiaries?

The project is still in the testing phase so the results are preliminary. The most important outcomes are:

- Increased awareness of the role of the local community in supporting people with intellectual disabilities and planning inclusive services;
- Families feel that they are not alone in the process and the role of a community support system is important;
- A tool to increase the possibility of independent living of persons with intellectual disabilities in the local community.

Lessons learned

- When the local community is at the centre of a support system families feel safer and the risk that the person with an intellectual disability ends up at an institution decreases significantly.
- It takes 1-2 years for a well-functioning support circle to be created.
- There is a need for continuous monitoring.

The search for people in the circle requires overcoming social stereotypes and the need to prepare volunteers for cooperation.

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URL	https://kregiwsparcia.pl/
Related Web site(s):	https://psoni.org.pl/
Related resources	https://www.youtube.com/watch?v=2ooWMG453yM https://www.youtube.com/watch?v=Xj_rqX60jWg

Example 8: HELPIFIC Service IT-platform

Institute: Contributor: Zzolt Bugarszki, Helpific Estonia / Helpific Hungary

Helpific (https://helpific.com) is a web-based enabling environment for individuals with disabilities to find support in their local community to live independently.

Helpific was established in 2014 in Tallinn, as a result of the special hackathon event Enable Hackathon. The original purpose was to find ways to build trustful relationships between vulnerable people and fellow citizens in the community. Helpific was established by developers, marketers, social workers and disabled people.

Location

Estonia, Hungary, the Netherlands, Croatia and Ukraine

Stakeholders and partners

Helpific aims to innovate the traditional welfare system involving peer-to-peer elements in long-term care to complement existing welfare and market-oriented models.

The development model of Helpific was created in cooperation with universities, research institutions, service providers and NGOs in order to pilot the platform in different geographic, cultural and legal contexts.

A Helpific team consists of three basic functions:

- IT development;
- Marketing and communications;
- Consumer relations.

IT development

The Helpific's IT development is managed from Tallinn, Estonia and Budapest, Hungary. The server capacities and IT headquarters are located in Tallinn. The first version of any new functions is introduced in the Estonian language first, tested and piloted in Estonia and then translated into different languages.

Marketing and communications

One of the most important activities in a Helpific team is continuous marketing. Team members dealing with marketing issues need to be trained how to use Helpific's social media sites, how to maintain relationships with the local media and how to shape the communication strategy of Helpific.

The main communication strategy of Helpific is provided by Helpific Estonia and consists of the main principles of the company's communications in addition to the visual elements used by Helpific initiatives in different countries.

Consumer relations

Building up an online community requires continuous efforts to answer messages, respond to inquiries and solve problems. Responsiveness is vital, as Helpific promises an easy-to-handle tool for registered members who must be able to rely on it in case of any difficulties. Helpific also analyses user behaviour, and follows visitor statistics in order to optimise the platform to the user's needs. Safety, security and creating an atmosphere of trust is very important. An emphasis on consumer communication helps to solve most of these issues.

Methodological approach

Helpific's platform has been developed to address the challenges of the current welfare system. Over the last decades deinstitutionalisation has radically changed the landscape of the care system. Community-based services started to replace large institutions and vulnerable people who had been excluded from the society had more opportunities to maintain their independent life in the community. Another critical point is, despite the current community-care system being geographically located in the community, it usually creates very limited connections between service users and fellow citizens in the neighbourhood. There is a call to create a more sustainable and diverse model for long term care.

Helpific aims to mobilise existing community resources and rely more on the concept of participation and social integration with the help of modern ICT tools. The platform connects citizens on a peer-to-peer level and strengthens neighbourhoods and local communities. Helpific provides an innovative tool for housing-related services and residential support services with the goal to increase the social capital of vulnerable people and create new social contacts beyond the capacities of welfare services. Helpific's mission is to promote an independent life for people with disabilities and to contribute to the development of stronger communities.

Implementation

At the development stage, Helpific works in a non-profit way, running teams of volunteers and paid staff in different countries. Development of the Helpific platform occurs with the involvement of universities, service providers and NGOs and with a large community of volunteers who embrace the platform's values and ideas.

Helpific works as an impact-oriented enterprise promoting social innovation based on a modern sharing economy model. It aims to innovate the traditional welfare system by including peer-to-peer elements in long-term care to complement existing welfare and market-oriented models. The platform creates person-to-person encounters in local com-

munities between vulnerable people and fellow citizens based on neighbourhood, mutual interest and informal connections instead of formalised professional or clinical relationships.

Matchmaking

When a help seeker is connected with a helper and the help has been provided this is called matchmaking. The main purpose of the Helpific platform is to enable matchmaking by providing an easy, fast and safe online tool. The platform promotes matchmaking by ensuring that if any new help request or help offer is published an automated e-mail notification is sent out to all the registered members in that given area. Helpific is based on city and country levels. Only those who allow e-mail notifications will receive these messages. According to our experience, e-mail notifications are extremely useful tools to receive answers to help requests. In Estonia, once a new help request goes out around 500 to 600 other members visit the website by clicking on the link in the e-mail notification and within a few hours the request receives a reply.

This seems to be a self-generating process. More help requests drive more traffic to the platform and more traffic leads to more registrations. With more registrations, there is an increased chance of answers, and users are motivated to use the platform regularly based on previous good experiences.

Many times disabled people or people with mental health problems also offer help, and we have witnessed ordinary citizens asking for help on the platform. Helpific fully encourages this reverse of user behaviour as a great way of empowerment.

Challenges

Even though Helpific is a web-based online ICT tool, personal encounters are essential. Therefore, the importance of face-to-face meetings with potential users must be highlighted and is necessary to explain the concept, encourage people to sign up, and to have a

fruitful conversation with people about Helpific, the situation of vulnerable people and the sense of community.

To successfully complement the web-based working method with personal community development methods is one of the main challenges of Helpific.

Results and lessons learned

There are hundreds of successful matches on the Helpific platform. Based on this, a user experience analysis was conducted that is available here:

http://blog.helpific.com/2017/03/user-experience-analysis-in-estonia.html

In order to improve participation and social inclusion, actions targeted at the policy level, public opinion and specific participation domains, are necessary.

Contact details	info@helpific.com
URL	https://helpific.com/en https://volunteer.helpific.com/
Related Web site(s)	https://zeroproject.org/practice/pra191395est-factsheet/
Related resources	https://www.youtube.com/watch?v=zh3PV6pOQeM

Example 9: INVEMA

Institute: INVEMA e.V: Kreuztal, Germany

INVEMA e.V. is a private association working to ensure the inclusion and integration of people living with disabilities. It was established in 1993 with the main objective of providing support for people living with any form of disability to live an independent and self-determined life that is in line with the desires of the individual as much as possible. The association functions consciously as a voluntary non-profit, non-governmental organisation providing internal and external support for people living with disabilities to enable them to cope with independent life.

Location

Kreuztal, Siegen-Wittgenstein, NRW, Germany

Stakeholders

The foundation for the establishment of INVEMA e.V is based on the aspiration that every individual is given the opportunity and freedom to participate independently in all aspects of life regardless of age, gender or disability.

In this regard, INVEMA e.V aims to create the opportunity for people living with any form of disability to choose where they live, with whom they live with and with which specific support. INVEMA e.V. is organised by flat hierarchies with managers and employees performing interconnected functions to realise the objectives of the association.

Accordingly, the organisation of INVEMA e.V. is made up of:

a) Board members

b) General assembly

The board is made up of a chairperson and a deputy, a cashier, a secretary and five advisors. The board is elected by the general assembly for a three-year term with the possibility of unlimited re-election. The board is responsible for the day-to-day administration of the association. This function, carried out on voluntary basis, mainly involves the execution of the resolutions of the general assembly and the conclusion and termination of employment contracts. The board meets on the invitation of the chairperson at least three times per year. Decisions of the board are made by a simple majority vote.

The general assembly as the highest decision-making body of the association is responsible for all tasks, provided that certain tasks have not been delegated to another body in accordance with the statutes of the association. The general assembly also carry out functions including:

- The acceptance of the annual report and the cash report for the resolution on the discharge of the board;

- The appointment of the cash auditor;

- The determination of the membership fees;

- The implementation of changes to the statutes;

- The dissolution of the association.

Methodological approach

INVEMA e.V. and its services serve as a direct contact and companion for people living with disabilities and provide a means to enable them to live independently. Thus, the onus lies on the development and implementation of individual targeted and specific support plans with evaluation procedures. This requires a one-to-one relationship approach that is sometimes adopted in situations where pooling of client resources makes sense.

INVEMA e.V. clients reach out to the service via referrals, an online contact form and informal information from family and friends. Consequently, INVEMA e.V. is able to develop tailored-made services for individual support.

The association is growing steadily and has modified its services to include any form of disability in all areas of life in accordance with the contemporary social dynamics, wishes and demands of its customers. As a result, INVEMA e.V. provides services based on the demands, needs and aspirations of its customers.

INVEMA e.V. is dedicated exclusively and directly to charitable or benevolent welfare purposes. The sphere of the association includes but is not limited to the following:

Provision of an all-encompassing counselling and information centre for people with disabilities and their relatives, offering life counselling on a physical, psychological and social level particularly:

a. For individual support arrangements;

b. In dealings with authorities;

c. In legal and financial matters;

d. For self-help competencies.

INVEMA e.V. promotes the integration of disabled people:

a. In culturally customary social structures through support, accompaniment and assis-
    tance;

b. In personal conflict situations (at work, in education, in leisure time and at home).

INVEMA e.V. engages in awareness-raising activities, with the aim of counteracting the stig-
matisation of people with disabilities in favour of a holistic view of them and their enhan-
ced social role. This includes:

a. Informing about innovative forms of support for people with disabilities in other coun-
    tries;

b. Critical examination of institutionalised support practices with a 'blame and shame'
    campaign on exclusive events and practices in the district;

c. Presentation of the personal stories of people with disabilities that document positive
    and negative experiences on the right to be included.

Implementation

Since 1993, INVEMA e.V has increased their range of services from 'counselling and con-
tact point' with intensive public relations activities to 'family support service' in 1996 and
'support services for inclusive education of disabled and non-disabled children in regular
schools' to 'outpatient supported living services' for people with intellectual disabilities in
2003. 'Personal assistance for severely disabled persons' was introduced in 2007 and 'sup-
ported employment in the regular labour market' was introduced in 2009.

In addition to public funding for the services, the association receives financial support through:

- Membership fees;
- Cash and in kind donations;
- Subsidies;
- Proceeds from collections and promotions;
- Other donations.

Since its establishment, the association has been a critical actor in the local disability system that was traditionally based on segregating services such as special schools, residential homes, sheltered workshops and other segregating special services for persons with disabilities characterised by excluding settings.

INVEMA e.V has made a name for itself in the Siegen-Wittgenstein district by working in accordance with the UN CRPD and declaring unconditional participation in all areas of life for people living with disabilities. The association has thus contributed to the gradual development of local support services and public infrastructure towards inclusion.

Challenges

25 years after its establishment, INVEMA e.V. has realised that the goal of an inclusive community is still a long way off. The main challenge has not only been inadequate financial support but institutional and social cooperation. This does not mean, as it did in the past, suspending a human right until all basic conditions are optimal, but rather the task and obligation to work for better basic conditions.

Results and Lessons learned

The commitment and persistence of INVEMA's engagement has paid off. The association initiated outpatient support offers that have enabled many people with disabilities to participate equally in all areas of life.

350 employees are committed to making this participation possible by providing support for about 450 customers in the Siegen-Wittgenstein district. This results in about 200,000 outpatient assistance and support hours per year.

INVEMA e.V. has provided countless consultations and individual assistance in the areas of school, leisure, living and work with the primary aim of supporting persons with disabilities to enjoy independent living.

"Inclusion is not only the goal, but also the way. We will continue to make clear what inclusion really means in our region and which environmental and attitudinal barriers stand in the way of the goal of an inclusive society".

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Example 9: Solidarity Neighbourhood - Community Development with Elderly People with and Without Disabilities

Contributor: Zsuzsa Gyenes, Hungarian Association for Community Development and Day Care Centre of XII. district

Solidarity Neighbourhood is a community development program launched in April 2014. The program is based in Budapest District 12, and was established with the objective of activating the elderly neighbours and involving vulnerable people. At the end of 2016, the

Community Development Association officially terminated cooperation with the program that is currently still active.

Location

Budapest (12th District), Hungary

Stakeholders

The program was commissioned by the municipality of the 12th District as a reaction to the emerging need for a care centre. The program was launched in 2014, within the framework of a geriatric care institution (currently called Hegyvidék Welfare Center) and managed by the institution's manager. Hungarian Association for Community Development was responsible for the realisation of the program. The community development program and the associated groups were transferred to the Culture Salon in January 2017. Other local institutions also participated in the realisation of the program including the local cultural social space, the local history museum, the library and the day-care centre. The target group of the program is the elderly people living in the district.

The definition of the target group was based on the neighbourhood, pensioners living in the 12th district, however, **there was also a special focus regarding involving people with disabilities**. The executors of the program placed a high emphasis on involving as many elderly locals as possible, and making the program as accessible as possible. **As a result of these efforts, disabled people living in the target area were also actively taking part in the program**. However, it must be emphasised that these people were addressed as elderly people living in the district, based on their citizenship, to reduce the stigma of disability as much as possible.

Implementation

The program was launched by approaching professionals and providing them with sensitising training in the form of a short workshop. The process also involved conversations

within the community, based on interviews conducted with the elderly. Shared neighbourhood training activated local elderly people who engaged in the program by becoming volunteers. The professionals became community mentors and started their work in groups (later named Hegyvidék Neighbours).

In order to achieve diverse local publicity, training and a workshop for volunteer reporters was conducted and another volunteer group of the program was established: the Local Publicity Workshop. The independent platform for their activities is the online magazine edited and operated by participants, called Kopp-kopp 12. kerület honlap (Knock-knock 12th district website). Occasionally, a printed version was also published.

The community development process is an informal training program in which informal training events were also involved. Further goals of the project include strengthening the engagement of the activated professionals and volunteering neighbours, enhancing their self-esteem and confidence, improving their competencies and relationships with each other, supporting their community work and creating the framework for their jobs enabling them to shape their identity.

The group of neighbourhood volunteers and community mentors was established (Hegyvidék Neighbours) with two to three hour-long meetings every second week. This group provides a framework for the operation, space for planning, organising, evaluating, sharing information, acknowledging and supporting each other in case of events or communities organised by individual neighbourhood volunteers or by the group. The meetings are moderated by a community developer (the professional manager), thus providing the possibility for ongoing learning and training. **The neighbourhood volunteers with disabilities are equal members of the community and access the workshops with the help of their neighbours**. One of them, for example, became a volunteer reporter and has written articles on advocacy.

Methodological approach

A strategy for elderly care in the district was prepared and revealed the absence of sufficient care in the lack of capacity and resources. When designing the program, as well as making the information transparent, the emphasis was on activating the elderly and on help from their peers.

The target area is an aging district with little capacity utilised for elderly care. According to the proposal of the Association for Community Development a generic community development program was also launched involving the general activation of the local elderly people in its development strategy.

Three programs were simultaneously running during the process:

- Building an information point;
- Reinforcing volunteering;
- Community development.

The information point for the elderly was designated to make all kinds of relevant information accessible (in addition to information about social benefits). The volunteer program improved the capacity for home care by involving volunteers within the framework of a traditional organisational volunteering program. It does not only recruit, select, train and mentor volunteers, but also prepares the employees of the organisation and embeds the volunteers in the organisation's daily operations. However, the community development program functioned individually with the intention to connect the volunteers of the information point to the community development program. There were also events focusing on the relationship with the volunteers of the home care program. The local elderly people could participate in the community development program as neighbourhood volunteers, volunteer reporters or the community mentors of the professionals.

Neighbourhood volunteers are locals engaged in activities in favour of the local community while also forming a community themselves. The community mentors are local professionals, engaged in the neighbourhood volunteer program and local initiatives. They act as a bridge between the organisational system and the volunteers, activating the locals and involving them in the community development program.

Challenges

Expanding the target group and the numbers of volunteers while continuously involving new members was challenging. It is hard for new neighbourhood volunteers to join the existing active core as the members have a strong bond that has the side-effect of making it hard for new volunteers to join them. The mentors made efforts to handle this situation. The greatest challenge of the program was the cooperation of the elderly in dealing with illnesses and death together.

Results of the practice

The program personally contacted 51 experts from six institutions in addition to public institutions, including civil organisations and the church. Approximately 1,500 elderly people were personally addressed at events and programs for small groups. 94 community face to face interviews about where they live and how they feel about it were conducted with local elderly people. From this group of interviewees, around 20 people joined as permanent neighbourhood volunteers to consider and discuss local issues and organise weekly community events as a way to solve them.

The civilian, community attitude and operation was evident in the groups organised or lead by the volunteers. Examples for the established groups include:
- Rozi salon, consisting of three hours of craft workshops and talks;
- Self-training group (two hours every second week) consisting of educational lectures held by well-known professionals;
- Local history club;

- Hospital visiting club;

- Forest walking club.

Seven groups have been launched so far (out of which three are still active, and two are being reorganised). The oldest group is the health-preserving forest walking club, held three times a week, with five to six participants on each walk.

One advocacy case was conducted together with the members (other cases were dealt with by the volunteers themselves). Community events took place (sometimes as part of bigger events) and community talks are currently organised regularly about topics consi-dered important to the volunteers.

Lessons learned

The elderly resident is seen an 'experience expert', who has first-hand experience of even the tiniest deficiencies, such as the lack of accessibility. As a result of the confidence and knowledge gained during the volunteering, they are able to communicate this to those in charge who may not be aware of these deficiencies.

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