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SELF-DETERMINATION OF PEOPLE WITH DISABILITIES

Literature review

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PART 1

CONTEMPORARY DISCOURSES REGARDING PEOPLE WITH A DISABILITY

Before taking off with a thorough definition of self-determination and precise elaboration on factors influencing and promoting self-determination in different stages of lives of people with disabilities, we set the literature scene discussing contemporary discourses on people with a disability. Individualist perspectives of disabilities as medical diagnoses with static criteria and predictable prognoses are still omnipresent and are contra-intuitive with regard to processes of empowerment of people with a disability. Therefore it is important to introduce this literature review with a focus on the social model of disability through the lifespan, the guiding international frameworks on inclusion and participation and the importance of intersectionality and relationality.

1 The social model of disability: focus on inclusion and participation across the lifespan

Disability has long been studied from a medical perspective, highlighting an impairment that hinders daily life and is perceived as a burden for the person concerned and their family and friends. The terms used systematically referred to abnormality: “backward,” “unstable,” “feeble-minded” (Roca, 1992). This stigmatizing view gave rise to research aimed in particular at exploring “lower states of intelligence.” Studies then highlighted the complexity of what is considered abnormality, pathology, or even intellectual deficit (Binet, 1903; Canguilhem, 1966; Huteau and Lautrey, 2003). Disability became the subject of campaigns and new scientific studies (Vial, 1990; Roca, 1992) which showed that people with disabilities are not subhuman but deserve respect and consideration, with specific support from an early age. A paradigm shift then began. It is in this context that the concept of inclusion took on its full meaning and became particularly prevalent in Disability Studies. “This field of research, which emerged in the late 1970s at the intersection of academia and activism, proposes a social model of disability” (Beudaert, 2025, p. 76).

The UN convention on the Rights of Persons with Disabilities recognizes “that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others” (UN, 2006, p.2).

This definition is closely tied to a social construction of disability, and, by extension, to the social construction of 'normalcy': “the ‘problem’ is not the person with disabilities, the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person” (Davis, 2013). To this day, the power of normalcy continues to uphold and reproduce notions of typical bodies, medical universal truths, and diagnostic characteristics that define what we consider ‘disability’ (Davis, 2013). Frequently, well-intended policies and institutions treat disability ‘as a problem in need of a solution’ (Mitchell, David & Snyder, 2000) rather than as a situation caused by social conditions in a disabling society (Priestly, Finkelstein, Davis, 2022). Researching along lines of (support for people with a) disability requires that we critically engage with and challenge disability categories, recognizing how normative powers always influence those categories. The social model of disability focuses on the experience of disability and how we respond to that experience (Titchkosky, 2021). Goodley & Runswick-Cole (2014a) argue that ‘disability’ has the radical potential to trouble ‘the rational, independent, autonomous subject’ that we so often invoke when conceptualizing ‘the human’ and designing our structures and society. People with a disability invite us to pause and rethink from the perspective of interdependence and interconnection; challenging conventional expectations of what it means to be human (Goodley, 2014).

It is crucial to examine and reconsider processes of inclusion and participation (in which concepts of autonomy and self-determination are implicated) from a life-course perspective (spanning childhood, adolescence, adulthood and older age) and across various contexts and relationships in which human lives are embedded (e.g., kindergarten,

schools, leisure activities, workplaces, neighborhoods, residences, etc.) (Shogren & Ward, 2018).

Unlike integration, which requires disabled people to make personal efforts to adapt in order to achieve their goals (e.g., attending a so-called “mainstream” school or being hired by an organization), inclusion takes a different approach: it is up to the organization to adapt in order to welcome the disabled person in optimal conditions by reducing obstacles and constraints (Chamak, 2018). This undoubtedly requires a minimum prior knowledge of the disability, but also and above all recognition and effective consideration of the situation presented. Indeed, disability sometimes poses difficulties in adapting to the workplace in the immediate or longer term, and it is necessary to prepare what will promote acceptance, facilitate presence on site, and support the evolution of the disabled person's situation.

This consideration of disability should not imply that the person will be passive, waiting for the resources that the organization will make available to them. A discussion between the stakeholders will make it possible to identify needs and match them with the possibilities offered, or even to identify new ones.

Furthermore, inclusion highlights another dimension of people with disabilities. They are not incapable or incompetent because of their disability. They have knowledge, skills, and tastes that deserve to be examined and integrated into the process of welcoming and supporting them. As Brigitte Bouquet points out, “inclusion focuses on people's potential and needs and aims to adapt the environment and involve the various stakeholders so that people, regardless of their disability, have a place in all areas of social and private life” (Bouquet, 2015, p. 21). It is therefore up to the reception facility to set up an organization adapted to the identified needs and to provide the person with the necessary material resources.

This inclusive approach has other effects: disability becomes a collective consideration and is no longer viewed as an individual difficulty stemming from a person who, due to their situation, poses a problem (Ebersold, 2019). This position, which favors a systemic approach and takes into account the person's environment (Oliver, 1996), questions the very functioning of the structure or reception space, regardless of its status, and its ability to develop inclusive management, respectful relationships with others, and democratic practices that provide spaces for discussion where it is possible to express any difficulties.

The UN Convention on the Rights of Persons with Disabilities, through Article 19, affirms the right to full inclusion and participation in the community. Article 26 further mandates State Parties to take effective measures to enable people with disabilities to achieve and maintain full inclusion and participation in all aspects of life and society (UN, 2006). Inclusion can be understood as a process by which all individuals, without exception, become equally valued members of society and actively engage with their environment (Lang et al., 2019; Soresi et al., 2011; Burke et al., 2018). Inclusion is a dynamic and ongoing process of removing barriers to create an environment that welcomes all people, irrespective of differences such as gender, race, language, sexuality, and disability, and guarantees access to critical life domains in society (Jones, 2010; Ballard, 2013). Therefore, inclusion is not merely about ‘physical presence’ but also about being supported (Brix et al., 2020) and about valuing and utilizing diversity as an asset in both intimate social networks and broader communities (Licsandru & Cui, 2018). Inclusion, then, becomes both a personal and collective experience of equity, embedded in social roles, networks, and interactions, and is deeply connected to societal structures and politics (Simplican et al., 2015). Approaching inclusion from a social model of disability is inherently linked to uncovering ableism: "the social, cultural, and political conditions of contemporary life that emphasize ability and denigrate disability" (Goodley & Runswick-Cole, 2014a; Campbell, 2009), and with disablism, defined by

Thomas (2007, p. 73) as "a form of social oppression involving the social imposition of restrictions on the activities of people with impairments". These perspectives acknowledge the active role institutions (such as education, welfare services etc.) play in enculturing (involuntary) processes of exclusion and pathologizing difference.

Titchkosky (2011) explores how issues of inclusion are closely related to questions of access: who gets access to what, and how? Everyday practices of inclusion and exclusion often go unnoticed, and the barriers limiting access for people with disabilities are sometimes naturalized as reasonable and justifiable (Titchkosky, 2011). Titchkosky refers to this process as "disability's inclusion as an excludable type" (p. xii).

The UN Convention on the Rights of Persons with Disabilities acknowledges the ongoing barriers that people with disabilities face in participating as equal members of society, ensuring equal opportunities in civil, political, economic, social, educational, and cultural spheres. It obligates State Parties to take appropriate measures to facilitate full and equal participation and access for people with disabilities (UN, 2006). As described by the slogan of the disability rights movement "Nothing about us without us" : this movement advocate for accessibility, protest against discrimination and assert that people with disabilities should be considered the experts on their own needs (Koontz, Duvall, Johnson, Reissman & Smith, 2022).

The concept of participation, closely tied to inclusion, is multidimensional and complex, encompassing various life domains, spaces, networks, and roles. In medical contexts, participation pertains to the active role of patients in their care and healing process (Halabi et al., 2023; Nilsson et al., 2018). Physically, participation involves adapting environments to suit the body in everyday settings (Ginis et al., 2017). Socially, participation refers to connecting within communities (Aroogh & Shahboulaghi, 2020). Publicly, participation entails engaging in civil decision-making and democratic

processes (Addink, 2019). Overall, research suggests beneficial relationships between higher levels of participation in social, educational, and work-related activities, on the one hand, and emotional well-being and quality of life, on the other (Cegarra et al., 2013; Ginis et al., 2017).

2 As more than disability: focus on intersectionality

While people with disabilities are often primarily addressed in terms of their disability identity, they simultaneously hold multiple identities. Davis (2013) asserts that "intersectionality complicates the general rubric of disability" (p. 12) by highlighting the multiple axes on which individuals may face exclusion, leading to positions of multi-marginalization. Intersectionality emphasizes that "identity is made up of many salient parts, and the intersections of those parts must be viewed in their totality" (Annama, 2014). The same support needs may lead to different outcomes for children, young people, and adults from varying cultural backgrounds (Wehmeyer & Shogren, 2021) or socio-economic statuses. These disparities are most apparent in the disproportionate representation of students from multicultural and multilingual backgrounds in special education settings, with limited access to the regular curriculum and other factors associated with academic success (Wehmeyer & Shogren, 2021). Systemic structures, without sensitive consideration of intersectionality, play an active role in selectively segregating the most vulnerable individuals with disabilities (Sebrechts, 2014). This highlights the invisible ways in which ableism, coupled with intersecting factors such as culture, language, and ethnicity, reinforce each other, perpetuating exclusion and multi-marginalization (Voulgarides, Etscheidt & Henandez-Saca, 2023).

Up until today, research on self-determination has not sufficiently included demographic characteristics, nor addressed the way self-determination practices have a different impact on different subgroups of students with disabilities in relation to ethnicity (Burke et al., 2021; Trainor et

al., 2020; Scott et al., 2021). However, a few existing studies have demonstrated that ethnicity mediates self-determination scores, especially for Black and Latina students with disabilities (Shogren, Shaw et al., 2018). Hsiang-Yi & Szu-Yin (2012) summarized that children with different cultural and/or linguistic backgrounds were less likely to be motivated to develop self-determination skills and their parents were less involved in the education plans and promoting self-determination of their children. Lipscomb et al. (2017) discuss that Black young people with disabilities were less likely to receive appropriate support during the transition to high school than White and Asian youth with disabilities. Scott et al. (2021) found that students from different ethnic backgrounds experience structural racism and ableism in systems that are supposed to promote advocacy, knowledge of rights, and self-determination. Such barriers lead parents to take up the role of advocates for their children and contest structures that reproduce inequality in education and transition care (Trainor et al., 2020).

When defining and investigating concepts like self-determination, autonomy, inclusion, and participation, it is essential to focus on culturally responsive sensitivity and partnerships that recognize the disadvantaged situations of specific children, youth, and adults with disabilities, along with other identity markers (Kotten, 2018). Intersectionality cautions against the risk of "relying on single stories of disability and how it appears, moves, and behaves" (p. 234). Titchkosky (2024) urges us to recognize disability in its complexity, prompting a reimagining of our relationships with one another in the context of disability.

3 As more than the individual: focus on relationality

In academic literature, the concept of self-determination is often associated with terms like ‘self-regulation,’ ‘autonomy,’ ‘independence,’ ‘self-knowledge,’ ‘personal choice,’ and ‘control’ (Mumbardo-Adam, Vicente & Balboni, 2022) which tend to overlook the relational ties, support systems,

and contextual factors these concepts require. By centering relationality in the lives of people with disabilities, we acknowledge that interdependence is and should always be implicated in well-established concepts such as autonomy and self-determination. People with disabilities navigate a context that provides them with the necessary support and opportunities to exercise self-determination (Mumbardo-Adam et al., 2022). Consequently, the discourse of 'becoming a causal agent of your life' (Mumbardo-Adam et al., 2022, p. 2) can promote a normative and reductionist view of self-determination, one that applies only to individuals who are capable of acting autonomously. A meta-analysis by Kuld et al. (2023) reveals that tools and programs aimed at promoting self-determination often prioritize individual choices and autonomy, ultimately limiting the self-determination of vulnerable groups who require support to exercise autonomy. Engaging in dialogue, writing, or conducting research with people with disabilities is always a collaborative process involving both the individual and their network. Therefore, self-determination should be interpreted as capacity building within community life and autonomy should always be seen as in the context of interdependence (Palmer et al., 2013). Core concepts such as inclusion and participation emphasize interpersonal relationships, bidirectionality, and fulfilling socially valued roles. Therefore, adopting an ecological perspective that broadens self-determination into a relational and socially anchored concept is crucial (Abery et al., 2008).

Recent research indicates that the contexts in which people with a disability find themselves still often offer limited opportunities to promote self-determination (Lindsay & Varahra, 2022), and as a result, are often associated with a relatively low level of participation in broader society. Due to the limited emphasis on self-determination for people with disabilities, recent literature has focused on 'supported decision-making' as a step toward greater autonomy and self-determination (Shogren, Wehmeyer, Lassman & Forber-Pratt, 2017). Supported decision-making primarily focuses on identifying and implementing support for decision-making and

maximizing participation (Shogren et al., 2017). This is a concrete example of the importance of an ecological and relational focus on self-determination, inclusion and participation.

The focus on relationality and bidirectionality centers on the goal of becoming part of a growing, inclusive community. Osgood, Foster & Courtney (2010) state: “Meeting the support needs of vulnerable groups is linked to becoming a full member who contributes to society, thereby benefiting the lives of everyone” (p.220). Social inclusion is then related to promoting interdependence and valued relationships between people with and without disabilities (Shogren & Wehmeyer, 2021). This model of interdependence encourages individuals to develop their competencies as members of an inclusive community (as friends, neighbors, citizens) rather than as independent individuals in a demanding environment (Shogren & Wehmeyer, 2021). Also, the paradigm of shared citizenship is a powerful innovative paradigm giving words and guiding actions towards these goals (Schalock, Luckasson, Tasse & Shogren, 2022). Shared citizenship is based on the assumption that each person is (1) ‘not only included in the group, but has the privileges, rights, and obligations that such belonging entails’ and (2) has ‘a common stake in the past, present, and future of the group and its resources’ (Shalock et al., 2022, p. 427). The paradigm of shared citizenship guides efforts and actions that foster full participation, respect, equal rights, membership in all societal aspects and valued contribution to the community (Shalock et al., 2022).

PART 2

WHAT IS SELF-DETERMINATION?

A large number of definitions of self-determination exist, varying according to theoretical models. A general definition can be found in the "American Psychological Association Dictionary of Psychology," where the concept of self-determination is described as referring to "the control of one's behavior by internal beliefs and decisions rather than by external demands" (American Psychological Association, 2007). Another frequently used definition is: "the set of skills and attitudes in a person that allow them to act directly on their life by making free choices uninfluenced by undue external agents" (Wehmeyer, 1999). In other words, a person acting with self-determination will act according to their own will, without external constraints. Obviously, no choice is entirely independent of influences: self-determination is a goal one strives toward but cannot fully achieve (Sarrazin, 2012). It is not limited to making choices; it implies that the person has received learning that allows them to know themselves, identify their preferences, etc. (Haute Autorité de Santé (HAS), 2022). It is also important to specify that self-determination does not mean that a person always obtains what they desire most: choices may be made based on the situation and available alternatives. For example, a person may choose to stay in a nursing home because they know that their relatives do not want them to return home and would make their life difficult: even if the person would have preferred a different situation (and thus, ideally, to stay at home), they demonstrate self-determination by choosing the nursing home (Sandman, 2005).

This notion of self-determination is often confused with other concepts, such as social role valorization, autonomy, or empowerment. Starting with social role valorization, this concept is complementary to self-determination: our social roles are often multiple ("mother or father," "son or daughter," "patient," "employee," "voter"), and the valorization of these roles helps identify what should be done or avoided to achieve a goal that benefits devalued individuals or groups (e.g., improving attitudes or skills) (Lemay, 1996). It is thus a broad concept, aiming to strengthen individuals'

social roles, while self-determination emphasizes the ability to act according to one's own will (Wolfensberger, 2002). Regarding autonomy, it refers to the fact that a person acts in accordance with their interests, independently. It focuses solely on the behavior exhibited. Self-determination is broader and involves an interdependence with the environment (Lachapelle et al., 2022). For example, a person with a disability may be autonomous in choosing the timing and modalities of in-home support services. In comparison, a person with a disability demonstrates self-determination by choosing their type of housing and/or the services they desire. Autonomy is therefore an integral part of self-determination and a necessary condition for it (Pluss, 2016), as we will see through various theoretical models. This reflection also applies to empowerment: the latter refers to “a process characterized by exercising greater control over achieving goals that are important to a person, an organization, or a community” (Valérie and Le Bossé, 2006). An example of empowerment would be the process by which a person with a disability acquires the means to live independently, developing their skills, building a potential support network, acquiring technological aids, etc. These last two concepts are found within certain theoretical models of self-determination. We will present here the four most common ones (Lachapelle et al., 2022): (1) the Self-Determination Theory (SDT), (2) the Tripartite Ecological Model of Self-Determination, (3) the Functional Model of Self-Determination, and (4) the Causal Agency Theory.

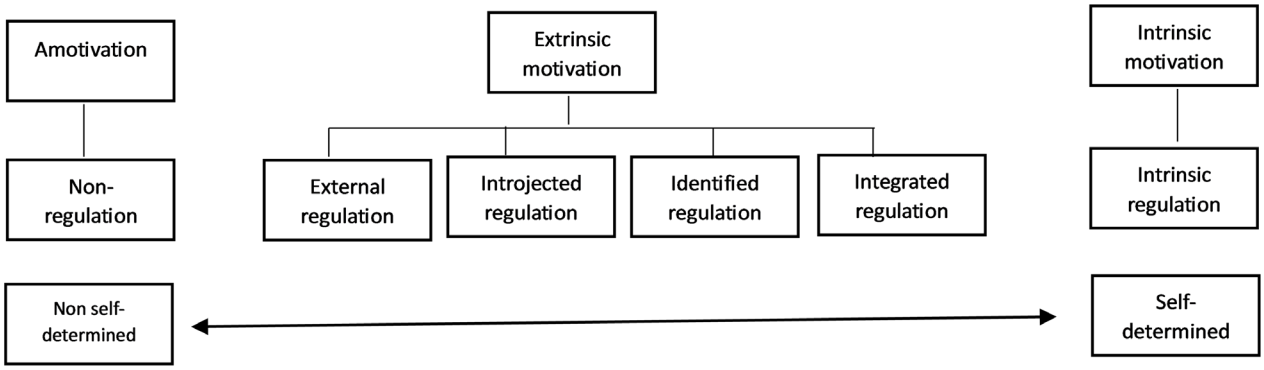
1 Self-Determination Theory (SDT)

This model is based on the premise that all human beings possess three fundamental psychological needs: (a) autonomy; (b) social affiliation; and (c) competence. The necessity of meeting these different needs is essential to explain how individuals pursue certain goals and the content of these goals (Deci and Ryan, 2000). First, autonomy implies that an individual can make choices and preferences and perceive themselves as the origin of their actions. Next, social affiliation refers to the need to feel loved, accepted,

and part of a group. Finally, competence refers to the perception of feeling capable and effective. The search for the satisfaction of these fundamental needs constitutes the basis of motivation for our behaviors (Lachapelle et al., 2022).

According to this theory, there exists a continuum of behaviors ranging from non-self-determined to self-determined, depending on our motivation (see Figure 1). As represented in the diagram, at one extreme of the continuum are non-self-determined behaviors, characterized by a lack of motivation. At the other end of the continuum, we find self-determined behaviors, defined by intrinsic motivation. The latter is characterized by the satisfaction of needs inherent to the individual (Deci and Ryan, 2000). Actions are thus performed for the pleasure and/or interest the person finds in them (Lachapelle et al., 2022). For example, a child does their homework because they enjoy it, or a person plays cards simply for the pleasure of playing.

Figure 1 Self-determination continuum (Lachapelle et al., 2022).



Between the two extremes of this continuum, we find behaviors driven by extrinsic motivation, which can manifest in four different ways (Ryan and Deci, 2011):

- **External regulation**: The behavior is performed to obtain an external reward or avoid punishment (e.g., a child does their homework to be allowed to watch television or to avoid being sent to their room, or a

person plays cards to please the nursing home staff or to avoid their criticism).

- **Introjected regulation:** The person performs an action to boost their self-esteem or avoid guilt (e.g., a child does their homework to feel more competent or to avoid feeling guilty for not doing it, or a person plays cards because they believe it helps keep their mind sharp).
- **Identified regulation:** The person acts based on personal values (e.g., a child does their homework because it is important for them to be perceived as a reliable and competent person, or a person plays cards because they value being seen as an active individual).
- **Integrated regulation:** The person identifies with the action (e.g., a child does their homework because they see themselves as "someone who does what is expected" or as "competent," or a person plays cards with others because they perceive themselves as "sociable").

Self-determination theory is built upon four mini-theories that have been integrated to explain the underlying logic and origin of self-determination theory (Ryan and Deci, 2004):

- **Cognitive Evaluation Theory:** Aims to describe the effects of social contexts on intrinsic motivation. Two cognitive processes affect intrinsic motivation: the perceived locus of causality, referring to the need for autonomy (if the source is perceived as more external, intrinsic motivation decreases), and perceived competence, referring to the need for competence (the more competent a person feels, the stronger their intrinsic motivation). Regarding the need for social affiliation, feeling supported increases the likelihood of intrinsic motivation.
- **Organismic Integration Theory:** Concerns the internalization and integration of values and regulations. It is based on the premise that individuals naturally integrate their experiences. If external

encouragement comes from significant others or a reference group, individuals can internalize an activity they were not initially intrinsically motivated for, integrating and regulating it within their "self." Internalization is seen as a continuum rather than a dichotomy.

- **Causality Orientations Theory:** Describes individual differences in people's tendencies to orient themselves toward a social environment that supports their autonomy, controls their behavior, or leads to amotivation. There are three orientations: autonomous, where behavior is regulated based on one's interests and values, supporting intrinsic, integrated, and identified motivation; controlled, where behavior follows external directives, referring to external and introjected regulation; and impersonal, which focuses on feelings of inefficacy, referring to amotivation.
- **Basic Psychological Needs Theory:** Explains the relationship between motivation, the fulfillment of fundamental needs (autonomy, social affiliation, and competence), and well-being. When these needs are met, well-being improves. While these needs are universal, the way they are fulfilled varies depending on age, gender, and culture.

A definition of self-determination based on this theory is: "the ability to choose and have choices, rather than being driven by contingencies of reinforcement, motivations, or other forces or pressures, in order to be the determinant of one's actions" (Lachapelle et al., 2022). In summary, this theory teaches us that self-determined behavior is based on intrinsic motivation. In other words, to foster self-determination in a person, it is essential to nurture their intrinsic motivation for certain behaviors. The foundation of this intrinsic motivation lies in the three fundamental psychological needs (autonomy, social affiliation, and competence). Thus, when a person has choice, feels socially integrated, and perceives themselves as effective, they will be more likely to engage in a behavior

purely for the enjoyment of it—rather than to avoid criticism or to please someone else.

2 The Tripartite Ecological Model of Self-Determination

According to this model, self-determination includes deciding on the areas of life where one wishes to exercise control and the degree of control exercised (Lachapelle et al., 2022). As represented in Figure 2, self-determination is found at the intersection of three elements: (1) the degree of control a person exercises; (2) the level of control they wish to exercise; and (3) the degree of importance attributed to it.

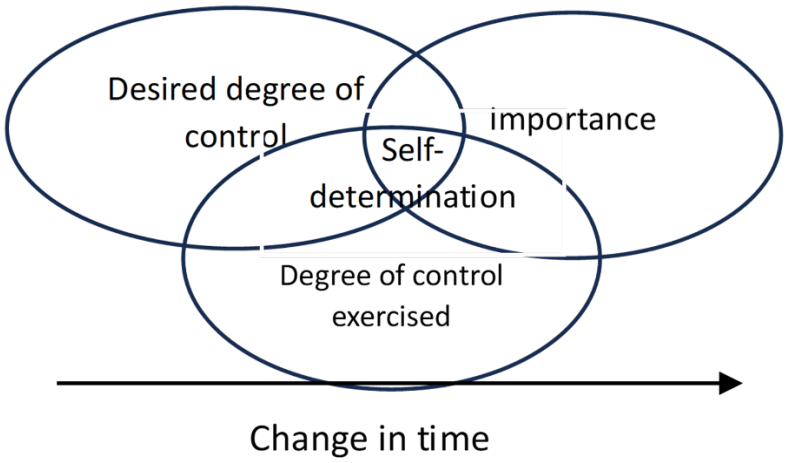


Figure 2 The tripartite ecological model of self-determination (Lachapelle et al., 2022).

Regarding the degree of control exercised, it is important to specify that it varies along a continuum ranging from "total control" to "lack of control." In general, most people fall somewhere in the middle of the continuum: many decisions are made in a shared or collaborative manner. Taking into account the desired level of control is essential, as it reminds us that most people do not seek total control over every aspect of their lives.

For example, they may appreciate shared control when it comes to raising their children, while they might find it appropriate to delegate certain professional decisions—where they feel they lack the necessary skills—to others. Conversely, they may desire total (or near-total) control over medical decisions that concern them. It is therefore crucial to keep in mind that forcing individuals to take on control they do not wish for is just as unethical as denying them the control they desire. However, it is common for individuals with no prior experience of control to indicate that they would rather not have it—this could justify excessive control from others over their lives. It is therefore important to analyze a person's opinion both before and after they have had the experience of control (Lachapelle et al., 2022).

In this model, self-determination is embedded within microsystems, which are themselves nested within larger systems: the mesosystem, exosystem, and macrosystem (Caouette, 2020). The microsystem refers to the immediate environments a person interacts with, such as family, work, and school. These environments can promote self-determination in seven ways (Abery and Stancliffe, 2003): (1) Meeting a person's basic needs, ensuring they have the energy to develop self-determination skills; (2) Respecting and accepting the person, showing empathy and consideration for their feelings, values, interests, and opinions; (3) Providing opportunities for the person to exercise control over certain situations; (4) Reinforcing and encouraging self-determined behaviors; (5) Promoting social participation and inclusion; (6) Encouraging interactions with role models of self-determination; (7) Supporting the person's abilities, needs, and desires. The mesosystem refers to the interactions between the different microsystems in a person's life (Caouette, 2020). It promotes self-determination by fostering collaboration between close relations and professionals. The exosystem consists of environments where the person is not directly involved but whose decisions affect them. In this context, self-determination is influenced by how support is provided, the training of professionals, and how laws are implemented (Abery and Stancliffe, 2003).

The macrosystem encompasses the beliefs, values, and principles of a given society. Self-determination is shaped in four ways: (1) Encouraging deinstitutionalization and community living; (2) Adopting laws that promote integration and social participation; (3) Developing social protection systems that preserve self-determination; (4) Considering cultural specificities regarding self-determination.

3 The Functional Model of Self-Determination

This model was developed to account for the impairments/disabilities of some individuals. In this model, self-determination includes four characteristics (Wehmeyer, 1999):

1. Behavioral autonomy, or the ability of a person to express their preferences, make choices, and act accordingly;
2. Self-actualization: the development of one's talents/skills;
3. Psychological empowerment, referring to a person's perception of their control, influenced by their motivation, locus of control (internal – "what happens to me depends on me" or external – "what happens to me is due to external events"), and sense of self-efficacy;
4. Self-regulation, meaning the tendency of a person to influence the course of their life through self-knowledge (of their strengths and limitations).

These different elements are influenced by personal and environmental factors (see Figure 3). Thus, the necessary skills for self-determined behavior include: (1) Making choices; (2) Making decisions; (3) Solving problems; (4) Setting goals and achieving them; (5) Self-monitoring, self-evaluating, and self-reinforcing; (6) Practicing self-instruction; (7) Advocating for and defending one's rights; (8) Having an internal locus of control; (9) Having a sense of self-efficacy and the ability to anticipate the

outcomes of one's actions; (9) Having self-awareness; (10) Having self-awareness; (11) Knowing oneself (Wehmeyer, 2003). The practical implications of this model are described in the section 3 (self-determination in the context of individuals with disabilities)

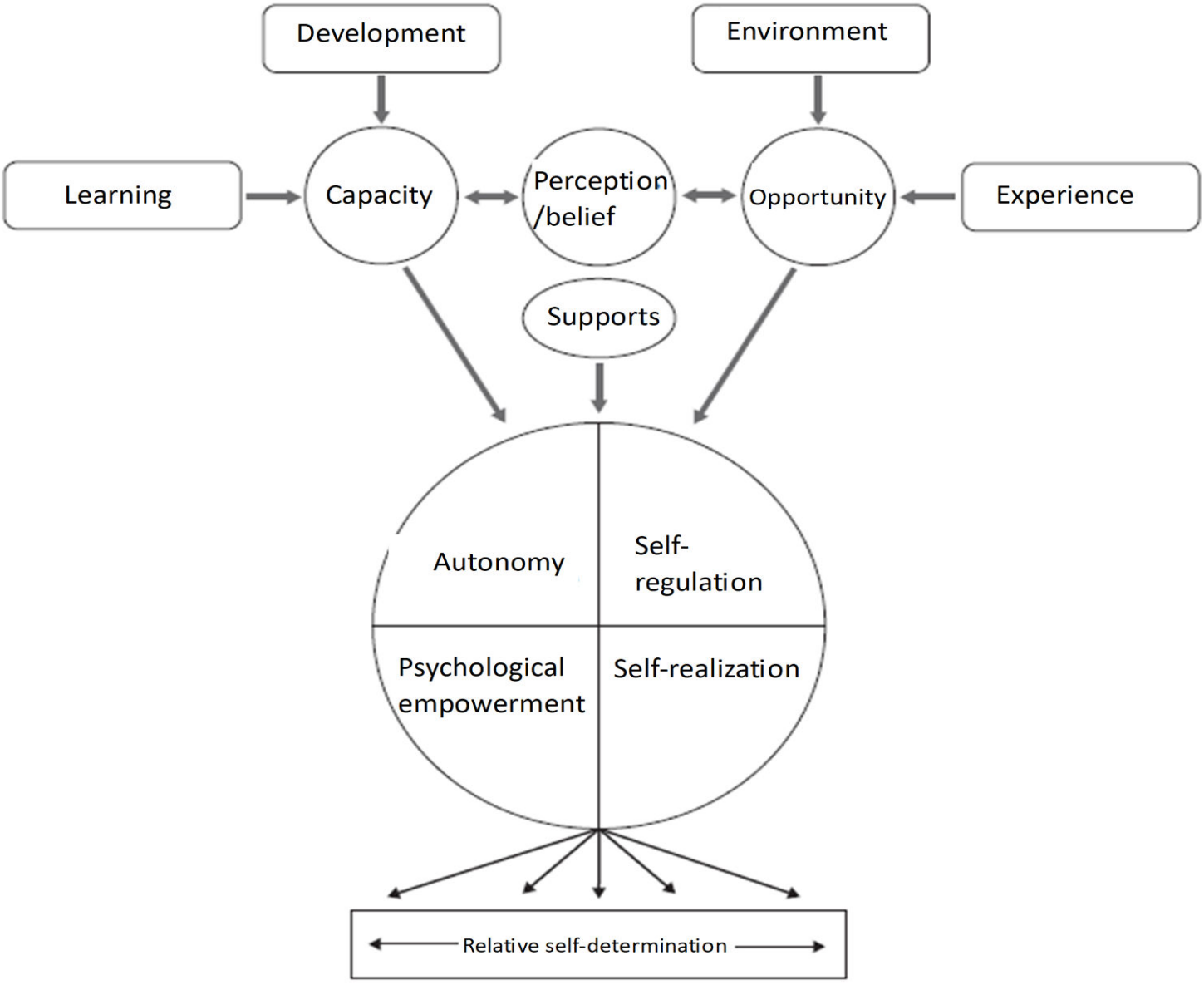


Figure 3 Functional model of self-determination (Lachapelle et al., 2022)

4 The Causal Agency Theory

This theory is an extension of the functional model of self-determination, integrating theoretical advancements in understanding disabilities and positive psychology (Shogren et al., 2015). The goal of the Causal Agency Theory is to explain how people become self-determined. In this conceptualization, self-determined actions are those that allow a person to be a "causal agent" in their life (Lachapelle et al., 2022). In other words, people who are causal agents are actors in what happens to them. In contrast, others make decisions for them, forcing them to act in a certain way against their will (Shogren et al., 2015).

As illustrated in Figure 4, causal actions are motivated by the three fundamental psychological needs: autonomy, social affiliation, and competence (Shogren et al., 2015). They consist of three characteristics/functions: (1) possessing beliefs in controlled actions, meaning individuals believe they have the necessary resources for their action; (2) voluntariness, meaning there is a conscious choice based on the person's preferences; (3) agentic behavior, meaning identifying the path to take to reach a goal or create change. This leads to agency and then to self-determination (Shogren et al., 2015; Lachapelle et al., 2022).

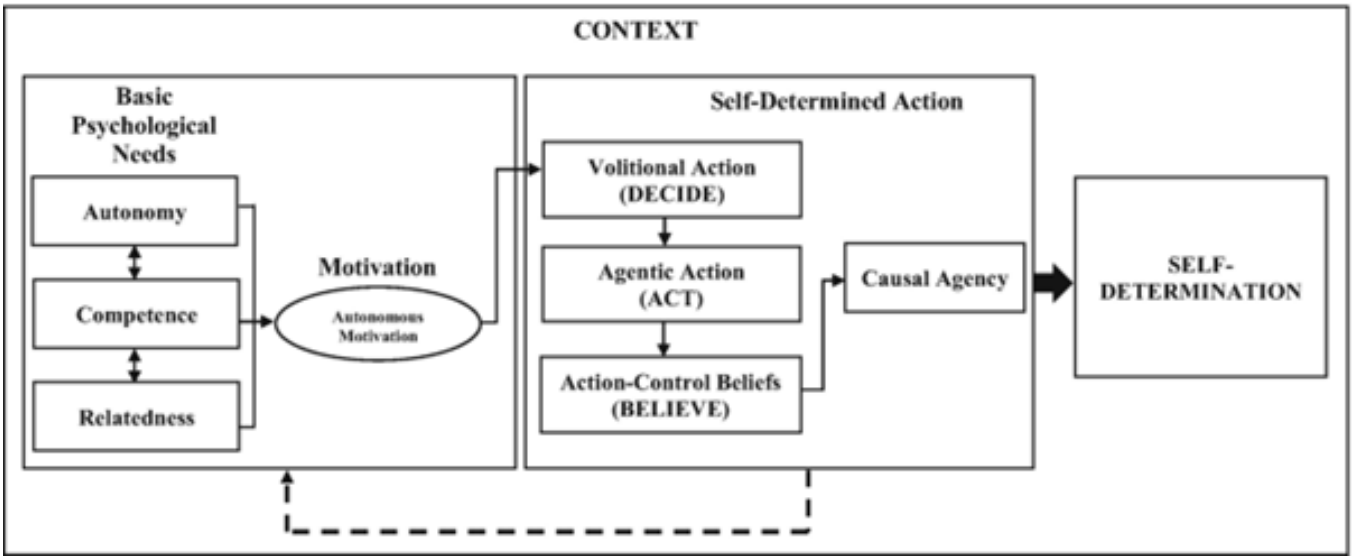


Figure 4. Causal agency model (Shogren, Wehmeyer and Palmer, 2017).

PART 3

SELF-DETERMINATION IN THE CONTEXT OF PEOPLE WITH DISABILITIES

1 The context

As described in part 1, it's important to discuss the context of disabilities in our societies nowadays. First of all, it is important to remind that while it was long considered an individual pathology, disability is now seen as being linked to the context and society in which the person evolves (Geurts et al., 2020). The notion of disability thus includes two fundamental elements: the life situations that shape disability and subjectivity (in other words, the individual's perspective), which impacts how a person reacts (Hamonet and Magalhaes, 2003). This perspective moves away from a "passive" position ("the person is disabled, and nothing can be done about it") toward an active stance where both the individual and society play an active role in the situation. In cases of disability, it is possible to foster greater self-determination. In this regard, the Convention on the Rights of Persons with Disabilities states, "Concepts such as charity, assistance, or rehabilitation are outdated and must give way to those of self-determination and participation" (Schmuck, 2020).

Furthermore, the societal context for people with disabilities is marked by various stigmas, creating a divide between so-called "normal" individuals and those with disabilities, who are perceived as "different" (Gargiulo, 2016). These stigmas have significant consequences, as they can lead to the perception that people with disabilities are less capable of performing certain tasks or making decisions, thereby limiting their opportunities to prove otherwise (Shifrer, 2013). It can also lead to marginalization, unequal access and exclusion as explained in part 1.2. People with disabilities may also internalize these stigmas and thus self-stigmatize, leading them to see themselves in line with discriminatory beliefs and consequently devalue themselves (Ali et al., 2012; Gargiulo, 2016).

While disability itself carries some stigmas, some individuals face multiple layers of stigmatization. This is the case, for example, for older adults with disabilities (Martins et al., 2022), as illustrated in part 6, as well as for women

(Moloney et al., 2017; Damaiyanti, 2022) and individuals from ethnic minorities (Shaw, Chan and McMahon, 2012). Notably, disability appears to be a dominant social category: individuals are often first identified by their disability before other factors such as gender or ethnicity are considered (Rohmer and Louvet, 2009).

It is important to consider that disability exists within a broader environmental context. In order to account for various contextual elements, the International Classification of Functioning, Disability and Health (ICF) and the Human Development Model – Disability Creation Process (HDM-DCP) were developed. The ICF introduces the idea that disability does not result solely from personal factors, but also from environmental factors, implying that the relationship between impairments and disabilities is not linear (Sarrazin, 2020). Regarding the HDM-DCP, it provides an understanding of disability based on the interaction between an individual's personal characteristics and their living environment, which can either facilitate or hinder the performance of activities (Fougeyrollas, 2021). It considers life situations within both their human and material contexts, and allows for a distinction between a person's abilities or disabilities and the outcomes resulting from the interaction between the individual and their environment, as well as the consequences for their social and daily activities. This framework helps to understand that performing a life habit—such as attending a leisure activity—is situational and does not solely depend on the person's characteristics or abilities (Sarrazin, Sylvestre & Fougeyrollas, 2020).

The part 4, 5 and 6 of the literature review will discuss the importance of supporting self-determination across different stages of life. However, it is important to keep in mind that childhood, adolescence, adulthood, and old age are not static, biologically defined, and clearly separable stages but rather societal constructions connected to normative ideas about citizenship, successful careers, long-term relationships, financial independence, marriage etc. Currently, people all over the world are reimagining such milestones (Salt, Melville, & Jahoda, 2019). For people with

disabilities, there is always the vulnerability of being "off-time" when development and autonomy occur through "other-than-normal" pathways rather than the normative ones (Vandenbussche, 2020; Woodman & Wyn, 2013). Therefore, literature argues for a non-categorical or lifespan perspective on care for people with disabilities, whose lives are always in development and transition. It is important not to build "high walls" between age groups and to provide support for people with disabilities in a fluid and activating way across categories and ages (Nguyen, Stewart, & Gorter, 2017). Self-determination should be considered a lifelong process for every person, with or without a disability (Zatta & McGinnity, 2016).

2 Why Promote Self-Determination?

One of the reasons for which the development of self-determination is important is its link with the quality of life of people. Indeed, the extent to which people with disabilities are actively engaged in life decisions and have the opportunity to make choices is closely linked to their quality of life (Wehmeyer, 2020). Extensive research has explored the relationship between the concept of quality of life, as developed by Shalock and Verdugo (2005), and self-determination (Wehmeyer & Schwartz, 1998; Wehmeyer, 2020). The quality of life model comprises eight domains: personal development, self-determination, interpersonal relations, social inclusion, rights, emotional well-being, physical well-being, and material well-being (Shalock & Verdugo, 2005) (See Table 1).

Table 1 (Shalock & Verdugo, 2005).

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

International studies confirm the beneficial relationship between self-determination and quality of life (Lachapelle et al., 2005). Individuals with a higher degree of self-determination typically report a better quality of life, experiencing greater control over their choices and environments

(Lachapelle et al., 2005; Wehmeyer, 2020; Lanniello & Corona, 2024). Increased self-determination is associated with more fulfilling life experiences across various domains (Kim, 2019; Wehmeyer, 2020) and higher reported personal growth (Lanniello & Corona, 2024; Wehmeyer, 2020; Lachapelle et al., 2005). The same holds true for closely related concepts such as inclusion and participation: investing in greater inclusion and participation in education and society fosters environments where people with disabilities can exercise self-determination, resulting in improved quality of life (Cegarra et al., 2023; Lanniello & Corona, 2024; Gomez et al., 2022). An inclusive environment, equipped with accessible resources and space for personal development, promotes both participation and a sense of control over one's life (Soresi et al., 2011; Vicente et al., 2020).

Mumbardo-Adam et al. (2024) conceptualize self-determination as a key strategy for enhancing quality of life, especially when applied in two complementary ways: supporting the development of talents and creating opportunities for personal growth. Concerning this second point, a specific attention must be given to the context : how the family, the school, the employer, the institution (...) create opportunities for self-determination?

Building on the importance of adopting a relational and interdependent perspective in the lives of people with disabilities, it is also important to recognize emerging frameworks such as Family Quality of Life. Zuna, Summers, Turnbull, Hu & Zu (2010) define Family Quality of Life as 'a dynamic sense of well-being of the family, collectively and subjectively defined and informed by its members, in which individual and family-level needs interact' (p.262). Family Quality of Life pictures the quality of life of a certain individual with a disability as in dynamic interaction with its surroundings (Zuna et al., 2010). The literature is consistent in stating that the quality of life of individuals is strongly related to the quality of life of their families, which acknowledges continuous interdependency. Higher family involvement correlates strongly with greater life satisfaction, higher levels

of self-efficacy, and better well-being for the whole family (Wehmeyer & Shogren, 2021).

Moreover, self-determination is both a means of transforming the medico-social offer and a lever for transformation: indeed, promoting self-determination means recognizing and developing people's skills, and at the same time enabling people to take responsibility for their own change (Guegan, Le Guillon and Le Morvan, 2025). Support for self-determination can be seen as the link between "what is" at present and "what could be" when optimal conditions are met (Thompson et al., 2009). People with disabilities themselves express the importance of self-determination in achieving their goals and dreams (Hagiwara, Shogren and Turner, 2022).

3 How to Foster Self-Determination in People with Disabilities?

Several strategies have been studied to promote self-determination. A systematic review on this topic concerning individuals with severe or profound intellectual disabilities (Kuld et al., 2023) identified several effective methods, including learning to make choices (regarding activities, food, interactions, etc.), developing problem-solving skills, engaging in meaningful activities and relationships, participating in society, promoting individuality and dignity, training professionals and family members, advocating for one’s rights, supporting basic psychological needs.

It is also necessary to have a comprehensive vision of self-determination, recognizing the fundamental role of both individual resources and the socio-environmental context (Nota et al., 2007). Thus, to bridge the gap between the "theory" of self-determination and the reality on the ground, a socio-ecological perspective on interventions is essential (Walker et al., 2011). In this perspective, social variables are seen as mediators, serving as an intermediary between an individual’s characteristics and environmental factors (such as opportunities for making choices). Social variables refer to three different forms: (1) social efficacy, meaning the skills,

strategies, and social behaviors required to access opportunities or improve quality of life, such as forming friendships, joining a group, negotiating, etc.; (2) social capital, which refers to various social connections that enhance a person's quality of life; and (3) social inclusion, in other words, inclusion of people with disabilities in different environments (school, workplace, etc.).. This holistic approach implies that interventions promoting self-determination should include tools that increase opportunities for self-determination, as well as efforts to develop individuals' decision-making abilities and expand their social networks.

However, certain challenges have been identified in the practical implementation of these strategies. A recent qualitative study among professionals (Mumbardó-Adam et al., 2020) highlighted difficulties at different levels. First, at the macro level, there is a societal difficulty in understanding disability, necessitating efforts to reduce associated stigmas. At the meso level, challenges in collaboration between various stakeholders (families, professionals, and individuals with disabilities) have been noted. Finally, at the micro level, the main challenge is providing practical resources and individual training to develop people's self-determination skills. Several factors can be perceived as barriers to the development of self-determination among professionals: significant intellectual limitations, a tendency toward impulsivity, the presence of behavioral disorders, limited comprehension, and a reduced awareness of danger make fostering self-determination more challenging (Caouette, 2020).

Fostering Self-determination on the Micro Level

To foster self-determination, the functional model can serve as a foundation to highlight the importance of practical aspects (Geurts et al., 2020). As a reminder, the four components of this model are: (1) Behavioral autonomy; (2) Self-regulation; (3) Psychological empowerment; (4) Self-realization. Regarding behavioral autonomy, the ability to act according to one's preferences and interests, establishing a climate of trust is crucial, allowing the individual to express their opinions. Ensuring confidentiality in

discussions can contribute to this trust. Additionally, setting a clear framework, defining objectives, and establishing a timeline for meetings are key elements. For self-regulation (the set of strategies to achieve a goal), individuals need to develop problem-solving, planning, self-management (observing their own behavior), and adjustment skills. Providing personalized support materials can facilitate this process. Regarding psychological empowerment, which refers to an individual's perception of control over important aspects of their life, it is necessary to highlight their strengths and capacities rather than defining them solely by their weaknesses. Finally, self-realization, which involves self-knowledge, underscores the importance of describing individuals in terms of their strengths rather than focusing exclusively on normative deviations (even in professional reports).

It is crucial to recognize that there is no single way to promote self-determination. We must keep in mind the importance of individualizing the approach based on each person’s specific needs and characteristics (Geurts et al., 2020). Ideally, clinicians and educators should implement interventions with multiple components, such as individual learning sessions, group activities, or coaching (Lindsay & Varahra, 2022). Indeed, self-determination is a multifactorial construct, and the most effective programs for enhancing it are multidimensional in nature (Wehmeyer et al., 2012). As highlighted in a recent report by the French General Inspectorate of Social Affairs (Guegan, Le Guillon & Le Morvan, 2025), the freedom of choice for individuals is only made possible by the diversity of available services and how they are implemented. Moreover, whenever possible, encouraging a collaborative decision-making process is important for building the person's trust in decisions and enhancing their understanding of the process (Delaney, 2018). Self-determination does not mean that a person must do everything alone and entirely independently: seeking support, advice, or help that is meaningful to the person and contributes to their well-being is an integral part of self-determination (Geurts et al., 2020). In fact, when a

person is highly dependent and unable to express their choices in conventional ways, self-determination also involves mobilizing the resources in their environment. These resources help influence the person's life and context in alignment with their goals, through a partnership based on mutual respect—even within an asymmetrical relationship due to the person's dependence (Skarsaune, Hanisch & Gjermestad, 2021). This requires a cooperative support process, in which both individuals must perceive themselves and each other as competent (Paul, 2012).

Finally, it is also important to point out that self-determination requires learning, and therefore involves taking risks and stepping out of a comfortable position, where everything is decided by others for one's well-being, towards the unknown. When supporting a person with a disability, it is essential to consider what they might lose in moving toward self-determination (Sarrazin, 2012).

A Focus on Peer Support

Another strategy to help foster self-determination is peer support. Peer support can be defined as "a practice of accompaniment or support between peers who mutually recognize one another as equals due to having lived similar experiences. It is a practice rooted in the sharing of experiences and peer relationships, promoting the production of rare experiential knowledge to resolve unresolved issues or face life's challenges, and grounded in self-determination" (Gardien, 2025). Peer support is therefore a dynamic based on shared experiences (e.g., disability) between one person in a support role and another in a recipient role (Rebord, 2022).

When someone is facing hardship or a difficult situation and the strategies they have previously learned are no longer effective, turning to people who have gone through similar challenges makes complete sense—whether for emotional support, social connection, or concrete help (Gardien, 2021). Moreover, if the peer appears to be doing well, they become a source of hope for the future: by identifying with them, the individual may develop

greater self-confidence and unlock their potential (Gardien, 2021). Peer support involves building strong, trusting relationships (Scott & Doughty, 2012). It also allows for the progressive co-construction of experiential knowledge (that is, knowledge acquired through personal experiences). For example, E. Gardien (2021) recounts the following story: "A young paraplegic man often tells the story of meeting another wheelchair user—leader of an international disability rights movement—who met him at the airport to accompany him by train to a conference. During the journey, he witnessed how casually this charismatic leader explained to railway employees that he truly regretted their employer's lack of attention to accessibility, especially given the impact on the workers' health when they were forced to lift passengers in wheelchairs from the platform into the train. At that moment, the young man suddenly realized that other identity paths were available to him. Living in a wheelchair didn't mean being a burden or apologizing in interactions with non-disabled people. That train ride, along with the observation and exchanges with his peer, decisively changed his identity, behavior, and life." It should also be noted that experiential knowledge is constantly evolving—it is reshaped, questioned, and expanded through new experiences. Peers are often recognized as experts in validating the truth of particular experiential knowledge (Gardien, 2017).

This sharing of experiential knowledge supports self-determination in multiple ways: it helps individuals better understand their past and present situations, gain clearer awareness of their personal resources, and strengthen their self-observation skills so they can share their experiences to peers (Gardien, 2022). In addition, peer support enables individuals to focus on their strengths, express their needs and concerns, and develop strategies to participate in decision-making—thus enhancing their self-determination (Rebord, 2022). A study that implemented peer support in classrooms with students who had severe disabilities showed an increase in students' self-determination. This was achieved through better identification of opportunities to make choices, knowing when to ask for

help, and experiencing social valorization through the peer relationship (Brock, Biggs, Carter, Cattey & Raley, 2016).

Focus on Communication Accessibility

In order to make communication more accessible for people with disabilities, several alternatives have been developed. Here, we will focus on two methods: Augmentative and Alternative Communication (AAC) and the Easy-to-Read and Understand method (known in French as Facile à Lire et à Comprendre – FALC).

First, Augmentative and Alternative Communication (AAC) encompasses the various methods that enable people with disabilities to participate in social interactions. These may be alternative methods, for individuals who do not use spoken language, or methods that enhance or improve the person's communication abilities (Jullien & Marty, 2020). Four types of AAC can be distinguished (Jullien & Marty, 2020): (1) Unaided communication (e.g., gestural support); (2) Low-tech aids (e.g., the use of pictograms); (3) Mid-tech aids (e.g., use of switches); (4) High-tech aids (e.g., communication apps on tablets).

To facilitate the understanding of written messages and communicate effectively with individuals with intellectual disabilities, the Easy-to-Read and Understand (FALC) method was developed (Unapei, 2009). This approach involves specific guidelines to ensure that written, audio, or video information is accessible to all. Among these guidelines, it is recommended to identify the target audience and involve them in the creation of the content. This allows them, for example, to give advice on the topics to address and provide feedback on how easily the information can be understood. Additionally, the language used should be simple and consistent (the same word should be used for the same concept throughout the document). Sentences should be short and written in the active voice (for example, "The doctor will send you a letter" instead of "You will receive

a letter from the doctor"). For more information about this method, all relevant guidelines can be found on the website falc.be.

Fostering Self-Determination on the Meso Level

The consideration of disability in the workplace first manifested itself in incentive laws aimed at encouraging greater inclusion, for example through workplace adaptations. As a result, technology and specially designed tools can be used to help people with disabilities; and while this does not eliminate disabilities, these new possibilities at least help to reduce them (Sperandio, 2007). In this respect, ergonomics plays a major role because, in the preparatory phase of the activity when needs are assessed, it considers perspectives that are sometimes unprecedented. As Alain Lancry (2016, p. 94) points out: "Depending on the nature of their disability, people may be excluded from certain work situations but may be able to be included in others. There is therefore a strong link between disability and work situation."

In reality, it is a question of fairness. It should be noted that this issue is at the heart of many debates on the organization and functioning of the so-called “mainstream” environment (school, associations, professional life, etc.) and on the implementation of specific measures for people with disabilities (Colella & Bruyère, 2011). At the professional level, managers, whether they are company directors or heads of an organization or department, are required to organize and adapt the professional activities of people with disabilities, but the reality is mixed.

Faced with the reluctance and inaction of certain leaders, the law has become much more restrictive (Barel & Frémeaux, 2012), establishing, for example, quotas with penalties for organizations that do not comply with legal provisions. This is the case in France with Law 2005-102 of February 11, 2005, known as the “law on equal rights and opportunities, participation, and citizenship for people with disabilities.” As a result, company policy, relayed by the human resources department, now provides for a disability

officer responsible for identifying needs and creating working conditions and an environment that is favorable to all employees with disabilities. This translates into the provision of resources at several levels: organizational, material, and also relational.

However, twenty years after the 2005 law, and fifty years after the June 30, 1975 law promoting the rights of people with disabilities, it is clear that people with disabilities continue to face misunderstanding and prejudice (Rohmer & Louvet, 2006; Naschberger, 2008), obstacles, and sometimes discrimination in their social and professional inclusion (Corby et al., 2019; Eskyté, 2019; Boudinet, 2021).

Management focused on promoting integration or inclusivity therefore seems to be the preferred approach, as it combines the pursuit of performance with respect for personal integrity (Aubert et al., 2010), while also taking into account the emotional dimension of leadership (Garant & Letor, 2014). Lifelong learning (Danvers, 2009) is an essential foundation for progress in this direction and for developing managerial skills which, without denying the challenges of productivity and competition, will acquire human qualities, play the collective intelligence card, and develop professional ethics.

Similarly, a manager who is themselves disabled faces challenges—fighting prejudice, proving their competence, etc.—but they also bring significant strengths to the table, drawing on their experience and their ability to cope with difficulties and solve or work around problems. In this sense, disability can be seen as an asset to be leveraged (Jammaers & William, 2021).

To promote self-determination for people with disabilities at the organizational level, it's necessary to develop intentional strategies that empower individuals, foster supportive environments, and build leadership capacity. Key approaches include offering real opportunities for choice-making, supporting autonomy, training staff effectively, and involving people with disabilities in leadership and policy development.

A core aspect of self-determination is supporting people to make their own choices and express their preferences. This requires not only a willingness to listen but also the right tools—such as communication aids and assistive technologies—that help people with communication difficulties participate meaningfully (Kúld et al., 2023; Kúld et al., 2024; Algozzine et al., 2001). Organizations should build structures that actively promote individual decision-making and provide opportunities to develop skills like problem-solving, goal setting, and self-advocacy (Wehmeyer & Abery, 2013; Burke et al., 2018; Wehmeyer et al., 2013). For individuals with severe or profound disabilities, structured training programs and empowerment interventions can be especially effective in increasing participation and autonomy (Kúld et al., 2023; Burke et al., 2018; Algozzine et al., 2001).

Another important strategy is fostering collaborative partnerships between people with disabilities and professionals. These partnerships must be built on mutual respect and shared decision-making, and they require a shift in professional attitudes—from controlling to supporting roles (Kúld et al., 2024; Cudré-Mauroux et al., 2020; Skarsaune, 2022). This means professionals need to be open to learning from people with disabilities and willing to adapt their ways of working accordingly.

Supportive environments and strong relationships are also critical. When environments are familiar, responsive, and emotionally safe, and when people are surrounded by supportive families, peers, and professionals, they are more likely to feel empowered to make choices and assert their preferences (Kúld et al., 2023; Kúld et al., 2024; Skarsaune, 2022). Inclusive policies can further reinforce these efforts by prioritizing autonomy and dignity—such as through person-directed planning or flexible living arrangements (Kúld et al., 2023; Powers et al., 2002; Walker et al., 2011).

The broader context in which people live and work also plays a role. Environments that actively encourage choice-making, social inclusion, and meaningful engagement tend to promote self-determination more

effectively. This is why social-ecological approaches—those that consider both individual and contextual factors—are particularly useful in guiding organizational practices (Kúld et al., 2023; Walker et al., 2011; Skarsaune, 2022).

To implement these strategies successfully, organizations must invest in staff training. Staff and caregivers should be equipped with knowledge about what self-determination involves and how they can align their practices with evidence-based models (Sánchez et al., 2020; Kúld et al., 2023; Algozzine et al., 2001). This includes learning to step back and support people in developing their own capacities rather than making decisions for them.

Programs that help individuals build concrete self-determination skills—such as decision-making, problem-solving, goal setting, self-advocacy, and self-management—have proven highly effective. These programs can take many forms, including classroom-based curricula, experiential learning, peer mentoring, and coaching (Lindsay & Varahra, 2021; Field, 1996; Cudré-Mauroux et al., 2020; Burke et al., 2018; Algozzine et al., 2001). Importantly, the development of leadership capacities among people with disabilities is a powerful lever for change. Supporting leadership and investing in organizations led by disabled individuals can drive long-term, systemic progress in self-determination (Powers et al., 2002).

Overall, organizational strategies to promote self-determination for people with disabilities are most effective when they combine autonomy-supportive practices, inclusive environments, meaningful partnerships, and opportunities for skill development. With well-trained staff, strong leadership from within the disability community, and the thoughtful use of technologies and tools, organizations can empower individuals to take charge of their lives and participate fully in society. The result is not only increased autonomy and well-being but also more responsive and inclusive systems of support.

Fostering Self-Determination on the Macro Level

Promoting self-determination in politics for people with disabilities requires a comprehensive approach that tackles structural and attitudinal barriers, fosters leadership development, and ensures meaningful, accessible, and inclusive participation. Key strategies include improving accessibility in political processes, creating supportive leadership pathways, and reforming laws and policies to actively encourage and enable political engagement.

People with disabilities often face significant obstacles when attempting to engage in political life. These include inaccessible political environments—both physical and procedural—limited support or accommodations, and a lack of targeted resources. In many cases, restrictive laws or benefits systems can inadvertently penalize or discourage political involvement. Social exclusion and the absence of proactive recruitment or mentoring by political parties further limit participation (Waltz & Schippers, 2020).

However, several key actions can help dismantle these barriers. Ensuring physical and procedural accessibility in political settings is a foundational step. Legislation should clearly mandate the inclusion of politicians with disabilities under equality laws. Direct support—such as funding, aides, or training—is essential to enable participation. Furthermore, political parties have an important role to play by actively identifying, mentoring, and supporting disabled individuals who demonstrate leadership potential (Waltz & Schippers, 2020).

Waltz and Schippers (2020) identify specific political barriers and their corresponding solutions:

- Inaccessible spaces should be addressed through structural and procedural accessibility improvements.

- The lack of support can be mitigated by offering targeted services and accommodations.
- Exclusion from recruitment processes requires intentional efforts by political parties to recruit and mentor candidates with disabilities.
- Finally, restrictive benefits systems and outdated policies need reform to prevent penalizing individuals for engaging in political activities.

Developing leadership among people with disabilities is a vital part of advancing self-determination in political life. This includes investing in both individuals and organizations led by people with disabilities. Supporting disability-led leadership strengthens the capacity for advocacy and policy influence, enabling individuals to shape agendas that reflect their lived experiences (Powers et al., 2002).

Collaborative efforts across different disability communities also play a powerful role. Cross-disability partnerships enhance collective voice and representation in policy-making, contributing to more inclusive and intersectional political outcomes (Powers et al., 2002; Ward & Meyer, 1999). Moreover, promoting self-advocacy—by offering opportunities and skill-building around communication, negotiation, and civic engagement—empowers individuals to participate more actively and meaningfully in political processes (Algozzine et al., 2001; Ward & Meyer, 1999).

Structural change at the legislative and policy level is essential to support and sustain political participation for people with disabilities. Laws should explicitly protect and promote the right to political engagement. This could include the introduction of measures such as representation quotas, job-sharing roles in political offices, or other inclusive practices that lower entry barriers and increase visibility (Waltz & Schippers, 2020).

Beyond legal frameworks, political and organizational environments must also be designed to meet fundamental psychological needs—

autonomy, competence, and relatedness. When people with disabilities feel that their participation is supported, valued, and effective, they are more likely to engage meaningfully and assert their political agency (Kúld et al., 2023; Shogren & Ward, 2018).

Overall, promoting political self-determination for people with disabilities involves more than improving accessibility. It requires intentional leadership development, supportive policies, cross-disability collaboration, and environments that foster autonomy and participation. By removing barriers, nurturing leadership potential, and ensuring inclusive political systems, we can help ensure that people with disabilities are not only included in political life but can actively shape and lead it.

4 Specific Issues Related to Self-Determination

We will now address self-determination in relation to several specific issues, namely living habitat, sexuality, financial management, and end-of-life decisions.

The specific issue of habitat

When we speak about habitat for people with disabilities, we mean not just their physical home but also the full environment around them — including social settings and digital spaces. This environment needs to be designed in a way that everyone, regardless of disability, can access and use it safely and comfortably. This means that housing, public places, community centers, parks, and even websites or apps should be built or adapted to reduce barriers. A well-designed habitat promotes independence, social participation, and overall well-being for people with disabilities. It includes principles like universal design (making things usable by all people without adaptation), home modifications (like ramps or widened doorways), assistive technologies (such as screen readers or hearing aids), and policies that guarantee equal access and rights. The

ultimate goal is to create places where people with disabilities do not feel left out or limited but are empowered to live their daily lives fully and actively (Lindsay, 2024; Kamuzhanje, 2002; Lin, 2018; Parra, 2016). In this way, the habitat is not just a physical location but a foundation for social inclusion and dignity (Lindsay, 2024; Kamuzhanje, 2002; Lin, 2018).

A key legal framework supporting this is Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). This article clearly states that people with disabilities have the right to live independently and be part of their community. It ensures that everyone can decide where and with whom they live, on equal terms with others, and should not be forced to live in particular institutions or settings against their will (United Nations, 2006). This means the concept of habitat—whether it is a private home, a shared living space, or an institution—directly affects how well people's rights are respected and realized. The type of habitat can either enable or limit people's ability to make decisions about their lives, be active participants, and experience real freedom. Therefore, it is crucial to understand how different living environments shape people's experiences of control and participation.

The relationship between habitat and self-determination in people with disabilities

Living environments have a strong influence on self-determination—that is, how much people can make their own choices and control their lives. This relationship depends on several factors: the level of autonomy the habitat allows, how socially included people feel, and the nature of the physical and social surroundings. For example, supported or sheltered housing can provide much-needed help and opportunities for social contact. Yet, these models sometimes limit residents' freedom to make decisions, leading to feelings of invisibility or exclusion, which reduces their engagement and sense of belonging (Argentzell et al., 2022; Agbih, 2019). Some groups—such as asylum seekers or older LGBTQ+ people—may face additional challenges in collective living arrangements, where experiences

of discrimination, social exclusion, or insecurity are more common. These negative experiences further reduce opportunities for participation and self-determination (Agbih, 2019; Thomas et al., 2023).

Conversely, inclusive housing models that actively involve residents in decision-making, prioritize diversity and safety, and promote empowerment can greatly enhance social participation and personal agency (Thomas et al., 2023). Physical features also matter: access to shared spaces like gardens, common rooms, or community areas can encourage social interaction and give residents a greater sense of ownership and control (Kingsley et al., 2024; Argentzell et al., 2022). However, it is important to note that barriers to participation are rarely just about the housing itself. Broader social and institutional factors, such as lack of clear information, limited time and resources, or poor coordination between different support services, often play a significant role in limiting people's choices and involvement (Heaton et al., 2023; Mitschke et al., 2024). Therefore, promoting self-determination requires a holistic approach that looks beyond the physical habitat to the larger social and policy context that affects people's lives.

Types of living habitats for people with disabilities

There are roughly three main types of living arrangements for people with disabilities: individual, collective, and institutional. Individual housing means living alone or with family in one's own home or apartment, often with support tailored to the person's needs. This type of living arrangement usually offers the greatest independence, freedom to make choices, and supports overall well-being (Douglas, 2022; Oliver, 2020; Lindsay, 2024). Collective living refers to group homes or shared apartments where several people with disabilities live together and share support services. While collective living can foster social interaction and mutual support, it may sometimes reduce residents' personal freedom and privacy (Fisher, 2019).

Institutional housing includes traditional care homes or large residential facilities that provide intensive supervision and care. These institutions have been criticized for limiting self-determination, community integration, and individual rights, which is why many countries are moving towards smaller, person-centered housing models (Oliver, 2020; Wiesel, 2024; David, 2024). There are also hybrid models such as permanent supportive housing (PSH), which combine independent living with available support services for those who need them (David, 2024). Globally, policy and practice are shifting towards more individual and inclusive living arrangements that respect the right to independent living and full social participation (Oliver, 2020; Wiesel, 2024; Lindsay, 2024). The success of any housing type depends heavily on how accessible it is, how affordable it is, and how well the right support is provided (Douglas, 2022; Aitken, 2019; Lindsay, 2024).

The specific issue of Sexuality

When discussing self-determination for people with disabilities, one frequently raised issue is sexuality. Self-determination in this domain refers to the ability to express one's desires and preferences and have them acknowledged and respected (Boivin and Fournier, 2022). Several key points emerge:

- Transition to adulthood: Many parents are surprised by the emergence of sexuality in their children with disabilities, as if the disability itself had ruled out this aspect. However, failing to acknowledge a person's sexual identity can lead to difficulties in self-recognition (Boivin and Fournier, 2022).
- Medical dominance: The presence of various medical interventions (speech therapy, physical therapy, psychomotricity) in the lives of people with disabilities can lead to a particular bodily experience, where their body is perceived as something to be "fixed" rather than a source of pleasure (Boivin and Fournier, 2022).

- Institutional intimacy: Respecting privacy and modesty can be challenging in institutional settings where individuals depend on others for daily activities such as washing or dressing. This can create the impression that their body "belongs to everyone" (Boivin and Fournier, 2022).

When it comes to the final point, it is important to highlight that, in general, institutional practices regarding intimacy and sexuality need to be re-evaluated in order to better support personal intimacy. For example, something as simple as knocking before entering a resident's room is still not always standard practice (Boivin & Fournier, 2022). Moreover, sexuality is often seen as "a problem to be solved": for example, by providing information or managing excessive impulses (Guénoun, Essadek, Mauran, Veyron-Lacroix, Ciccone & Smaniotto, 2024). The structure and rules of collective living environments—such as how displays of affection are managed, shared bedrooms, restricted visiting hours, or the inability to lock one's door—can exacerbate the challenges of developing romantic and sexual relationships (Fournier, 2017). In fact, compared to people with disabilities living at home, those living in institutions are three to four times less likely to be in a relationship or have a sexual partner—even at the same level of disability (Giami & de Colomby, 2008). Lastly, working together to find ways to build self-confidence is an essential tool for supporting emotional and sexual health. People with disabilities need increased opportunities to meet others and to explore their capacity for seduction by strengthening their self-esteem—often unfairly diminished by an ableist society. To achieve this, peer support (through one-on-one coaching or group expression) is one possible avenue, along with the training of professionals (Rebord, 2022).

The specific issue of managing finances

A significantly higher proportion of people with disabilities, compared to people without disabilities, experience barriers to financial services and are identified as 'unbanked' (Puli, Layton, Belle, & Shahriar, 2024; Loseva,

2021; Kim & Lee, 2024). Thohari & Risky (2021) define these barriers as administrative, infrastructural, and behavioral (discriminatory behavior towards them). On the other hand, financial institutions have few clients with disabilities, and this invisibility perpetuates the idea that mainstream accessible financial services are not a priority (Puli, Layton, Belle, & Shahriar, 2024; Loseva, 2021). Our society does not consider people with disabilities as individuals who manage and engage with money (Loseva, 2021), which results in discriminatory practices (Thohari & Rizky, 2021). This perception is closely linked to the cycle of lower employment rates and financial instability (Kim & Lee, 2024), making it difficult to save, invest, or plan with money (Gutterman, 2024). In general, people with disabilities experience low levels of financial well-being, which is connected to lower levels of overall well-being (Kim & Lee, 2024) and fewer opportunities to build independent, inclusive lives (Gutterman, 2024).

As a result, the self-determination of people with disabilities in financial matters is also low. They are often left with no option but to rely on others to manage their finances, depend on sharing codes and data for authentication, and face potential risks such as fraud, theft, debt, and a lack of financial privacy (Puli, Layton, Belle, & Shahriar, 2024; Loseva, 2021; Gutterman, 2024). Often, parents continue to fully manage their children's bank accounts, reinforcing the idea that financial services should be designed for the able-bodied (Loseva, 2021).

The concept of guardianship is often raised when there is suspicion of a person's inability or incompetence to manage money (Millar, 2013). Guardianship is a legal process by which the court appoints a guardian to make decisions for someone identified as (partially) incompetent to make decisions on their behalf (Millar, 2007). This form of substitute decision-making removes many rights from the person with a disability (Jameson, 2015). Therefore, guardianship should not be seen as self-evident and potentially threatens the self-determination and (financial and social) inclusion of people with disabilities (Millar, 2007; Millar, 2013; Jameson et al.,

2015). While there are many variations of guardianship, depending on different contexts and situations, research shows that full or plenary guardianship is the most commonly used, although it is highly contested by people with disabilities, self-advocates, and informal networks (Jameson, 2015). Millar (2013) clearly states that guardianship should be considered as a last resort, after deliberately balancing the importance of protecting people from negative decisions and supporting autonomy. Furthermore, it is crucial to be transparently informed about less intrusive and restrictive alternatives, such as supported decision-making, models of person-centered planning, representative payees, and many other financial planning mechanisms depending on the country and situation (Jameson, 2015; Millar, 2013; Carney, 2019).

Redesigning financial services from the perspective of (physical and digital) accessibility and changing the mindset about people with disabilities as unattractive clientele, along with targeted policies and strategies, are the first steps toward greater financial inclusion (Puli, Layton, Belle, & Shahriar, 2024). Accessibility of financial services is not a one-size-fits-all approach and should be tailored to particular needs (Kim & Lee, 2024; Gutterman, 2024). Furthermore, the voices of people with disabilities should be consulted when designing financial systems that address barriers to banking, receiving credit, financial advisory services, and so on (Puli, Layton, Belle, & Shahriar, 2024). Directly involving people with disabilities in planning financial services and training programs will facilitate positive interactions between people with disabilities as potential clients and service personnel (Gutterman, 2024).

Frameworks of self-determination can provide valuable insights into these matters. By building financial literacy among people with disabilities and their networks, their profiles and needs can become clearer in navigating everyday banking services (Puli, Layton, Belle, & Shahriar, 2024; Loseva, 2021). Financial literacy is defined as "the extent to which individuals can understand and use information related to their personal finances"

(Thohari & Rizky, 2021, p. 49; Huston, 2010). Loseva (2024), for example, has developed an interactive tool to support people with disabilities in learning how to invest and manage money. Research by Kim & Lee (2024) suggests that financial knowledge and socialization within the family are important mechanisms to improve the financial well-being of people with disabilities and empower their financial confidence. Financial education programs can be an essential factor in providing people with disabilities the necessary information, skills, and self-confidence to manage their finances successfully (Kim & Lee, 2024). Moreover, Gutterman (2024) emphasizes the idea of assisting people with disabilities in their journey toward greater financial empowerment, defined as the "ability and confidence of individuals and communities to make positive financial decisions that promote their long-term financial stability and well-being."

The specific issue of the end of life

Although the end-of-life needs of people with disabilities are the same as those of the general population, there are differences in the care provided, particularly for people with intellectual disabilities (Grindrod, 2021).

As regards the specific issue of self-determination at the end of life, for the general population this has become the rule: decisions (such as artificial nutrition or the choice of whether or not to be resuscitated in the event of cardiac arrest...) are made by the patient or their legal representative. So most people decide to let death come (and not delay it any longer). However, this can be a very heavy responsibility for the person or their representative (Kunz and Rüegger, 2018). In the context of palliative care, self-determination can be defined as: “A decision-making process that includes personal assessment, support and advice from others, and activities that enable one to end life and die in peace.” (Bakitas, 2005). With regard more specifically to people with disabilities, the first observation is that over the last 40 years, life expectancy has increased considerably: people are living better and longer and, as a result, are also faced with more

end-of-life decisions (Dusart, 2015). However, a survey carried out in France in 2015 found that, in the case of terminal illness for people with disabilities; the seriousness of the situation was explained in only one third of cases. This was deemed impossible or undesirable in another third of cases, and finally, for the final third, the institutional team did not know what had been said by the medical profession and had to work with uncertainty (Dusart, 2015). Another survey carried out in Switzerland found the same thing, observing that people with intellectual disabilities were not very involved in decision-making processes or were left to face end-of-life decisions alone (Wicki et al., 2015). Yet these discussions are essential: death is not a failure of medicine but an integral part of life (Kunz and Rüegger, 2018). In this context, it is important to pay attention to the spiritual needs of each individual (Heller et al., 2011). It has also been shown that when palliative care teams are trained to communicate specifically with people with disabilities, there is an improvement in symptom management in the terminal phase (McCallion, Ferretti and McCarron, 2021). Nevertheless, carers feel that they are poorly prepared for the end of life (Ryan et al., 2011) and feel that more discussion/preparation is needed (Belperio et al., 2023).

In the context of disability, there is also the question of requests for euthanasia: these requests are sometimes perceived as rational or legitimate in view of the disability, and the depression observed among people is considered to be “rational” (“in view of these difficulties, everyone would be depressed!”). Nevertheless, it is clear that a disability does not automatically lead to a desire to end one's life, and it is even common for people who have acquired a disability to declare that their life is better than it was before the disability (Gill, 2004). The depressive affects of a person with a disability are more closely linked to social factors: isolation or the absence of a significant role for the person (Gill, 2004).

5 Self-determination and ethic

Promoting self-determination for people with disabilities is a fundamental ethical goal, but it raises complex considerations. Key ethical issues include respecting autonomy, ensuring meaningful participation, balancing protection with empowerment, and addressing power imbalances and communication barriers.

Respect for autonomy and individuality

Self-determination is a basic human right. However, people with profound disabilities are often denied this right because others assume they are not able to make choices or that their preferences do not matter (Skarsaune & Hanisch, 2023; Skarsaune, 2022; Van Der Meulen et al., 2018). These assumptions can lead to exclusion and a lack of respect for the person's dignity and autonomy.

Ethical support requires recognizing that every person is unique and may express their needs and wishes in different ways. For people with profound disabilities, communication often happens through non-verbal or physical means rather than spoken words (Skarsaune & Hanisch, 2023; Skarsaune, 2022; Holmberg et al., 2024; Nicholson & Matross, 1989). It is important not to expect everyone to make decisions in the same way.

Respecting the autonomy and individuality of people with disabilities also means moving beyond traditional views of independence. Autonomy is not only about making choices alone—it often happens in and through relationships. This is especially true for people who need more intensive support to express preferences and make decisions (Davy, 2015; Stefánsdóttir et al., 2018; Davy, 2019; Björnsdóttir et al., 2015, et al., 2014). This idea is known as relational autonomy.

Relational autonomy sees autonomy as something that grows through supportive and trusting relationships. It involves support and advocacy, when offering the right kind of help, encouragement, and

information so people can make their own choices (Davy, 2015; Stefánsdóttir et al.; 2018, Davy, 2019; Björnsdóttir et al., 2015, et al., 2014). But also enablement, by removing barriers and creating environments that allow people to participate and decide for themselves (Davy, 2015; Stefánsdóttir et al., 2018; Cardol et al., 2002; Duda, 2024).

In practice, this means taking a person-centered approach: understanding each person's preferences, needs, and social context, and making sure they have the chance to participate in decisions (Cardol et al., 2002; Ells, 2001; Kenzie & M., 2024; Duda, 2024). Access to information and support with communication is essential, especially in important life decisions (Björnsdóttir et al., 2015; et al., 2014).

Effective support balances care and autonomy—it respects the person’s individuality without taking over and builds warm relationships without ignoring their right to choose (Davy, 2019; et al., 2014).

Respecting the autonomy and individuality of people with disabilities means creating supportive and enabling relationships and environments. By embracing relational autonomy, offering personalized support, and ensuring access to communication and information, we can empower people with disabilities to make their own choices and to fully participate in all areas of life.

Informed consent and capacity

Assessing and supporting a person’s decision-making capacity is a critical part of ethical and person-centered care. It is not enough to ask whether someone can give consent in a traditional way. Professionals must actively explore how each individual can be supported to participate in decisions about their own life. Decision-making capacity is not a fixed trait—it can vary depending on the context, the nature of the decision, and the support provided (Holmberg et al., 2024; Nicholson & Matross, 1989; Casimiro et al., 2023). This means that assessments must remain flexible and responsive, and should be regularly revisited.

When a person cannot provide explicit or informed consent—due to cognitive, communicative, or other limitations—ethical frameworks call for alternative approaches that continue to center the person's values and preferences. This includes advance directives, where individuals express their wishes in anticipation of future incapacity, legal representatives or guardians who help ensure decisions align with the person's known values and best interests, and supported decision-making, which emphasizes shared responsibility and enables participation, even when extensive support is needed (Holmberg et al., 2024; Nicholson & Matross, 1989; Casimiro et al., 2023).

Applying these approaches ethically demands a strong commitment to accessibility and inclusion. Professionals must tailor the decision-making process to each person's communication style and cognitive abilities. This involves providing information in accessible formats, using inclusive communication strategies, and fostering environments in which individuals feel empowered to express preferences and make choices (Casimiro et al., 2023). Ethical support also requires awareness of potential biases or communication barriers that may lead to underestimating a person's capacity. The goal is not to replace the person's voice, but to create the right conditions for meaningful participation—something that often relies on trust, time, and support from people who know the individual well.

A human rights perspective reinforces this inclusive approach. According to the UN Convention on the Rights of Persons with Disabilities, all individuals possess legal capacity, and consent procedures must promote autonomy and participation rather than exclusion (Lombard-Vance et al., 2023). This shifts the focus away from substituted decision-making and toward supported models that recognize the person's right to be involved in decisions affecting their life.

Complementing this, a person-centered approach insists that consent processes be tailored to the individual's unique abilities, needs, and circumstances. Rather than applying blanket exclusions, systems and

professionals must find ways to honor each person's autonomy and lived experience (Dunn et al., 2023; Wark et al., 2017; Fisher, 2003).

Taken together, these ethical principles guide the development of systems that empower individuals, respect their dignity, and ensure that their participation in decision-making is genuine, informed, and meaningful.

Balancing protection and empowerment

One of the central ethical tensions in supporting people with disabilities lies in balancing the need to protect individuals from harm with the imperative to empower them to make their own choices. Professionals often encounter situations where protective measures—such as restraints, close supervision, or substituted decision-making—are seen as necessary to ensure safety. However, such interventions can conflict with a person's right to autonomy and self-determination, particularly when they restrict an individual's ability to take risks and make independent decisions (Van Der Meulen et al., 2018; Nicholson & Matross, 1989; Bennesved et al., 2023). While protection is often well-intentioned, overly restrictive practices, even if justified by concerns for safety or structure, may ultimately undermine autonomy and dignity. These measures are ethically problematic unless they are clearly necessary, proportionate, and demonstrably in the person's best interest (Van Der Meulen et al., 2018; Bennesved et al., 2023).

Balancing protection and empowerment requires moving beyond a purely risk-averse mindset. Ethical care involves a more nuanced approach that upholds both the individual's right to be safe and their right to meaningful participation in decisions about their life. This includes resisting the default to paternalism and instead fostering autonomy through supported decision-making, building trusted relationships, offering accessible information, and applying inclusive communication strategies (Nicholson & Matross, 1989). Respecting autonomy sometimes means accepting the possibility of failure or harm—provided that the individual has

been meaningfully involved in the process and that safeguards are in place to respond when needed. The goal is not to eliminate all risk, but to create conditions where individuals can grow, learn, and exercise agency within a safe and supportive environment.

This ethical tension is mirrored in broader legal and care systems, where decisions often reflect a balancing act between protecting individuals—especially those with cognitive or psychosocial disabilities—and respecting their right to self-determination. Practices such as guardianship can limit autonomy, and without critical reflection, they may sideline the voices of the very individuals they aim to protect (Fallon-Kund et al., 2017; Dan, 2020; Andersen, 2022). Overprotection, especially when applied to children or people with intellectual disabilities, can result in disempowerment, dependency, and restricted social participation (Buhagiar & Lane, 2020; Andersen, 2022).

To counter these risks, empowerment strategies must be at the heart of ethical practice. Empowerment means enabling people with disabilities to exert control over their lives, participate in society, and make decisions about matters that affect them. This involves actively including individuals in the design of interventions and research processes (Dan, 2020; Suarez-Balcazar et al., 2023; Fawcett et al., 1994), promoting self-advocacy and self-determination, and ensuring access to information about their rights (Buhagiar & Lane, 2020; Whaley et al., 2019; Fawcett et al., 1994; Sprague & Hayes, 2000). It also entails shifting power dynamics in service systems, so that the preferences and voices of people with disabilities are not only heard but prioritized (Hagner & Marrone, 1995; Whaley et al., 2019; Sprague & Hayes, 2000).

Awareness of power dynamics is essential. Professionals and caregivers must recognize their own influence and avoid imposing values or reinforcing stigmatizing models of disability (Dan, 2020; Hagner & Marrone, 1995; Sprague & Hayes, 2000). Empowerment is most effectively achieved through mutual, respectful relationships that validate the

contributions, needs, and choices of people with disabilities (Sprague & Hayes, 2000). This includes ensuring their involvement in decision-making processes at all levels—personal, organizational, and policy-related—which is essential for both protection and empowerment (Suarez-Balcazar et al., 2023, Whaley et al., 2019; Fawcett et al., 1994).

In sum, balancing protection and empowerment is a continuous ethical undertaking that requires critical reflection, awareness of structural power, and a deep commitment to including people with disabilities in decisions about their own lives. Ethical support safeguards against harm not by eliminating risk altogether, but by fostering autonomy, promoting participation, and strengthening the individual's right to self-determination.

Power imbalances and participation

Ethical guidelines emphasize the importance of addressing power imbalances between professionals and people with disabilities, recognizing that such imbalances can lead to exclusion, disempowerment, or tokenistic forms of participation. Genuine inclusion requires more than simply consulting individuals or checking a participatory box, it involves creating conditions where people with disabilities have real influence over decisions that affect their lives (Skarsaune & Hanisch, 2023; Skarsaune, 2022; Casimiro et al., 2023). To counteract systemic and interpersonal hierarchies, professionals must foster caring, empathetic relationships that prioritize mutual respect and trust. This means actively engaging with individuals not only as recipients of care or support, but as experts in their own lives—individuals whose perspectives, preferences, and lived experiences are central to ethical practice. Meaningful participation must be embedded in all levels of decision-making, from personal support planning to organizational governance, in ways that uphold dignity, promote agency, and challenge exclusionary norms (Skarsaune & Hanisch, 2023; Skarsaune, 2022; Casimiro et al., 2023).

Power imbalances remain a significant barrier to participation for people with disabilities. Addressing these imbalances requires intentional strategies at individual, organizational, and societal levels to promote empowerment, choice, and meaningful involvement. Empowering people with disabilities and actively involving them in decision-making processes are key to improving participation and reducing disparities in influence and control.

Institutional structures and professional dominance often define norms, codes of conduct, and decision-making processes in ways that restrict the agency of people with disabilities, particularly in residential care or group home settings (Svanelöv, 2019; Guldvik & Askheim, 2021; Jackman-Galvin & Partridge, 2022). These power imbalances are reinforced by traditional care models, inaccessible language, and information-sharing practices that marginalize or exclude disabled individuals from meaningful engagement (Whaley et al., 2019; Guldvik & Askheim, 2021; Dan, 2020; Jackman-Galvin & Partridge, 2022).

To address these issues, empowerment and engagement must be prioritized. Supporting people with disabilities to take control over their lives, make choices, and influence the systems that affect them is essential. This involves using preferred and respectful language, ensuring transparent communication, and working alongside “experts by experience” to reshape care and support structures (Whaley et al., 2019; Hammel et al., 2008; Dan, 2020). Person-centered and inclusive approaches offer powerful tools to challenge systemic inequalities, but these must be embedded in organizational culture and relational practices—not just formal policies (Beresford, 2021; Dan, 2020; Jackman-Galvin & Partridge, 2022). Co-production and participatory methods, such as involving people with disabilities as co-researchers and co-designers of services, also play a crucial role in dismantling power hierarchies and ensuring that interventions are grounded in lived experience (Pasin & Karatekin, 2024; Pettican et al., 2022).

However, barriers to participation persist across various domains. Environmental constraints—including physical, social, economic, and policy-related factors—can significantly limit engagement (Hammel et al., 2015; Hammel et al., 2008). Limited mobility and unemployment further reduce opportunities for social and civic participation (Pasin & Karatekin, 2024). Conversely, supportive environments and positive social attitudes can serve as strong facilitators (Hammel et al., 2015; Hammel et al., 2008). Having real choice and control over one's participation—and being able to define what meaningful involvement looks like—is also essential to fostering autonomy and inclusion (Whaley et al., 2019; Hammel et al., 2008; Dan, 2020).

In conclusion, reducing power imbalances and enhancing participation for people with disabilities requires more than surface-level changes—it demands a fundamental shift toward empowerment, inclusive practices, and systemic transformation. Meaningful participation is best achieved when individuals are given real opportunities to exercise choice, shape their environments, and assert control over the decisions that impact their lives.

The Development of Risk and Legal Liability Concepts in Supporting People with Disabilities

It is important to include a section on the development of the concept of risk and legal liability within the ethical framework because this topic deeply influences how the self-determination of people with disabilities is put into practice. Understanding how risk is perceived and managed, alongside concerns about legal responsibility, shapes the decisions made by caregivers, professionals, and policymakers. These decisions can either support or restrict the autonomy of individuals with disabilities, affecting their ability to make choices and live independently. Exploring this topic sheds light on the ethical tensions between protecting individuals from harm and respecting their right to take risks as part of exercising their self-determination.

Balancing Autonomy and Safety: Ethical Challenges in Risk Management

Balancing autonomy and safety for people with disabilities is an ethical challenge that requires care providers to constantly weigh respect for self-determination against the need to ensure protection. An effective approach is the application of a flexible framework, such as the Safety–Autonomy Grid, which helps determine how autonomy and safety can be balanced in each situation, with attention to the changing needs and preferences of the client (Marnfeldt & Wilber, 2025).

In practice, it appears that care providers often make use of discretionary space and make decisions as a team, engaging in conversations and collaboration with clients and their networks to find solutions that respect both autonomy and safety (Perone, 2023; Van Loon et al., 2023). Relational autonomy, in which autonomy is seen as something that arises in connection with others, provides a useful perspective: care can only truly be supportive if it allows space for the client's own choices and voice (Davy, 2019; Pols, Althoff, & Bransen, 2017; Van Loon et al., 2023).

Different care models, such as the participatory or emancipatory model, emphasize the importance of empowerment and supporting self-direction, whereas the protectionist model puts more emphasis on safety and protection (Sampaio & Guilhem, 2022). In everyday practice, tensions often arise between policies that promote autonomy and routines that prioritize safety, especially in high-risk situations such as medication management or fall prevention (Perone, 2023; Gappmayer, 2021).

Recognizing dependence as a normal part of the human condition and actively involving clients in decision-making are crucial to safeguarding both autonomy and safety (Gappmayer, 2021; Davy, 2019; Van Loon et al., 2023). In this way, care providers can, through customization and ongoing dialogue, respect the freedom of people with disabilities without losing sight of their safety.

Ethical Tensions Regarding Legal Liability in Disability Support

The ethical tensions surrounding legal liability in the support of people with disabilities revolve around finding a balance between professional responsibility and respect for self-determination. Care providers and physicians have a legal duty to act with diligence, prevent harm, and ensure confidentiality—even when there is no formal treatment relationship—which increases the ethical pressure to always act in the client's best interest without undermining their autonomy (Vanderpool, 2013). At the same time, safeguarding self-determination requires that clients retain as much control as possible over their own lives and decisions, which can sometimes conflict with professionals' tendency to avoid risk due to fear of liability (Vanderpool, 2013; Ricardo et al., 2025). Clear communication, transparent documentation, and strict adherence to professional standards are essential to avoid both legal and ethical pitfalls and to maintain client trust (Ricardo et al., 2025).

In addition, the literature emphasizes the importance of continuous training and reflection on ethical dilemmas, so that professionals not only meet legal requirements but also place the human dignity and freedom of choice of people with disabilities at the center of their work (Ricardo et al., 2025; Vanderpool, 2013). This creates a constant tension between protecting clients from potential harm and respecting their right to self-determination, where ethical considerations and legal responsibilities must go hand in hand (Vanderpool, 2013; Ricardo et al., 2025).

From Protectionism to Empowerment: The Changing Ethics of Risk

The ethics of risk management in care are shifting from a protective, paternalistic approach to one that emphasizes empowerment, where patients and care providers are seen as partners. Traditionally, the focus was on protecting individuals from risk—often through strict protocols and by

limiting autonomy—but recent research highlights the importance of patient empowerment and shared decision-making, especially in mental health care, where professionals increasingly view patients as essential partners in managing risk and expect them to actively contribute to their own safety and well-being (Rimondini et al., 2019; Card, 2020).

This evolution calls for an ethical framework that not only manages risks but also safeguards the rights, autonomy, and well-being of both patients and providers—for instance, by balancing the duty of care with staff well-being, as was evident during the COVID-19 pandemic (McDougall et al., 2020; Macpherson et al., 2024). In public health, such as in child protection, this shift implies a broader understanding of risk that focuses on promoting development and well-being, rather than merely preventing harm (Parton, 2019).

At the same time, this approach demands new skills, more humanistic training, and a shared sense of responsibility, with universal values and justice at the core (Macpherson et al., 2024). The shift from protection to empowerment requires transparent, systematic decision-making and acknowledgment of the complexity of risks, where ethical reflection and collaboration are essential (McDougall et al., 2020; Card, 2020).

Moral Responsibility and Risk-Taking in Supportive Environments

Ethically allowing risks for the well-being and growth of people with disabilities revolves around respecting their dignity of risk—the right to make their own choices, even when those choices involve potential dangers, because this is essential for personal development and autonomy (Chicoine & Kirschner, 2022; Seale, 2014; Borgström, Daneback, & Molin, 2019). Traditionally, a protective, paternalistic approach has often been used, but this can limit opportunities for independence and self-realization (Chicoine & Kirschner, 2022; Gappmayer, 2021).

Supportive environments—where caregivers, families, and professionals collaborate—can make risk-taking responsible by offering education, building social skills, and providing safety nets when necessary (Chicoine & Kirschner, 2022; Seale, 2014; Jacobs, 2019; Wiesel et al., 2024). Positive risk management, which focuses not only on danger but also on opportunities for growth, is increasingly seen as an ethically desirable approach (Borgström, 2021; Seale, 2014; Borgström, Daneback, & Molin, 2019).

It is crucial to actively involve people with disabilities in decisions about their own lives, centering their desires and capabilities (Jacobs, 2019; Luckasson, Tassé, & Schalock, 2022; Wiesel et al., 2024). At the same time, this demands a careful balance between safety and autonomy, where moral responsibility is shared among the individual, their network, and professionals (Jacobs, 2019; Luckasson et al., 2022; Wiesel et al., 2024).

Ethically responsible risk-taking does not mean ignoring dangers, but rather creating a supportive context in which people with disabilities can learn, grow, and fully participate in society (Chicoine & Kirschner, 2022; Seale, 2014; Jacobs, 2019; Borgström et al., 2019; Wiesel et al., 2024).

The Ethics of Precaution: Navigating Risk in Disability Services

The ethical debate in disability services often centers around the tension between avoiding harm (precaution) and promoting opportunities and independence. Traditionally, the emphasis has been on preventing risks and harm, with care providers inclined to make decisions that primarily ensure physical safety—sometimes at the expense of the client's autonomy. However, recent ethical analyses stress that avoiding harm should not always be the highest priority; respecting autonomy and enabling opportunities for self-determination are equally important, especially since severe limitations on autonomy can hinder the pursuit of a meaningful life (Keating, 2018).

In practice, this means that care providers must consider not only physical risks, but also the psychosocial value of self-chosen risks for people with disabilities. The concept of dignity of risk highlights that taking risks is sometimes essential for personal growth and for experiencing self-agency (Kondrat, 2022). At the same time, it remains crucial to protect vulnerable groups from disproportionate harm, especially in situations like the COVID-19 pandemic, where the risk of exclusion and discrimination is high (Sabatello et al., 2020).

The challenge lies in finding a balance between protection and promoting opportunity, where ethical decision-making is not solely about harm avoidance, but also about supporting autonomy and inclusion (Sabatello et al., 2020; Keating, 2018; Kondrat, 2022).

Legal Liability and Ethical Duty: Implications for Care Providers

Legal liability has a significant impact on the ethical decisions of healthcare professionals, as it influences the balance between professional responsibility, moral integrity, and legal consequences. Care providers are often faced with situations where their ethical duty to do what is best for the patient may conflict with the risk of legal liability—for instance, in cases of negligence or failure to comply with informed consent (Mei-Che, 2004; Aondowase et al., 2021; Horner et al., 2016).

This tension can lead to defensive care, where professionals act primarily to avoid legal claims rather than focusing solely on the patient's well-being, which can undermine the trust relationship with patients (Mei-Che, 2004; Hughes, 2021). In many countries, legal accountability of care providers is assessed against professional standards, yet ethical principles such as justice, respect for autonomy, and the prevention of harm remain essential complements to the legal framework (Birkeland, 2022; Kamran & Syahrul, 2024).

It is therefore important that care providers not only possess legal and ethical knowledge, but also have the ability to think critically and reason morally to justify their actions (Mei-Che, 2004; Kamran & Syahrul, 2024). In complex situations—such as refusing treatment or using telemedicine—care providers must carefully weigh how to balance their ethical duty with legal responsibility to provide optimal and equitable care (Stanberry, 1998; Horner et al., 2016).

PART 4

SELF-DETERMINATION IN THE CONTEXT OF DISABILITY AND CHILDHOOD

1 The context

The majority of research has focused on self-determination during adolescence and in school-aged children. However, recent research has started to concentrate on self-determination in young children (Erwin et al., 2009; Palmer et al., 2013), stating that preschool children can express preferences, make choices within appropriate environments, and are able to express a sense of autonomy within safe spaces (Hsiang-Yi & Szu-Yin, 2012). Therefore, much research focuses on promoting self-determination in the context of schooling, as well as in relation to family life and parenting strategies and practices (Arellano & Peralta, 2013; Meral et al., 2023; Carter et al., 2013).

2 Why promote self-determination during childhood?

Literature states that foundational skills to foster self-determination—including problem-solving, planning, expressing personal preferences, choice-making, and goal-setting (Palmer, 2010; Shogren et al., 2015)—are and can be shaped from early childhood onward (Erwin, Brotherson, Palmer, Cook & Summers, 2009; Meral, Wehmeyer, Palmer, Ruh & Yilmaz, 2023). According to Erwin et al. (2009), self-determination in early childhood is about looking toward the future and balancing family values with child preferences in order to develop lifelong skills. The Self-Determination Foundations Model, as conceptualized by Palmer et al. (2013), identifies specific appropriate skills that are precursors or foundations of self-determination in the lives of young children: (1) opportunities for choice-making and problem-solving, (2) self-regulation, and (3) engagement. The model suggests that the skills, attitudes, and knowledge leading to self-determination can develop and be fostered at an early age (Lee, Palmer, Turnbull & Wehmeyer, 2006).

For primary school-aged children, exploring self-determination relates, among other things, to selecting friends, engaging in leisure activities, and making larger choices about one's own life (Erwin et al., 2009). Students with disabilities who leave primary education with higher levels of self-determination achieve more positive results in life than their peers who were less self-determined at that stage (Lee et al., 2006).

3 How to foster self-determination during childhood?

It is very important for early caregivers to facilitate and provide sufficient support during early childhood education and care (Hsiang-Yi & Szu-Yin, 2012). Early explorations with self-determination involve making simple choices, engaging in supported problem-solving, and making decisions about participating in play, sharing toys, etc. (Erwin et al., 2009).

When it comes to children of primary school age, explicit teaching of self-determination has promising effects for all children, including those with disabilities (O'Brien, 2018; Wehmeyer et al., 2013). Research suggests that instructional activities to promote self-determination should happen at the level of the class, in small groups, and individually, and that this forms an important preparatory stage for transitioning to post-primary education, which requires higher levels of independence (O'Brien, 2018).

Traditionally, the home is considered the first context offering opportunities to develop (precursor skills of) self-determination (Lee et al., 2006). Much research has investigated the role of the family in facilitating self-determination in (young) children (Brotherson et al., 2008). These studies, for example, have elaborated on parents' perceptions and beliefs about self-determination and their own perceptions of control (Arellano & Peralta, 2013). Authoritative and autonomy-supportive parenting, as opposed to permissive and overprotective styles, are considered to positively impact children's growing capacity for self-determination (Meral

et al., 2023; Cavendish, 2017). A study by Arellano & Peralta (2013) demonstrated that parent strategies to foster self-determination decline with the severity of their child's disability—children with the most severe challenges receive fewer opportunities to take control.

However, the impact of parenting styles also seems to be mediated by demographic and socio-economic factors such as urbanization, parent income, and parent education level (Meral et al., 2023; Cavendish, 2017). Moreover, a study by Meral et al. (2023) highlights the impact of cultural factors on parenting styles and practices related to fostering self-determination. Whereas self-determination is well-known as a concept in European-American individualist-oriented cultures, it is interpreted differently in Mediterranean and non-Western cultures that emphasize collectivist values (Alrabiah, 2021; Palut, 2009). Various cultures define and engage with self-determination in different ways and may strive toward independence through various pathways (Hsiang-Yi & Szu-Yin, 2012). Cross-cultural perspectives on concepts like self-determination, as well as the relatedness between children and their families, are important (Meral et al., 2023; Chu, 2018). These insights highlight the importance of diversity and culturally responsive tools, assessments, and strategies when investigating and promoting self-determination in children with disabilities (Shogren, 2011). Building cultural competence for professionals and identifying one's own cultural values while listening for indications of others' values becomes incredibly important (Hsiang-Yi & Szu-Yin, 2012).

Literature is consistent on the importance of partnerships between parents and professionals in recognizing and supporting the development of self-determination in childhood (Erwin et al., 2009; Palmer, Summers, Brotherson et al., 2013). Such collaborative relationships should start with egalitarian expectations and establishing ambitious yet realistic objectives to help the child's self-esteem and self-awareness grow from an early age (Arellano & Peralta, 2013). Family-professional partnerships based on mutual agreement, across childcare, preschool, and educational settings, are

beneficial for effective home-school relationships that foster self-determination at home, at school, and in the wider community (Palmer et al., 2013; Turnbull, Turnbull, Erwin, Soodak & Shogren, 2011; King, 2009). In this regard, Brotherson et al. (2008) identify different strategies to be explored with families: (1) engagement with the home environment, (2) making choices in the home environment, (3) exercising control over the home environment, and (4) supporting self-esteem at home. Overall, educating and parenting toward the self-determination of children builds on viewing children with disabilities as individuals with strengths, rights, and the desire to become independent (Arellano & Peralta, 2013).

4 The specific issue of scolarity

The schooling of children and adolescents with disabilities remains a sensitive issue. While the right to education is regularly reiterated (see, for example, the United Nations Convention on the Rights of Persons with Disabilities, adopted by the UN in December 2006 and signed in March 2007), it is the methods of implementation that are sometimes the subject of heated debate. Can children with disabilities be educated in so-called "mainstream" schools, i.e., alongside other students without disabilities? If so, what arrangements need to be made to accommodate and support them? What benefits do these students derive from the mainstream environment, given that it has not been formally established that embracing diversity erases differences and has beneficial effects on self-esteem? (Chevallier-Rodrigues et al., 2019). In reality, it comes down to the resources dedicated to fully understanding disability, what it encompasses, and providing appropriate responses, developed in collaboration with those most affected, primarily the children themselves (Palmer, 2022).

According to Charles Gardou (2008, p. 125), "A persistent temptation remains: that of placing these special students in special places under the responsibility of specialists. Such exclusions from the educational process, mostly arbitrary, represent nothing less than inequalities in treatment: they

are forms of mistreatment, acts of violence likely to generate further violence. When the School penalizes the most vulnerable, social violence increases." It is clear that this is not merely about assigning students to educational structures specially designed for them. It is about a principle of equity in treatment — a profoundly social, even societal issue. But for this principle to be effectively applied, inclusion must take into account the child's environment and individual needs. C. Gardou advocates for the personalization of learning pathways and the establishment of a genuine continuum between teaching and support (Gardou, 2008). The training of educational staff represents a major challenge: "In many cases, except for those with specialized training, they face a paradoxical injunction: they are asked to actively contribute to the education of students with special educational needs, without having received training designed and delivered for that purpose. Most often, they are merely made aware of the issue or provided with general, fragmented knowledge — knowledge that is largely ineffective because it is disconnected from experiential learning and from the demands of daily professional practice" (Gardou, 2008, p. 133).

The French law of 2005, already mentioned, emphasizes the need for compensation in order to establish or restore equality of rights and opportunities. The educational pathways of students with disabilities, in accordance with the law, are based on three fundamental pillars:

1. A Personalized Schooling Project (Projet Personnalisé de Scolarisation, PPS), which is part of the personalized compensation plan now granted by law to every person with a disability.

2. A reference teacher, who coordinates the schooling support team for each student, composed of parents and professionals involved in the child's education. This team ensures the effective implementation of the PPS and evaluates its impact on the student's schooling.

3. The development of schooling within mainstream educational institutions, either through individualized support in a regular classroom (by School Life Assistants) or through collective support systems (pedagogical groupings of students with the same type of disability), in the form of Special Education Classes (CLIS) in primary schools and Pedagogical Integration Units (UPI) in secondary schools (Gachet, 2008, p. 138).

Thinking from the perspective of promoting self-determination and inclusive pathways, there are many opportunities within education. However, we notice that young adults with intellectual disabilities are often quickly directed towards special education and rarely make the reverse transition back into inclusive pathways in society (Daelman, De Clercq, Van Hee et al., 2025).

Research conducted in the Flemish context (Daelman, De Clercq & Van Hee, 2025) shows that the experiences of young adults with (suspected) disabilities within education vary widely. Common themes include limited study choices, a lack of inclusion, and high mental pressure. Many young people feel that they have few options within the education system. In special education, they are often guided toward study tracks that do not necessarily align with their interests or abilities. This leads to frustration and, in some cases, early school leaving.

Students in mainstream education, on the other hand, often encounter a lack of reasonable accommodations—such as accessible learning materials and classroom support. For many, the transition to higher education is difficult (Daelman, De Clercq, Van Hee et al., 2025).

Theoretically, young people with disabilities have the right to participate in the same educational opportunities as their peers. In practice, however, they are often directed toward programs that prepare them for sheltered work environments or low-paid jobs (European Agency, 2006). Crowley (2022) concludes that “students with disabilities consistently lag

behind their peers in terms of employment rates, participation in higher education, independent living, and opportunities for success within the community" (p. 169).

Young people with disabilities have fewer opportunities for advancement after secondary education (Covington & Rowlett, 2021), experience greater socioeconomic disadvantage, are more likely to face difficulties in their studies compared to their peers, and report higher levels of unemployment and social isolation (Shogren & Wehmeyer, 2021).

There is a clear need for more flexibility in educational pathways, better-aligned support measures, and stronger collaboration between education and care sectors. In addition, young people should be better informed about their rights to support and the possibilities available to successfully complete their education (Daelman, De Clercq, Van Hee et al., 2025).

A major shortage of assistants who can help support the educational trajectories of young adults with (suspected) disabilities has a significant impact on the inclusiveness of these pathways ((Daelman, De Clercq, Van Hee et al., 2025).

When we look at young people with disabilities who also have a multicultural and multilingual background, the outcomes after secondary education are even less favorable (Achola & Greene, 2016). The literature notes differences related to gender, age, race, class, and socioeconomic background, with certain groups finding themselves in particularly vulnerable situations of multiple exclusion (Crowley, 2022).

Current research emphasizes the strong idea of co-constructing educational provisions for children with disabilities and sharing professional practices in order to fully understand what inclusion entails and to work collaboratively—intelligently and coherently—so that each child, together with their family, is supported in developing a meaningful project aimed at growing autonomy. Magdalena Kohout-Diaz and Hervé Benoit advocate for

the creation of interprofessional spaces to progressively build a learning community. As these authors point out, “Better than appeasement through the subordination of pedagogy to medicine—or vice versa—it is about constructing, around the goals of non-discrimination and accessibility, educational contexts supported by research, training, field practitioners, and public policies, fostering a shared sense of competence and collective efficacy” (Kohout-Diaz & Benoit, 2024, p. 6).

There is a need for greater flexibility in study pathways, better-tailored support measures, and stronger collaboration between education and care sectors. In addition, young people should be better informed about their rights to support and the opportunities available to successfully complete their education ((Daelman, De Clercq, Van Hee et al., 2025). A significant shortage of assistants who can support the educational trajectories of young adults with (suspected) disabilities has a major impact on the inclusiveness of these pathways (Daelman, De Clercq, Van Hee et al., 2025).

Fostering learning environments and supporting the development of self-determination: teachers’ professional posture.

Self-determination does not solely depend on interventions designed to support certain skills; it also involves specific attitudes and professional postures to be adopted. Teachers describe several attitudes (e.g., believing in students’ potential, accepting risk) and postures (e.g., observing, waiting) that directly concern their professional practice. By emphasizing the importance of giving students time, they embody a posture of withdrawal. Furthermore, when they refer to the need to let go, they acknowledge that they must accept a certain level of risk in order to create more opportunities for their students to experience self-determination. When teachers stress the importance of “believing in students’ potential” or “trusting them,” these are attitudes that foster the development of self-determination. They demonstrate that the teacher’s role goes beyond the activities proposed to students and also extends to their underlying beliefs (Charette et al., 2022).

Taking the time to observe students is also a posture that teachers consider essential for supporting self-determination. This strategy is likewise used by professionals interviewed by Cudré-Mauroux et al. (2020a), who highlight that “observation [...] helps to elicit self-determination in individuals by drawing on their interests and certain spontaneous initiatives. It involves identifying their ‘implicit’ self-determination needs and setting up the means to support their development” (p. 109). Supporting the self-determination of students with disabilities thus requires adopting an intervention posture that enables them to better take advantage of opportunities to exercise their autonomy (Charette et al., 2022). It also involves introducing greater flexibility into classroom organization and activity planning, so as to provide students with more opportunities to engage in acts of self-determination (Wehmeyer, 1997).

PART 5

SELF-DETERMINATION IN THE CONTEXT OF DISABILITY AND ADOLESCENCE (AND TRANSITION TO ADULTDHOOD)

1 The context

Self-determination is often discussed as a core concept as well as an essential predictor of success during the transition to adulthood (Wehmeyer, 2020; Mazzotti et al., 2020). Transition should be considered a continuous process of adaptation in all people's lives, encompassing crucial moments such as the start of kindergarten and the end of compulsory education (European Agency for Development in Special Needs Education, 2006). The transition to new life stages spans multiple life domains, locations, and an extended period of time (Wehmeyer & Shogren, 2021). Particularly, the transition to adulthood is associated with major changes regarding the embodiment of new roles, taking on additional responsibilities, making important decisions, and encountering shifting systems of support (Wehmeyer & Shogren, 2020). Clearly, it is another stage in developing autonomy and self-determination.

Transitioning to adulthood is viewed as a highly dynamic period in life that is accompanied by fewer protective structures (such as schools and education) and changes in legal and social statuses (Wehmeyer & Shogren, 2021). Gradually or abruptly, young people and their parents lose the structure of schooling and are introduced into the adult systems of care and complex bureaucracy (McKenzie, Ouelette-Kuntz, Blinkhorn & Démoré, 2016; Osgood, Foster & Courtney, 2010). Vandenbussche (2024) states that young people with disabilities arrive at a crossroads involving education, employment, welfare, the housing market, and relationships. It is a stage that involves planning for further education, community participation, possibilities regarding employment and adult life (Scott et al., 2021).

2 Why promoting self-determination during adolescence?

The literature agrees that the dreams and future plans of young people with disabilities are not fundamentally different from those of young

people without disabilities (Salt et al., 2019). However, time and transition appear to unfold differently in the lives of young people with disabilities, where changes occur over extended periods and multiple rhythms, rather than on fixed or average milestones (Vandenbussche, 2024; McKenzie et al., 2016; Salt et al., 2019). Young people with disabilities face the same challenges as their peers without disabilities, but often with fewer capacities, preparation, and resources (Osgood et al., 2010). Therefore, literature is consistent in emphasizing the importance of actively involving young people with disabilities in exploring and planning the next steps related to support, education, leisure activities, networks, and other aspects of their lives in young adulthood (Yeager & Morgan, 2023; Wehmeyer & Shogren, 2021). Higher levels of self-determination in young people are directly linked to more satisfying transition periods and more positive experiences in inclusive citizenship (Wehmeyer & Shogren, 2021; Kotten, 2018), as well as higher quality of life (Zatta & McGinnity, 2016). Moreover, actively involving young people as agents and supporting their self-determination would not only be beneficial for their individual trajectories but could also transform the healthcare and welfare sectors, leading to more responsive and personalized instruments, strategies, and services (Yeager & Morgan, 2023).

The Salamanca Statement for Action (UNESCO, 1994) already emphasized the importance of promoting self-determination in young people with disabilities as a key factor in their active participation in society: "Young people with special educational needs should be helped to make an effective transition from school to adult working life. Schools should assist them in becoming economically active and provide them with the skills needed in everyday life, offering training in skills that respond to the social and communication demands and expectations of adult life" (p.34). Nevertheless, large discrepancies still exist today in the way young people with disabilities are actively involved in and supported in taking charge of their trajectories (Trainor et al., 2016). Young people with disabilities continue

to face many barriers to accessing the labor market, leisure activities, education, and preferred living conditions and, as a result, struggle to become valued members of society (Trainor, Morningstar & Murray, 2016; European Agency, 2006). Careers, educational trajectories, leisure activities, and networks are not merely "presented" to young people with disabilities—they are the results of active choices made by these young people and their networks, based on a growing sense of self-awareness, life experiences, and significant information about future possibilities (Wehmeyer & Shogren, 2021). Constructing inclusive pathways is grounded in the self-determination skills of young people with disabilities and their networks.

3 How to foster self-determination during adolescence?

Wehmeyer and Shogren (2021) list strategies, interventions, and tools to assess and promote self-determination in young people with disabilities. Nguyen et al. (2017) argue that supporting this quality in people with disabilities during the transition to adulthood is not just about personal capacities but also about strategies to impact the fit between young people and their environment, which should provide opportunities for experimentation and growth in self-determination. Active involvement in their trajectory, self-advocacy in terms of exercising rights, and the development of self-determination are interrelated in the lives of young people with disabilities (Yeager & Morgan, 2023).

As mentioned earlier, it is crucial not to isolate self-determination as an individualized characteristic at this stage of life. Literature suggests that too much pressure or insufficient support in developing self-determination and independence during adolescence makes young people vulnerable to insecurity, risky behavior, and exploitation (AWKajak, 2024). Ecological models of self-determination, which view it as a dynamic factor within family and network interactions and as something that grows through opportunities in the environment, support a more balanced development

of this characteristic (Abery et al., 2008). Kotten (2018) argues that families and schools play vital roles in fostering self-determination and related qualities such as problem-solving, decision-making, and self-regulation. Parents, as the only continuous partners in their children's trajectories, possess unique knowledge and expertise, offering their adolescent children important learning opportunities related to self-determination (Kotten, 2018; Zatta & McGinnity, 2016).

4 The specific issue of (wishing to) becoming parents

Reproductive freedom, as well as the right of people with disabilities to choose to parent, has not been self-evident throughout history (Shandra et al., 2014), including a long history of ill-treatment and involuntary sterilization (Dotson et al., 2003; Mayes & Llewellyn, 2012; Mutcherson, n.d.). Acknowledging these violent histories that neglected the socio-economic realities of people, contributes to a strong emphasis on equal citizenship for people with disabilities today (Reinders, 2008). However, stigma is still attached to both sexual activity and parenting by people with disabilities (Rojas et al., 2016). Especially women with intellectual disabilities are often seen as incapable of making appropriate choices about parenthood and reproduction (Dotson et al., 2003; Gould & Dodd, 2014; Mayes & Llewellyn, 2012; Shandra et al., 2014). Research indicates that many women with disabilities do not feel in control of their bodies or their choices about contraception and sexual health (Ann Dotson et al., 2003). Literature elaborates on both biological and socially constructed barriers that limit the self-determination of people with disabilities regarding parenthood and deny them the opportunity to have children (Mutcherson, n.d.).

Healthcare for women with disabilities focuses on controlling their sexuality and reproductive capacity rather than supporting it (Shandra et al., 2014; Rojas et al., 2014). For example, they are more often advised to undergo

sterilization or terminate pregnancies. However, research with women with and without disabilities indicates that both groups are equally likely to wish for and intend to have children as a normal aspect of the life span (Shandra et al., 2014). The group of women with disabilities reported more insecurity and the awareness that their desires might not be easy to accomplish (Shandra et al., 2014). Literature shows that the role of a parent is desired by people with disabilities, as it also acts as a positive alternative identity and a defense against their enforced 'disability' identity (Gould & Dodd, 2012; Theodore et al., 2018). However, even prior to conception, 'presumed incompetence' is a reality for mothers with disabilities (Theodore et al., 2018; Mayes, Llewellyn & McConnell, 2011). More often than other mothers, mothers with disabilities receive the message that they are not fit to become parents and therefore must prove their 'fitness' and capacity to parent, living up to higher expectations than other mothers do (Gould & Dodd, 2012; Theodore et al., 2018). There is less literature available on the experience of fatherhood in relation to disability (Theodore et al., 2018; Drew, 2009).

While the discourse of 'presumed incompetence' is omnipresent in relation to people with (intellectual) disabilities wishing to become parents, less attention is given to societal circumstances that impact parenthood, such as poorer mental health, lower socio-economic status, different housing options, and the availability of fewer resources and intergenerational support networks compared to other parents (Gould & Dodd, 2012; Theodore et al., 2018; Emmerson et al., 2015). Such factors of multiple disadvantage are a consequence of how society positions people with disabilities (among other minorities) at the margins (Reinders, 2008). These factors impact parenting skills and the risk of losing custody (Theodore et al., 2018). Therefore, it is important to interpret disability (as well as parenting by disabled parents) as an entanglement of individual and environmental factors (rather than individual competence), which is equally true for parents without disabilities (Reinders, 2008).

This debate raises the question of what 'good enough parenting' is and whether it is up to anyone (e.g., doctors or professionals) to assess it in any way. Any idea of 'good parenting' is, by definition, loaded with ethics and subject to the values of a public liberal society (Reinders, 2008). Parents with (intellectual) disabilities around the world are subjects under scrutiny by services (Theodore et al., 2018) and experience a higher risk (up to 40% of all children born to parents with intellectual disabilities) of having their children systematically removed from their care (Booth, 2004; Gould & Dodd, 2012; Mayes & Llewellyn, 2012). Research by Gould & Dodd (2012) makes the sense of powerlessness within these procedures painfully apparent: parents with disabilities were mostly not consulted or involved in these decisions, the reasons for child removal remained unclear to them, and they were not informed about their legal rights or advocacy possibilities (Gould & Dodd, 2012; Mayes & Llewellyn, 2012; Drew, 2009). There is an intricate risk of child protection services positioning parents with disabilities as spectators rather than active agents in the lives of their children (Llewellyn, Traustadottir, McConnell & Sigurjonsdottir, 2010). Power imbalances need to be urgently addressed, and services should invest in two-way conversations and supportive procedures for parents with disabilities concerning custody of their children (Gould & Dodd, 2012; Mayes & Llewellyn, 2012).

When it comes to medically assisted pregnancy and fertility treatment, women with disabilities continue to experience discrimination in their desire to become parents when their 'potential fitness as mothers' is assessed (Mutcherson, 2009). There is a necessity to raise concerns and balance the power of fertility physicians in determining parenting skills and considering the welfare of future children based on the presence of a disability—leading to the refusal of service to certain groups of (aspiring) parents (Mutcherson, 2009). Furthermore, adoption services are known to put strict limits on who can or cannot adopt, widely discriminating against

parents with disabilities (or diseases) who wish to adopt a child (Mutcherson, 2009).

Literature strongly agrees on the necessity of a discourse on 'capability' and support when it comes to parenthood with disabilities. Historical discourses about 'who is worthy of bringing children into this world' have placed people with disabilities in a position of internalized stigma (Theodore et al., 2018) and low self-determination as parents, 'setting them up' for failure against the high stakes of child protection services that only confirm presumed incompetence (Drew, 2009; Gould & Dodd, 2012), fertility medicine, and adoption services. Furthermore, research by Mayes, Llewellyn & McConnell (2011) confirms that social networks and the presence of 'allies' contribute largely to developing, confirming, and maintaining the mother identity for women with intellectual disabilities.

Drew (2009) builds upon feminist literature on care (Kittay, 1999) to propose an ethical framework based on 'distributed competence' that avoids the widespread misconception that parenting is something people do autonomously. This framework is based on concepts such as autonomy in connection with resilience, support, reciprocity, and dependency, and allows care by—and for—parents with disabilities to be interpreted from a positive perspective (Drew, 2009). It creates room for debate about the impact and involvement of professionals in the lives of people with disabilities and their children, and how autonomy for parents with disabilities can be supported in a way that benefits their children and families (Drew, 2009).

Moreover, literature confirms that investing in training for parents with disabilities can benefit appropriate parenting knowledge and skills (Gould & Dodd, 2012). Research suggests that self-determination-based practices can be very supportive for parents with (and without) disabilities (Knowles et al., 2016). Such interventions do not explicitly teach parents to

be more self-determined but use practices based on choice-making, decision-making, problem-solving, self-monitoring, and self-advocacy to support parents with disabilities in fostering 'parent authorship' (Knowles et al., 2016).

5 The specific question of employment

There is a strong demand from young adults to shape inclusive workplaces in which they feel valued and supported. Young adults report that working helps them feel part of society, build social connections, and have a meaningful daily structure (Daelman, De Clercq, Van Hee et al., 2025).

Structural and contextual factors influence young people's career development and choices (Wehmeyer & Shogren, 2021). In the Flemish context of rising unemployment, the process of finding a job is challenging and lengthy for all young people, placing vulnerable groups in an even more difficult position (Brussels armoederapport, 2012). In 2023, youth unemployment (among those under 25) increased by 17.1% (RVA.be). Flanders is currently characterized by a dual labour market in which unemployment rates among young people with higher education diplomas are low, but extremely high among vulnerable groups without a diploma from higher and/or secondary education (Jeugdoverlegplatform, 2016).

These lower-educated young people are more likely to find employment through informal networks, yet these networks tend to be more limited among young people who are vulnerable to exclusion (Jeugdoverlegplatform, 2016).

Early work experiences (such as internships and weekend jobs) are an important predictor of a successful and fulfilling transition after secondary education (Wehmeyer & Shogren, 2021). Many young people are offered internships through their school, which helps them gain work experience and insight into their capabilities. However, for students in special education, this often leads automatically to a transition into sheltered

workshops or day centres, while other employment options receive less attention (Daelman, De Clercq, Van Hee et al., 2025).

The search for work is further complicated by uncertainties regarding financial support and benefits. Young people are often afraid of losing (part of) their allowances if they start working, even part-time (Daelman, De Clercq, Van Hee et al., 2025). Young adults with disabilities often find easier entry into disability-specific employment circuits or volunteer positions. Making regular jobs accessible and adaptable—particularly through flexible working hours, part-time options, manageable workloads, and built-in rest periods—is still far from being standard practice on the inclusive labour market, even though many young adults already make (unpaid) contributions in these contexts (Daelman, De Clercq, Van Hee et al., 2025).

There is a significant shortage of accessible "regular" jobs (for example, for young people with only a certificate) and of willingness among employers to seek a match between young adults' abilities and workplace expectations (Daelman, De Clercq & Van Hee, 2025). Stronger collaboration with companies and organizations is needed, along with policies that hold employers accountable—supported by subsidies—to offer sustainable, inclusive workplaces (Daelman, De Clercq, Van Hee et al., 2025).

A "life design" perspective becomes particularly relevant here: instead of focusing on job placement, where the right person is recruited for a predefined position, a job carving approach is needed (Wehmeyer & Shogren, 2021). This refers to a holistic process in which positions are shaped "to align with the unique needs, abilities, and interests of the job seeker and the sometimes unrecognized needs of the employer" (p. 62). Such negotiation is facilitated by building sustainable relationships with employers and services that support transition processes (Wehmeyer & Shogren, 2021).

In addition to employers, too little emphasis is currently placed on making full use of collegiality, mentorship, and buddy systems as important

forms of collective support. In this way, young adults with (suspected) disabilities could be guided and coached by experienced professionals in their field (Daelman, De Clercq, Van Hee et al., 2025).

Inclusive vocational training—which is a prerequisite for professional integration—must take into account this notion of interprofessionality, which is inherent to the collective work of various professional actors involved (teachers, social workers, educational practitioners, etc.). Indeed, within an inclusive learning framework, one of the main challenges is to address the many potential learning difficulties encountered by trainees. To achieve this, collaborative work is implemented among different professionals contributing to a given training program. It is important to note that high-quality vocational training, adapted to the needs of persons with disabilities, facilitates better professional integration for this population.

Moreover, the difficulties experienced by learners with disabilities during their training can often be explained by their fear of not gaining access to positions that meet their expectations (ibid.). Yet, young people with disabilities share the same professional aspirations as other young people in France (Ifop study for Agefiph, 2021, based on a sample of young people aged 18 to 30). However, they report facing discrimination and barriers to employment more frequently than their peers without disabilities (ibid.). Furthermore, according to the same study (ibid.), the job search process is objectively longer and more complex for young people under 30 with disabilities. They report that their job search takes considerably more time than that of the control group without disabilities—7.6 months on average compared to 4.2 months.

PART 6

SELF-DETERMINATION IN THE CONTEXT OF DISABILITY AND AGEING

1 The context

Over the last few decades, the proportion of older people has continued to rise. This demographic trend, which is still ongoing, can be explained by the decline in fertility and, above all, the increase in life expectancy. While this phenomenon can be observed in all societies, it is most marked in Europe: by 2040, more than one in four Europeans will be aged 65 or over (Kinsella and He, 2009). Throughout history, two representations of old age have always existed, either jointly or alternately. Depending on the era and culture, older people are sometimes seen as wise, as people of reference and experience (a positive view of ageing), while at other times it is the image of madness, senility, burden or decline (a negative view of ageing) that dominates. Today, images of old age emphasise the non-productivity of older people, portraying them as a burden in most industrial societies (Nelson, 2005). Older people are often seen as fragile, intolerant of change and cognitively impaired, which obscures the great cultural, social, physiological and psychological heterogeneity of the individual. In other words, the prevailing view of ageing is currently negative, tinged with ageism. The concept of ageism was introduced in 1969 by R. Butler in reference to the revulsion towards advancing age, illness and infirmity, and the fear of powerlessness, uselessness and death (Butler, 1969).

This phenomenon is important because it will influence our view of an individual's abilities and therefore our attitude: if we think a person is incapable of carrying out certain tasks, we will do it for them, which will reduce their autonomy. This is illustrated by a study in which residents of a nursing home were asked to solve a jigsaw puzzle (Avorn and Langer, 1982). In the first group, there was a great deal of help during training (for example, suggestions were made as to where to put the pieces, or one or other was put in their place). In the second group, the residents were given only verbal encouragement, and in the final group no help was provided during the

training sessions. The results speak for themselves: (1) performance improved in the verbal encouragement condition, (2) the level of performance remained stable in the group without training, and (3) in the group where people were given help, performance was worse after training than before! What's more, in the latter group, the subjects reported that they found the task more difficult and that they were less confident in themselves when performing it (unlike the group who received only verbal encouragement). In other words, excessive assistance can have deleterious effects on the autonomy, and therefore self-determination, of the elderly. A longitudinal study focused on changes in the feeling of control (which is a component of self-determination) and showed that this declines in older people: the older I get, the more I feel I have no control over what happens to me (Wolinsky et al., 2003; Mirowsky and Ross, 2011).

Regarding the specific notion of self-determination, authors have proposed a specific definition in order to better clarify this concept when referring to frail older people: ‘A process in which a person has control and legal/ethical rights, has the knowledge and ability to make a decision of their own choice and has the knowledge and ability to make a decision of their own free will.’ (Ekelund, Dahlin-Ivanoff and Eklund, 2014). This definition has the advantage of clearly defining the components of self-determination in the specific context of ageing.

When we refer to older people with disabilities, it is important to note that in addition to the stigma associated with the disability mentioned above, there is also the stigma associated with age (Martins et al., 2022). In other words, there is a double stigma. Given the impact of ageism on individuals, we can now ask ourselves about the deleterious impact of double stigmatisation.

In this context, a distinction must also be made between (1) ageing with disability and (2) disability during ageing. There is no consensus on the criteria distinguishing these two contexts, but two elements can be taken

into account: the age of the disability (generally, the disability would begin before the age of 64 to be considered as 'ageing with disability') and the duration of the disability (minimum 5 years before the age of 64) (Putnam et al., 2021). This distinction is important because people who age with disability have different socio-economic realities, and among older people with disability there is a high prevalence of early and difficult life experiences such as institutionalisation, lack of educational and social opportunities, low income and poverty (Van Heumen, 2021). One study compared people who grow old with a disability and those who develop a disability as they age: the latter reported lower life satisfaction and social participation. The former, on the other hand, report more discrimination (Kim and Roh, 2021).

2 Why promote self-determination in older people?

An early experiment highlighted the importance of self-determination for people's quality of life in nursing homes (Langer and Rodin, 1976). In this study, the nursing home was divided in two: one floor was devoted to the 'with responsibility' condition and the other floor to the 'without responsibility' condition. In the 'with responsibility' condition, the manager explained to the residents that it was their responsibility to make the nursing home a place where they were happy, to decide how they wanted to organise their room (with or without the help of the staff), how they decided to spend their time, to explain if certain things did not suit them... In addition to these elements, they were offered a plant, specifying that it was their responsibility to look after it. Finally, it was explained that there would be two cinema screenings during the week: it was up to them to decide whether they wanted to go and, if so, on which day. In comparison, in the 'no responsibility' group, the manager explained that it was the responsibility of the staff to ensure that the nursing home was a place where they were happy, that they had organised the rooms as well as possible, and that they could help them if anything was not to their liking. They were also

given a plant, and told that the nurses would take care of it. Finally, they were told that a film night was being organised and that they would soon receive information about the day they would be attending. The results indicate that residents in the 'with responsibility' condition declared themselves happier and more active than those in the 'without responsibility' condition. Also, residents in the 'with responsibility' condition were judged by nurses to spend more time talking to other residents, to visit people outside the nursing home more frequently and to talk to staff more. In addition, there were more residents present at the cinema session in the 'with responsibility' condition. Finally, 18 months later, it was observed that the mortality rate was lower in the 'with responsibility' condition (15%) than in the 'without responsibility' condition (30%) (Rodin and Langer, 1977).

Similarly, one study compared nursing homes with little or a lot of self-determination. To classify the NCMs, the following dimensions were assessed: residents' choice of mealtimes, the extent to which staff are responsible for residents' care, residents' freedom to decorate their rooms, whether residents are allowed to have pets (birds, goldfish, for example) and the extent to which staff encourage residents' personal initiatives. The results indicate greater life satisfaction in NCMs with self-determination (Vallerand and O'Connor, 1989). Furthermore, in a longitudinal study (5-8 months) of 128 residents of NCMs considered to be frail, it was shown that self-determination is linked to well-being (fewer depressive feelings, greater life satisfaction) (Kloos et al., 2019). One study also showed that when indicators of self-determination (particularly autonomy and relationships) were satisfactory, this was associated with greater well-being in people aged over 80 living in nursing homes: people reported more personal growth and more goals in their lives (Ferrand, Martinent and Durmaz, 2014).

3 How can self-determination be promoted in older people with disabilities?

Support can be provided at several levels: life planning (choosing priorities), expressing independence (expressing preferences), communicative and representational support (individual forms of communication and preferences based on long-term relationships or shared life experiences), support in building relationships and administrative support. However, providing meaningful support is a challenge: the effects of support are difficult to assess and there is a risk that it may have the opposite effect, disempowering the people concerned or making them more vulnerable to manipulation and abuse.... In the context of neurodegenerative diseases (Alzheimer's type), this is an even greater challenge: support for decision-making often comes late (at the beginning, it is usually a family member) and this transition is difficult to accept. It requires the use of tools that enable the continuity of the person's past preferences and values, and needs vary greatly depending on the progression of the disease (Carney and Then, 2021).

In order to promote self-determination with the older people, a good understanding of ageing is necessary. However, when a disability is added, particularly in the specific case of older people with intellectual disabilities, one problem is that they are often considered to be ‘eternal children’: as a result, age-related changes are not taken into account (Jormfeldt and Tideman, 2021).

PART 7

CONCLUSION

Self-determination is a multi-dimensional concept and several theoretical models exist. Considering the context of disabilities, the Functional Model of Self-Determination is particularly adapted as it was developed to take into account the impairments of individuals. In this model, four characteristics of self-determination are described (Wehmeyer, 1999): (1) Behavioral autonomy, or the ability of a person to express their preferences, make choices, and act accordingly; (2) Self-actualization: the development of one's talents/skills; (3) Psychological empowerment, referring to a person's perception of their control, influenced by their motivation, locus of control (internal – "what happens to me depends on me" or external – "what happens to me is due to external events"), and sense of self-efficacy; (4) Self-regulation, meaning the tendency of a person to influence the course of their life through self-knowledge (of their strengths and limitations). Yet, a definition of self-determination could be: "the set of skills and attitudes in a person that allow them to act directly on their life by making free choices uninfluenced by undue external agents" (Wehmeyer, 1999). We also have to keep in mind that self-determination is a goal that we strive forward but cannot fully achieved (Sarrazin, 2012). It implies that the person has received training that allows them to know themselves and identify their preferences (HAS, 2022).

Thanks to this synthesis of the literature, we highlight 10 "lessons"/major points concerning self-determination in the context of people with disability:

1. Disability is a social construction: the "problem" is not the person with disabilities but the way normalcy is constructed to create the "problem" of the disabled person (Davis, 2013). We have to challenge disability categories and conventional expectations of what it means to be human in order to fully support participation and inclusion of everyone (Goodley, 2014; Titchkosky, 2021).

2. We have to take into account the intersectionality and recognize disability in its complexity: it's coupled with other factors such as gender, culture, race, ethnicity, language…and can lead to multi-stigmatization (Voulgarides, Etscheidt & Henandez-Saca, 2023).

3. To support self-determination, we have to adopt an ecological perspective and recognize the importance of relational ties, support systems and contextual factors (Mumbardo-Adam, Vicente & Balboni, 2022).

4. The higher the self-determination, the higher the quality of life of people: supporting self-determination can be seen as the transition between "what is" and "what could be" (Lanniello & Corona, 2024; Thompson et al., 2009).

5. (There is no single way to foster self-determination: individualization is the key (Geurts et al., 2020). Interventions with multiple components (e.g. individual session, group discussions, peer-support…) should be implemented (Lindsay and Varahra, 2022). Collaborative decisions are essential: the goal is not for individuals to do everything independently but to do meaningful requests for support, advice and assistance (Geurts et al., 2020).

6. Organizational strategies to promote self-determination for people with disabilities are most effective when they combine autonomy-supportive practices, inclusive environments, meaningful partnerships, and opportunities for skill development (Kúld et al., 2023; Skarsaune, 2022; Wehmeyer & Abery, 2013).

7. Promoting political self-determination for people with disabilities involves more than improving accessibility (Waltz & Schippers, 2020). It requires intentional leadership development that empowers individuals and supports organizations led by people with disabilities (Powers et al., 2002).

8. Promoting self-determination during early childhood is essential: family is the first context to develop opportunities of self-determination and a good partnership between parents and professionals is an important key (Erwin et al., 2009).
9. During the transition to adulthood, the development of self-determination has to be thought not only about personal capacities but also about the environment, which should provide opportunities for experimentation (Nguyen et al., 2017).
10. In old age, it's important to keep in mind the risk of double stigmatization: stigmatization associated with disability and also with aging (Martins et al., 2022). Consequently, a good understanding of ageing is necessary and we have to be cautious to the risk of disempowering aged people by providing too much support (Carney and Then, 2021).

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The RAAVI-project brings together people with lived experience, researchers, caregivers, management teams from care and welfare institutions, and public administrations.

The project aims to develop a shared cross-border culture in which self-determination and respect for rights are central to support practices in care and welfare.

Its goal is to create environments in which persons with disabilities gain control over their own lives, regardless of their age, disability, or life path.

Based on a literature review, participatory research, and communities of practice, the RAAVI-project develops toolboxes that enable care professionals and management teams to take concrete actions towards both the people they support and their broader environment.

RAAVI

Repenser l’Autodétermination, Agir pour Une Vie Inclusive