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Supported Decision Making as a human rights mechanism for people with intellectual disabilities: the contributions of the school

Tomada de Decisão Apoiada como mecanismo de direitos humanos das pessoas com deficiência intelectual: as contribuições da escola

#### **Aline Albuquerque**

PhD. Professor of the Post-Graduate Program in Bioethics at the University of Brasília. E-mail: alineaoliveira@hotmail.com.

Orcid: https://orcid.org/0000-0002-5568-0790

#### **Paula Ramos**

PhD. Professor at the Federal University of Rio de Janeiro. E-mail: paularamos.ufrj@gmail.com. Orcid: https://orcid.org/0000-0002-8231-1237

**Abstract:** This study presents the school as an adequate space to strengthen the right to self-determination of people with intellectual disabilities, through the endorsement of formal and community mechanisms of Supported Decision Making (SDM). Objective: This article aims to discuss the SDM as a fruitful alternative to reinforce the rights of people with intellectual disabilities and to point out the contributions of the school to expand this mechanism. This is a theoretical research, studying the production of international knowledge. Results: The school participates with direct contributions (in the guidance of families and in the effective and supported inclusion of students with disabilities in the learning process) and indirect contributions (in the construction of a culture of respect for the rights of people with disabilities). Conclusions: In an ableist society, the establishment of SDM necessarily undergoes a cultural change in which the person with a disability is recognized as a capable and autonomous individual, who has the right to decide about her own life. This cultural change needs to start at school so that generations can grow up knowing how to deal with differences, respecting the different ways of existing and placing themselves in the world.

**Keywords:** Intellectual disability; School; Autonomy; Decision making.

#### Introduction

The global scenario of affirmation of the rights of persons with disabilities - which culminated in the construction of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), of 2007, ratified by 182 States, including Brazil – make it necessary to advance in the construction of legal provisions that allow putting these rights into practice. Considering that society is ableist, invalidating and stigmatizing people with disabilities, social transformations demand the recognition of the right to self-determination of people with disabilities, that is, the right to make decisions about their own lives.

In Brazil, at the majority age, people with intellectual disabilities suffer the suppression of the right to self-determination, in particular, through curatorship - here, understood as a Substitute Decision Making (SubDM) mechanism, in which a person makes a decision on behalf of another. The naturalization of curatorship assumes that this group presents, to some degree, a decisional or decision-making inability<sup>1</sup>. However, according to the UN Committee on the Rights of Persons with Disabilities<sup>2</sup>, curatorship and other SubDM mechanisms are considered as a last resort for people with decisional disabilities, even considering that they should be abolished.

Research shows that people with curatorship can experience significant negative impacts on their mental and physical health, longevity, functional abilities, and well-being<sup>3</sup>, and that people with disabilities who exercise greater self-determination have better quality of life, more independence, and greater community integration<sup>4</sup>. Likewise, women with intellectual disabilities who exercise their self-determination are less prone to abuse<sup>5</sup>. Indeed, according to the World Health Organization (WHO), people who do not maintain control over their own lives are at greater risk of being exposed to abuse, violence and exploration. Likewise, maintaining the person's own decision-making contributes to increasing self-esteem, self-confidence<sup>1</sup> and a sense of identity<sup>6</sup>.

Supported Decision Making (SDM) was proposed as an alternative to curatorship, one of the ways to offer, to those in need, a support mechanism for their decisions. SDM consists of formal and community mechanisms that provide decision-making support, guaranteeing the right to self-determination for all. In 2015, the National Association of Curators of the United States, which brings together more than 1,000 curators, prepared a document in which it pointed out that Supported Decision Making (SDM) should always be considered before resorting to curatorship, and a decision-making support process should be incorporated into that of curatorship, if necessary<sup>7</sup>.

This article is based on some assumptions that will not be analysed, but are the premises from which it starts: (a) legal capacity and decision-making capacity are always assumed; (b) curatorship is a suppression of human rights; (c) the most effective way to protect people is to promote their personal autonomy; (d) all persons are entitled to make wrong and irrational decisions; (e) people with decisional deficits are entitled to support.

In this context, it is considered that the school constitutes an opportune space to strengthen the right to self-determination of people with intellectual disabilities, through the endorsement of formal and community mechanisms of SDM. On the one hand, historically, the school environment

follows a pattern of guiding families to adopt curatorship for students with intellectual disabilities who turn 18. Thus, due to ignorance of other mechanisms, families seek this measure as a way to support and protect young people with disabilities. In this sense, it is important to expand the knowledge of schools and families about SDM. On the other hand, in the performance of its social role<sup>8</sup>, by effectively including students with disabilities, ensuring their active role in the social and pedagogical context, the school contributes to the promotion of experiences, values and lifestyles that value inclusion and social participation in society.

Faced with these challenges, this article aims to discuss SDM as a fruitful alternative to reinforce the rights of people with intellectual disabilities and to point out the school's contributions to expand this mechanism. It is a theoretical research, based on the production of international knowledge, whose scope is to develop theoretical contributions concerning a field of knowledge, in order to consolidate it and allow its practical incidence<sup>9</sup>. We used in this article examples of efforts to reduce the incidence of curatorship developed in the United States, owing to the lack of Brazilian publications. As for the theoretical framework used in this research, it is divided into three areas: SDM, right to self-determination from the perspective of human rights and inclusive school. In what refers to SDM, this article was based on investigations formulated by Shogren, Wehmeyer, Martinis, Blanck. Regarding the theme of the right to self-determination, in the studies by Albuquerque. Finally, this research was based on the investigations of Mantoan and Mariusse and Eyng about the inclusive school. It should be noted that this research does not involve a literature review or bibliographic research, as it is theoretical research, which presupposes the application of a certain theoretical framework to an object of study.

This article is structured in four parts: the first on the general aspects of SDM; the second about the inclusive school as a space for strengthening the rights of people with disabilities and the indirect contribution to SDM; and, finally, the last one analyzes the inclusive school as a space for disseminating information about SDM.

# **Supported Decision Making: General Aspects**

The concept of SDM emerged in Canada in the 1990s<sup>6</sup>, but the CRPD inaugurated a new phase for SDM by elevating it to human right status<sup>10</sup>, by the provision made in its article 12 that States Parties shall take appropriate measures to provide the access for people with disabilities to the support they need in the exercise of their legal capacity<sup>11</sup>. According to the aforementioned article, the exercise of legal capacity, which implies legal capacity – ownership of the right – and legal agency<sup>12</sup> – exercise of right – ,<sup>1</sup> may involve SDM, as a support for people with disabilities, in order to allow them to lead their own lives and make decisions. It so happens that the decisional disabilities that affect decision making do not only concern people with intellectual disabilities, but can involve, for example, disoriented patients, people with dementia or people with mental disorders who need support to make decisions. Thus, the SDM must also have as its legal basis, in addition to art. 12 of the CRPD, article 17 of the International Treaty on Civil and Political Rights<sup>13</sup>, which establishes the right to privacy, from which derives the right to self-determination and to conduct one's own life, according to one's will and preferences.

In this way, SDM should be seen as a mechanism for the realization of the right to self-determination<sup>6</sup>, which is a predictor of positive repercussions for the life of the supported person, such as their employability and community participation<sup>7</sup>. Indeed, SDM starts from the understanding that once the decisional inability is verified, the opportunity to make decisions about one's own life should not be denied, but rather support the person to gain confidence and promote their decision-making ability.<sup>1</sup> From the perspective of the disability model, SDM is based on the social-ecological model that considers that disability is not restricted to the physical, intellectual or sensory impairments of each person; but, on the contrary, it is in the society that imposes barriers to welcome human diversity. With this shift in the understanding of disability, the idea that impediments make up the unique profile of capabilities and limitations of human existence is strengthened.

Assuming the focus put into the removal of social barriers, supports and accommodations become necessary and allow people to be successful in the environment in which they find themselves and in the chosen activities, such as decision-making. These supports and accommodations include modification of the environment, such as removing cognitive and physical barriers to access and participation. The social-ecological model, therefore, is SDM anchor, insofar as it modifies the question to be asked, that is, instead of asking whether a certain person is capable of performing a task or

engaging in an activity (such as decision-making), one should ask what reasonable support it needs to be successful in its activities<sup>7</sup>.

The paradigm of support, including the support needed for decision-making, is based on three focal points for intervention: (a) increasing the supported person's capacity and decision-making skills and the possibility of making choices about their own lives; (b) modify the environment and contexts, in order to increase the possibilities of the supported person to develop their activities successfully in that environment; (c) support in a personalized way, creating strategies to overcome the gap between the person's capacity and the environment. Therefore, the key idea of SDM is that support should always be modulated based on each individual and their uniqueness; that is, it needs to be designed with the aim of providing the supported person with satisfactory performance in an inclusive environment<sup>7</sup>.

SDM, based on the supported person's right to self-determination and on the exercise of their right to legal capacity, has been gaining ground as an alternative measure to curatorship. For SDM to be effective, the supportee must trust another person for guidance and information so that they can make informed decisions. The mechanisms used for SDM can be classified into: formal or legal and informal or community. The formal mechanisms are: SDM Agreement; SDM Term; Advance Directives<sup>7</sup>; Person-Centred Planning and Individual Plan Program<sup>14</sup>. Community mechanisms vary depending on the country. WHO lists the following: Personal Ombudsman – Sweden; Open Dialogue – Finland; Independent Advocacy – Scotland; Peer Support – United States and Support Circles – United Kingdom<sup>1</sup>. It is noteworthy that Australia, Canada, Germany, United Kingdom, Israel, Ireland<sup>7</sup>, Brazil<sup>15</sup>, Peru<sup>16</sup>, Argentina<sup>17</sup>, Spain<sup>18</sup>, all have adopted SDM mechanisms in their legislation.

SDM ensures a series of positive consequences for the supported person, such as keeping him/her as the main decision maker on aspects related to his/her own life, avoiding the substitution of the decision that is operated in the curatorship and promoting his/her personal autonomy, self-management and self-care. In this sense, the benefits associated with effective self-determination stand out, such as independence in their lives, employability and community integration. Another positive aspect is the fact that SDM contributes to preventing social isolation resulting from undue curatorship, allowing the supported person to integrate into the community<sup>7</sup>.

SDM is a tool directed to help a person understand a situation, make decisions and communicate them. This support can be provided through: written, visual or audio informative

materials; meeting aimed at discussing the available choices; creating lists of pros and cons; role-playing activities to help the person understand existing choices; presence of the supporter at important moments and meetings to help the person take notes and remember later to discuss them; opening a joint bank account to manage their finances<sup>14</sup>.

Regarding people with intellectual disabilities, and based on the social-ecological model, the focus should not be on the degree of cognitive development and intellectual impairments that will lead to their curatorship; but rather about what types, intensity, duration and frequency of support you need to participate to the fullest in the decisions that impact your life. Indeed, the principle of maximum participation should guide the implementation of formal and informal SDM mechanisms. For example, when it comes to finance or complex health issues, the command is not that they make independent decisions, but rather that it is ensured support that maximizes their meaningful participation in decision-making<sup>6</sup>.

Generally speaking, the roles of supporters are: to explain issues, explore options, and support the expression of preferences; however, for people with intellectual disabilities who have greater decisional inability, support can be extended to the interpretation of signals and preferences, configuring the co-creation of preferences<sup>6</sup>.

Research carried out by Harding and Tascioglu, that involved people with intellectual disabilities in the United Kingdom, pointed out that the Mental Capacity Law facilitated the creation of a culture of support for decision-making related to daily life. People with intellectual disabilities receive the support they need from family members, paid caregivers and professionals to make choices about significant areas of their lives. However, it is recognized that there are complex issues, very difficult or impossible to be simplified, which results in the difficulty of support to be effective in decision-making for people with intellectual disabilities<sup>19</sup>.

# Inclusive school as a space for strengthening the rights of people with disabilities: indirect contribution to SDM

Several studies discuss the role of the school as a privileged space for the effective exercise of human rights, specifically with regard to the rights of people with disabilities<sup>20</sup>. According to Mariusse, Gisi and Eyng<sup>21</sup>, the challenge of consolidating a culture of human rights becomes even more difficult in Brazil,

a country marked by so many social inequalities, in which "part of the population is excluded from active participation in society and in that, many times, people are not, in practice, considered as human beings with rights" 21:445.

Specifically in relation to the rights of people with disabilities, in recent decades, several countries have been advancing in discussions, policies and practices focused on inclusive education. The struggle of people with disabilities converged with the claims for human rights, questioning the structures that imposed a condition of subordination and the numerous barriers that made it difficult or prevented their participation in the world, among them, schools. Considering the schools' potential for strengthening SDM, it is possible to identify indirect contributions (in building a culture of inclusion and respect for self-determination) and direct contributions (in information and guidance on SDM for people with disabilities and their families).

In this section, to address the indirect contributions of the school, it is assumed that the education project is a basic part of a society project, that is, to build a society that recognizes the right to self-determination of people with disabilities, it is it is necessary for the school to promote practices that strengthen the recognition of these rights. It may also be stated that to create a culture that recognizes the ability of people with disabilities to make decisions about their lives, students without disabilities need to learn about empathy, equality, respect for differences as a crucial part of the socialization process. In addition, it is important that students with disabilities take ownership of their right to self-determination.

For the learning of these values, several studies suggest the contribution of the inclusive school to promote respect for differences and the socio-emotional development of students with and without disabilities. Sirlopú et al.<sup>22</sup>, when analyzing students in the final years of elementary school in Chile, indicated that students without disabilities from inclusive schools presented a less paternalistic or prejudiced posture than those from schools that were not inclusive. In the same sense, when analyzing students without disabilities in elementary school in Italy, Consiglio, Guarnera, & Magnano<sup>23</sup> found that those who lived with students with Down syndrome had positive and less prejudiced opinions than those who did not.

On the other hand, studies show that in those students with disabilities, attending an inclusive school promotes an active attitude, with the development of independence and self-sufficiency. According to Newman, Davies-Mercier<sup>24</sup>, 34% of students with disabilities included in regular school

reported that they were able to carry out activities on their own "normally" or "very often"; when compared to students with disabilities in special schools, where this percentage dropped to 22% of students.

For this reason, it is considered that the inclusive school indirectly contributes to the expansion of SDM, insofar as it constitutes an important space to promote the recognition of the abilities of people with disabilities. This recognition, in the long term, builds a culture of respect for differences, a necessary condition for the implementation of SDM.

# The inclusive school as a space for disseminating information on Supported Decision Making

Historically, the school environment has been conducive to the adoption of curatorship, in such a way that it becomes a pattern, that is, when students with intellectual disabilities approach 18 years of age, parents are advised to take care of their children. In fact, this moment of transition of the person with intellectual disability to adult life is stressful and fraught with doubts for parents and other close people, as a result of the lack of knowledge and the difficult of keeping a standard behavior, therefore curatorship is particularly considered as a protective measure. Thus, SDM is not usually considered, much less encouraged, as an alternative to curatorship.

The US Department of Education has made efforts to reduce the incidence of curatorship, defining it as "one of the most restrictive forms of aid that can have negative effects on the individual". The Department produced materials with the objective of increasing the awareness of students, teachers, family members about the alternatives to curatorship, including the SDM<sup>7</sup>. In this article, guidelines produced in the American school environment are reported, as a means of opening dialogue regarding SDM in the school environment. These guidelines were built based on the activism of entities that bring together people with disabilities and that work in the field of SDM<sup>25</sup>. It is therefore, up to the school community to encourage students and their families to consider SDM and alternatives to curatorship.

In addition, another direct contribution refers to the effective and supported inclusion of students in the teaching-learning process. In a constructivist perspective, learning involves the active participation of the student, in which he/she makes choices and learns from mistakes for the construction of knowledge. With this point of view, students are encouraged to exercise their right to

self-determination in their learning process. In the case of students with disabilities, this model encourages the decision-making process about their own lives, in terms of learning. Throughout the student's journey at school, he/she must be actively involved in the decision-making process, because if involvement takes place at a younger age, this helps him/her to gradually form a support network and make decisions alone or that learn to share them with those they trust. Still, it is important to emphasize that the school community should stimulate decision-making on school matters<sup>26</sup>.

When the student with an intellectual disability reaches adulthood, discussions about SDM and alternatives to curatorship are necessary to inform students and parents about the benefits of maintaining the right to self-determination and the problems arising from curatorship. In general, parents have spent every year acting as key decision makers or informal supporters of their children's decision-making process, and this time it can be difficult and complex for the family. In this way, this process can be gradual and appropriate to the time of each family, so parents and students can start a collaborative action, aiming at promoting students' self-determination and their recognition that there are consequences when taking a decision.

Although it is well-known that parents tend to have a protective posture, it should be noted that protection should not be dissociated from the promotion of self-determination. Thus, the school community should encourage parents to assume less responsibilities, transferring the decision-making process about their education and other areas of their lives to their children, even if supported by their parents. It should be noted that students can choose to include their parents or to establish a wider decision-making network with the support of adults they trust. Students choose these people based on their individual confidence<sup>26</sup>.

In a study involving the Public Schools of the District of Columbia, in the United States, some activities that can be developed in the school community to prepare students to make decisions are highlighted: (a) provide self-defense courses for students; (b) engage students in problem-solving activities that encourage them to think critically about their decisions; (c) encourage students to assume key roles in meetings to raise their awareness of their educational strengths and needs; (e) advise students on ways to make the best decisions and show them the costs and benefits for each of the corresponding options<sup>27</sup>. In that same study, they mention the creation of a form necessary to process Supported Decision Making, in that students choose their adult network members based on trust and comfort. The student and network members complete and sign the agreement. It is important to note

that students must determine the members of their network. Adults may not act on the student's behalf without the student's written consent<sup>27</sup>.

These are some examples developed in schools across the United States, with a focus on the encouragement of the SDM mechanism. Overall, the commitment is to enable students to learn to make the decision that best meets their needs, that prepares them for the importance of seeking the support and guidance of their parents in the decision-making process. It is also important that the school helps in the development of the construction of support networks and in the learning about the exercise of self-determination<sup>27</sup>. In the Brazilian context, it is important to develop studies that allow the design of models that take into account the contexts and specificities of schools in the country.

#### **Final considerations**

Assuming that the curatorship disregards the rights of people with disabilities, the present article discusses the SDM mechanism as an alternative to be prioritized. In order to discuss the potential of this formal and community mechanism, this study was based on international studies on SDM and experiences of its application in the school environment in order to point out the role of the school as a privileged space for the promotion of SDM. It is worth noting that, in Brazil, the production of knowledge on the subject of SDM in schools is still quite incipient, so that, in this article, the theoretical discussions were based entirely on international production. However, for SDM to be recognized and implemented in the country, it is necessary to expand the studies and consider Brazilian singularities. In this sense, it was argued that the school participates with direct contributions (in the guidance of families and in the effective and supported inclusion of students with disabilities in the teachinglearning process) and indirect contributions (in the construction of a culture of respect for the rights of people with disabilities). In an ableist society, the establishment of SDM necessarily involves a cultural change in which the person with a disability is recognized as a capable and autonomous individual, who has the right to decide about his/her own life. This cultural change needs to be initiated at school so that generations grow up knowing how to deal with differences, respecting the different ways of existing and placing themselves in the world.

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# Supported Decision Making as a human rights mechanism for people with intellectual disabilities: the ...

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#### **Authors' contribution**

Contribution of each author to the article. Both authors contributed equally to the article by conducting research, writing the text and final review.

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