Relational Social Work

Self-Determination and Participation of People with Intellectual Disabilities: Advocating for Shared Decision-Making Processes in Social Work

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Abstract

The purpose of this article is to provide a theoretical reflection on the relationship between self-determination and participation in supporting people with intellectual disabilities. Social workers are required to respect people's self-determination and ensure their participation in support planning processes. However, these two principles often give rise to concerns among practitioners: people with intellectual disabilities are often marginalised in decision-making processes because of doubts about their ability to make decisions for themselves. Therefore, the meaning and application of the principles need to be questioned in order to provide an ethical guide for social workers working with people with intellectual disabilities. The article presents a reflection on this issue, drawing on social work literature and linking the resulting considerations to a participatory research experience undertaken by the author, in which a meaning of participation is built together with people with intellectual disabilities. The discussion highlights the links between the theoretical reflections and the insights gained from working with co-researchers and participants. The implications for practice are related to the need for social workers to be aware of the barriers that people with intellectual disabilities face, both in making decisions for themselves and in helping relationships.

Keywords

Intellectual disabilities, Social work, Self-determination, Participation, Social work research.

Introduction

The human rights paradigm, commonly referred to in social work with people with disabilities following the adoption of the *Convention on the Rights of Persons with Disabilities* (United Nations, 2006), is based on the idea of individual autonomy, understood as the

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ability to formulate and implement self-determined intentions and actions. Individual rights are affirmed so that they can be exercised and enjoyed by those entitled to them for full self-realisation (Araten-Bergman, 2024). The idea of autonomy is associated with independence and the ability to control one's thoughts and actions. However, it always implies a relationship with others (Lotan & Ells, 2010): individuals learn autonomy through interaction with others and their environment. In this sense, the development of capacities that support autonomy occurs in relationships, including helping relationships between individuals and professionals. The human rights-based approach to social work is founded on the principles of self-determination and autonomy. Rather than taking control of the content or purpose of interventions, practitioners should facilitate processes of self-determination. However, self-determination implies an awareness of one's own preferences, independent of external or internal influences, as well as the ability to express these preferences in order to fulfil them. If either of these conditions is lacking, it is important to recognise that providing decision-making support is fundamental to professional practice and promotes self-determination processes (Bigby, 2024).

Literature Overview

Self-Determination, Autonomy and Independence: Definitions and Reflections

The social work literature mainly references the functional self-determination model applied to intellectual disability by Wehmeyer and colleagues (Wehmeyer, 1999, 2020). According to this model, the development of an individual's functional self-determination is influenced by the opportunities provided by the environmental context in which the person can take on the role of a causal agent, that is, can influence aspects of their life. The interaction between capacity and opportunities is further conditioned by the level of autonomy (understood as the individual's ability to act without the help of others), self-regulation, self-efficacy and self-actualisation. These characteristics and their interactions place each person along a continuum with different degrees of capacity to express their intentionality. Therefore, first, it is not possible to describe people with intellectual disabilities in dichotomous terms, stating that an individual can or cannot be self-determining. Each person is self-determining to a certain extent, which is given by the outcome of the complex interaction between the various elements described in the model. It is emphasised in the model that the combination of all these elements is always original and linked to subjective specificity: autonomy is only one of these elements.

Wehmeyer's model of self-determination shows a direct relationship between self-determination and the social environment. Research highlights that environmental characteristics that have a significant impact on the possibility of self-determination and

autonomy include the availability of a network of relationships and the opportunity to access appropriate support (Shogren, 2020; Stancliffe, 2020). Factors include the support available to individuals that can compensate for lacking personal and environmental elements. Focusing on the relationship between individual and contextual elements in the model shows that in this dynamic, the helping action of social workers can have an impact. The concept of empowerment encompasses not only the individual but also their relationship with the social context, the norms and how the norms work. This influences each person's potential to express their will within a relational context. (Bigby, 2024).

Folgheraiter (2004) conceptualises autonomy in terms of agency and identifies three levels: self-sufficiency (i.e., self-care in relation to essential daily tasks); self-realisation (i.e., self-development, a component of self-determination included in Wehmeyer's model); and hetero realisation (i.e., the ability to care for others). Wehmeyer and Shogren (2020) challenge the most common notion of autonomy by decoupling it from independence: autonomy is understood as the ability to express intentionality. An autonomous person can thus be defined in terms of the extent to which they are able to make choices, rather than in terms of the intensity of support needed to put them into practice.

A third concept widely used in the context of working with people with disabilities and linked to autonomy and self-determination is independence. The importance of independence, understood as the ability to act and realise one's intentions without help, has been overstated by individualistic rhetoric to the point of being unrealistic. This is because the condition of independence is hardly attainable regardless of the presence of a disability. According to Kittay (2019), literature proposes a re-conceptualisation of the idea of independence through the notion of interdependence, which states that people are bound to each other by a relationship of dependence. The concept of interdependence is of fundamental value because it facilitates moving beyond a dichotomous perspective in which a person with a disability is either dependent or not. Assuming that they are, as are all people, the social worker does not focus on this but looks at dependency relationships and their characteristics to consider the support needed by those involved. If dependency relationships are understood as caring relationships, social workers will be able to understand the bidirectionality of the interpersonal relationships they observe, in which those involved share an interest in the well-being of the person with disabilities and recognise their positive value, rather than focusing on the negative connotation of the word «dependency» (Kittay, 2019). In this framework, working for autonomy may mean increasing rather than reducing care relationships, if they are useful for supporting people's self-fulfilment.

To conceptually synthesise the proposed ideas, autonomy can be considered a component of self-determination and is based both on the possibility of elaborating and communicating an independent and authentic thought to the outside world (independence) and on the possibility of translating intentionality into action without help (self-sufficiency and self-realisation); by contrast, self-determination is the result of a more

complex process and is realised when what happens corresponds to the intentionality of the acting subject.

Self-Determination in Practice: Freedom of Choice and Participation

Based on field research from the perspective of people with intellectual disabilities, Shogren and Broussard (2011) propose a definition of self-determination that includes three elements: the ability to make choices and have control over one's life, to set and pursue goals and to be able to speak for oneself. Self-determination is therefore strongly linked to the ability to make choices.

However, research shows that people with intellectual disabilities experience few choices and therefore struggle to manage decision-making processes (Shrogen, 2020; Stancliffe, 2020). Accordingly, they struggle to explore the available options and the implications of alternatives and do not develop the individual skills that support self-determined behaviour. The prolonged experience of a lack of correlation between one's actions, one's will and the outside world, due to a lack of choices, diminishes people's capacity for choice and resourcefulness and induces a passive attitude; this in turn leads to a reduction in individual capacity and a sense of learned helplessness (Parker & Crabtree, 2018). In other words, a negative dynamic is established that sustains the difficulties people with intellectual disabilities have in making choices. Compared with people without disabilities, people with disabilities experience a different development trajectory. Their capacities associated with choice do not always consolidate spontaneously in parallel with their cognitive abilities, and they struggle to legitimise their point of view, encountering resistance from the environment. In fact, the attitudes of people with intellectual disabilities towards the various issues that affect their lives, and therefore their ability to express their preferences, are not determined solely by their individual characteristics but are a response to the dynamics of the sociocultural context, as anyone else's. Thus, practitioner support could be significant in addressing the critical issues that arise in the environmental dimension.

Research shows that people with intellectual disabilities most often make decisions with others; thus, it is necessary to focus on the type of support they need rather than aiming for them to be able to make decisions alone (Williams & Porter, 2017). The centrality of trusting interpersonal relationships in this process has been highlighted in numerous research studies (Bigby, 2024). The implementation of forms of support for the decision-making processes of people with intellectual disabilities is fundamental to promoting the possibility of self-determination (Bigby, 2024; Shogren, 2020; Stancliffe, 2020).

A link between self-determination and decision-making processes can thus be highlighted: this connection provides a link with participation, which requires people to make decisions (Bigby, 2024; Svanelöv et al., 2019). Support, as shown in Wehmeyer's functional

model, is a crucial element in the process of promoting self-determined behaviour. The social worker's function in relation to the issue of choice can be placed within this element of the model: it is specifically to support the decision-making processes of people with intellectual disabilities (Bigby, 2024). However, if the practitioner does not adopt a consistent ethical and methodological position, the support offered may present some problematic issues (Bigby & Douglas, 2020): it may be driven by the values and perceptions of subjects other than the person concerned (e.g., in relation to the need for protection) or by the interests of third parties (e.g., resource constraints). Furthermore, it may be negatively influenced by a lack of communication skills on the part of stakeholders or by disempowering attitudes on the part of practitioners.

Awareness of the impact of power asymmetry in the relationship between people with intellectual disabilities and social workers is the fundamental starting point for any consideration of participation (Lotan & Ells, 2010). Research (Llewellyn & Northway, 2008) shows that practitioners' open, attentive and welcoming attitude does not necessarily translate into people's perception of involvement.

Participation requires precise and conscious methodological choices, not just an attitude or willingness to listen. In order to promote an authentically participatory process, social workers must recognise that they are in a reciprocal relationship. This is one of the core principles of the Relational Social Work approach (Folgheraiter, 2025; Folgheraiter & Raineri, 2017): both the practitioner and the person with a disability support each other, combining experiential knowledge and technical expertise. This recognises that help is relational, arising from the relationship to which everyone involved contributes. In the context of helping people with intellectual disabilities in particular, this means that the practitioner must recognise the person with a disability as capable of producing knowledge and as an expert by experience, and as someone who can help the social worker in their task. Participatory practice questions the relationship between power and truth (Marchisio, 2019); if the practitioner has the objective truth about the other (knows what should be done, how and what is good for the other), there is no space for the other to develop power over their own existence. Providing answers rather than engaging in dialogue inhibits the process of free action because it closes the spaces of the unexpected from which free action can emerge.

Exploring the Meaning of Participation through Research

Research Background

In order to highlight the context from which the data presented are drawn and to integrate the theoretical reflection, a brief description of the research experience considered here is given.

The study explored the participation experiences of young people with intellectual disabilities (aged 18–35) and their relationship with their social workers in the Italian context, specifically in the Lombardy region. This paper will focus on presenting the reflections that emerged from the research findings in relation to the following research questions: *How do young people with intellectual disabilities experience participation in everyday life? How involved do they feel in decisions that affect them? What difficulties do they encounter?*

The research was conducted using the participatory approach (Aldridge, 2015; Walmsley & Johnson, 2003): the process of constructing and realising the research design, from the definition of the research questions to the return of the results to the participants, was shared with three people with intellectual disabilities (two women and one man, aged 33, 31 and 28 years old respectively) in the role of co-researchers. They were self-selected from a self-advocacy group consulted by the academic researcher when searching for co-researchers.

All meetings of the research team were recorded. The content was summarised in reports written together at the end of the meeting. The research team (consisting of the academic researcher and the co-researchers) worked first on the research questions and then on the construction of the documents (research presentation letter, informed consent) and the research instruments (focus group outlines). The co-researchers participated in the data collection by facilitating the focus groups together with the researcher. Furthermore, the co-researchers contributed to the data analysis by commenting on the research findings presented to them through an accessible report prepared by the academic researcher based on coding the focus group transcripts (thematic content analysis was performed using MAXQDA 2020 software).

Thirteen focus groups were conducted (two face-to-face, eleven remotely using Zoom) with a total of 42 young people with intellectual disabilities (15 female and 27 male; average age 27 years) and two remote focus groups with 15 social workers (14 female and 1 male) working in the same localities as the young respondents. The research was conducted between May 2020 and October 2021; the course of the research was influenced by the pandemic in terms of timing and implementation method (in particular, most of the research activities had to be conducted remotely). The selection of participants was also affected by the pandemic. In fact, all the young participants belong to organisations that provided day services throughout the survey period. All participants communicate verbally: this was a selection criterion because remote access made using specific communication assistance or creative methods difficult.

Limitations and ethical approval

With regard to the limitations of the research presented here, the use of qualitative methodology does not allow for the generalisation of the research results. Furthermore,

this work must take into account possible conditioning due to the remote nature of the survey, despite the measures taken. Another limitation can be identified in relation to the population accessed for the survey: this research did not include people with more severe intellectual disabilities, so their views on participation are not represented. This could also be an area of research development of great interest and importance.

The research was conducted in accordance with the Code of Ethics of Università Cattolica del Sacro Cuore (Rectoral Decree No. 9350/2011). All participants signed an informed consent form written in accessible language.

Participation according to the respondents

The focus group outline was co-drafted with the researchers, starting with a discussion about the meaning of participation. This discussion highlighted the importance of daily experience in determining how engaged people feel and how much control they have over their own lives. Some of the research findings are now illustrated in relation to the experiences and meanings associated with participation according to the disabled people and social workers who participated in the research to enrich the theoretical knowledge of the idea.In particular, the codes of analysis which are concerned with the content of the following elements are discussed:

- the possibility for young people with intellectual disabilities to express their will;
- the implementation of conceding attitudes;
- the credibility that young people with disabilities feel they have in the eyes of others.

The participants had different experiences of these issues, which can be divided into four situations: the young people are free to express their will in all circumstances; the possibility to express themselves freely or to refuse something depends on the content of the request; they always say yes; and they are unable to say no.

R: (...) But even outside this context (editor's note: daytime service), do you feel free to say no to your friends, rather than to your family...
A3: Yes, but even there, I'm really free to do what I want... I just have to tell them!
(FG 4 – C: 216-217)

V: I... if I don't feel like doing something, I'm free to say no. (FG 1 – A: 499)

L: But I always say yes, I never say no. (FG 4 – C: 43)

M1: Everything's fine, always... I've never said no to anything... (FG 1 – A: 497)

M3: It depends. I can't always say no because some things are necessary.
R: For example?
M3: Like…the program I'm starting in two weeks, I'm waiting for that. (…) But I couldn't say no to this program. That's the first thing that comes to mind, I can't tell you anything else. (FG 1 – A: 473-475)

Regarding the ease or difficulty of saying 'no' in certain situations, the participants stated that they adopt a conceding attitude either to make the other person happy or because they are afraid of not being able to deal with any negative situations that might arise from their refusal. This shows that the interviewed young people are not always able to say what they think to people with whom they have a strong relationship of trust, such as carers or family members. It is not always easy for the participants to associate a positive or negative experience with the experience of feeling bound: some reported a negative experience concerning being obliged to do activities in which they had no interest (e.g., day care services), whereas others stated that they were always happy and willing to accept all proposals.

X: (…) No, I say… I say, I mean, I always say no to my parents or my friends, but then I regret it because I think that maybe… that maybe my parents and my friends might take it badly. (FG 6 – F 2: 453)

M5: Well, but now you can ignore other people… I can't even ignore other people… I can't ignore other people's judgements, I let myself be influenced too much. (FG 4 – C: 208)

GG: That other people end up feeling hurt, that's what…is wrong. (FG 6 – F 2: 363)

GG: One last thing: no, that… I mean, I usually always say that I'm fine, that is… actually, but in reality it's not true because… I don't want others to know that I'm not well, so I say, «I'm fine, thank you». Actually… (silence)
R: But why, if I may ask?
GG: Eh, so as not to… so as not to worry my parents… so as not to worry others. (FG 6 – F 2: 375-381)

Finally, most of the segments coded for credibility highlighted that the perception of being taken seriously depends on the interlocutor. In any case, some participants stated that they still feel unable to express their opinions.

A3: Mhmm…when it comes to friends, yes. But when it comes to my family, no… often I say something, but they either misunderstand what I said or they say 'yes, yes, yes' and then they forget, and it's as if I hadn't said anything, so…often I make decisions on my own because

I'm fine and... there's no point in talking about it... (...) Often, 'Oh, are you kidding?'... No, but okay... (FG 4 – C: 325-327)

M6: (...) My parents trust me and what I do, if they make a decision... (...) I'm twenty-five, I still have to mature because I don't feel completely mature at twenty-five... (...) They've given me this opportunity to make my own decisions (FG 4 – C: 317)

GG: Anyway, I mean... I never say... I never say what I think, but... but... I mean, I respect everyone else. (FG 6 – F 2: 637)

Additionally, the issue of participation, understood as the opportunity to partake in decision-making processes, was explored in the focus groups with social workers. In general, there was a broad agreement with the idea that young people with intellectual disabilities should be involved in the planning of interventions that impact them.

P7: The role of us social workers within the life project of people with disabilities is precisely to listen, to try to understand the desires and needs of the person and their family, and then to structure the project in close collaboration with any other specialist services involved in the person's life. (FG AS 2: 23)

P1: The thought I had while listening to the question was really a bit like... well, listening to their desires, that's what I thought. In the sense that the approach to these young adults who are entering adulthood, let's put it that way, is to be able to decode their desires, expectations and... also a little... in comparison to what might be, for example, families, who often have very different desires and expectations. (...) So, in reality, that was my thought, to listen to their desires. (FG AS 1: 30)

However, the social workers highlighted several obstacles to participative practices in their daily professional experience. Some were strictly organisational (standardisation of interventions, high level of bureaucracy in procedures, high workload, recourse to social services by families or organisations in emergency situations); others highlighted relevant issues at a methodological level. Without the ability to build meaningful relationships, the possibility of involving young people with intellectual disabilities in decision-making processes is lost or risks being tokenistic. Social workers struggle to provide young people with intellectual disabilities with the opportunity to be heard in the presence of communication barriers (e.g., people who communicate poorly or unclearly verbally) and severe disabilities that result in significant impairment of cognitive abilities.

P8: And also the difficulty of... of not letting our... our problem (editor's note: being overloaded), let's say, with the people we deal with, because it is only right that the person who comes to us should receive the right treatment from the service, which we are not able to

guarantee for everyone, and so we certainly find ourselves doing quality work in some situations, while neglecting others. (FG AS 1: 52)

P1: What is asked of us is to do increasingly highly skilled and professional work. Throughout our working lives, I believe we continue to train constantly, both to keep up to date with regulatory changes and also with methodologies and approaches, but I don't know how to put it... this high-quality work that we love, which I am sure we all love, is practically impossible to do in organisations (...) it is inconceivable to be able to do this work and it is also very painful when you are responsible for 250 families. (...) I want to emphasise this because all situations have the right to be listened to, accompanied and supported in the same way (...) Listening, connecting the network, strengthening informal networks, are all activities that require a huge investment of time and energy, so they would need a lot of care, that's it. What we feel is lacking at the moment, however, is precisely the possibility of doing this work with care. (FG AS 1: 51)

P5: And then, as my colleagues said, there is a difficulty from an organisational point of view, i.e., I am responsible for 150 users, so thinking about doing a job, um... let's call it caring for everyone, not a job of care, but a job that is well cared for with everyone, is really difficult. So, I realise that some situations are given more attention, while others are perhaps left in the background. And I sincerely regret that. (FG AS 1: 54)

P7: I would say it depends. There are people who are more involved, so interviews are not only conducted in the presence of the family, but the person is also always present, so it's really a discussion that everyone has together. Other people, where... it's a bit difficult to get them to participate actively in the decision-making process, but... we do ask them what they think, although they are not always able to participate actively in the project, depending on the type and severity of their disability. However, the general idea is always to try to involve them in all stages of the decision-making process. (FG AS 2: 35)

P6: We also have to think about the type of disability, because if we think about a physical disability that also makes it impossible to communicate with the citizen, it becomes difficult, even though I always try to include them and ask them to participate in the interview, but sometimes there are limits in the person in front of us who cannot communicate what they want. (...) I think we really need to understand what type of disability we are thinking about, as there are so many disabilities that we cannot generalise the idea of involving them all in the same way a priori. (FG AS 2: 39)

P1: In my limited experience, I see more difficulty with people with intellectual disabilities in being able to have a space for themselves; it is always the mother's voice that is perhaps more present in our meetings. (...) I find it more difficult with people with intellectual disabilities than with those who have physical disabilities. (FG AS 2: 40)

Discussion and conclusion

The results show that helping relationships can be seen both as a potential obstacle and support for the expression of the will of young people with intellectual disabilities. As outlined in the literature, the helping relationship would be a space that allows the other person to be themselves authentically, in order to lay the relational foundations that guarantee the involvement of people with intellectual disabilities and support self-determination processes. This idea of participation is consistent with the capability approach, particularly the specific application of the general theory that can be used to understand the life experiences of disabled people (Bellanca et al., 2011; Nussbaum, 2006). The authors argue that people with intellectual disabilities have limited opportunities because the collective imagination of their adult identity is restricted, which in turn inhibits their ability to imagine, perpetuating stereotypes in a cycle. Conversely, capacity building and empowerment are linked to the human rights paradigm. It is people's choices, desires and need for support that determine the content of their constantly evolving lives. The role of opportunities in this process is central (capabilities): the empowerment approach considers not only an individual's initial endowment of capacities, but also those derived from care relationships with others. These relationships can provide opportunities for acquiring new capabilities, which is particularly important in cases of intellectual disability where the capacity for self-determination is limited by a lack of accessible opportunities or difficulty in imagining, expressing or planning. Within this approach, the relationship between social workers and people with intellectual disabilities can be viewed as a means of exercising personal freedom, expanding opportunities and supporting capacity for self-determination.

Adopting a phenomenological perspective that focuses on intentionality and reflexivity (Bellanca et al., 2011; Folgheraiter, 2025) enables social workers to recognise that the subjectivity of people with intellectual disabilities is constrained by their social identity and the marginalisation they experience in both social settings and interpersonal relationships.

Consequently, people with intellectual disabilities need support in recognising, expressing and acting on their own subjectivity in the environment-individual relationship, where the process of transformation from ability to functioning takes place, which is precisely the object of social work. Promoting participation in helping relationships, as an opportunity to make choices and as a space to support one's agency, can strengthen the process of transforming resources and capabilities into actual functioning, that is, the realisation of the goals and projects that each person sets for themselves.

So, there is no linear cause-and-effect relationship between participation and self-determination, but a positive influence between the two can be argued. Participation can be understood as the relational dimension that supports self-determination: as seen, the ability to act intentionally depends on various environmental factors, including the relational dynamics between the person with intellectual disability and significant oth-

ers, including social workers (Stancliffe, 2020). Carey (2021) states that the positioning of people with intellectual disabilities between the lack of control and full control is the result of a continuous search for balance, situation by situation, in which the person moves between these two extremes, additionally influenced by their emotional state in relation to the object of choice and the people involved. In this dynamic process, and in particular, in the words of the young participants in the research, it can be seen that in the experiences of non-participation, they missed the starting condition required for being able to participate: the opportunity to be authentic in the relationship.

The concept of reciprocity, as mentioned (Folgheraiter, 2025) asks practitioners to consider how they position themselves in relation to others: it is not a question of allowing people with disabilities to participate but of positioning themselves as facilitators of the decision-making process in which people with intellectual disabilities have the right to participate, as it concerns their own life situation. Therefore, supporting decision-making processes means making one's skills available; social workers can help determine the content of the choice without manipulating or imposing their point of view. Helping relationships between people with intellectual disabilities and professionals are, by their very nature, caring relationships: the professional is immersed in the system of relationships they observe. Respecting the self-determination of people with intellectual disabilities, by adopting the interdependence perspective as defined above, allows this principle not to be seen as a limitation or constraint on professional action. In professional practice, respect for self-determination can only be seen in a 'negative' sense, as a limit: letting the other person decide and act according to their will, not exercising control, and not influencing their decisions. In this sense, taking the argument to its theoretical extreme, respect for self-determination can even become the negation of help, the logic of laissez-faire: the professional leaves the responsibility of deciding and acting to the other. By contrast, being in a relationship and doing participatory practice involves caring for the other person to ensure that one's interests are realised as much as possible.

For the involvement of people with intellectual disabilities to be genuine and to lead to participatory processes, it is not sufficient to ask them for their opinions and to give them a voice; this action is a necessary first step, but it is not sufficient. To be able to express their thoughts authentically, people with intellectual disabilities need to see themselves in an equal relationship that allows them to feel free to disagree and to feel that their opinions are considered as important as those of others. Therefore, in addition to a coherent methodological position, there is an urgent need for more structured and specific training to enable social workers to communicate effectively with people with intellectual disabilities or to use the necessary support (including other professionals) to help them work with people with more severe intellectual disabilities or who do not communicate verbally.

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