

The control of access to participants as a form of protection and self-protection. A challenge for researchers.

The participation of people with learning disabilities in research is absolutely necessary, both to focus the studies on the issues that concern them, and also to allow them to express criticism and make proposals to improve their lives. From this perspective, the exploration of Williams' article on the motives that guide professionals or informal supporters through whom access to people with learning disabilities is negotiated to facilitate or deny this access is essential to help researchers take actions that enhance inclusion of people with LD in the research. I would like to contribute some reflections on an element linked to the interconnected factors to which Williams refers, specifically to the **control** exercised ambivalently by gatekeepers. The decisions they make in the selection of the participants, on the one hand, and those related to the denial of access, on the other, may in certain situations obey a will to exercise a certain protective control towards the people themselves, towards themselves or towards the institutions with which they are linked. Going into greater depth as to the reasons for this response by the gatekeepers leads us to question both our role as researchers and aspects related to the organization and culture of the services that offer support to people with disabilities, as well as to the professionals in them. We will refer to each of these topics below.

Reflecting on how we develop research, how we explain it to the participants and what we do with the results can provide clues to the gatekeepers' response to our demands for participants with LD: Do the gatekeepers, and the participants with LD feel that the research is useful for improving their lives?; Do the expected results really affect the improvement of services?; Does it provide tools to professionals or informal supporters to offer better support to people with LD?; Do people with LD participate in the dissemination of the results? If the answer is affirmative, the gatekeepers perceive the need and relevance of the research processes and therefore may be motivated to favour the access of people with LD to the research. However, a negative response to these questions may explain part of the reluctance of gatekeepers to facilitate access for people with LD.

However, it is not only the assessment of the usefulness of the research by the gatekeepers that conditions the access of people with LD to the research. Self-protection is closely related to control. We cannot ignore other factors that may explain the control exercised by certain gatekeepers, especially from the institutional sphere. In contexts or territories where organizations have a predominantly protective vision (although they do not specify it) it is logical to think that they are not interested in collaborating in research that seeks support for people to exercise greater control over their own lives, or in studies that inquire about the transformation of supports in community contexts. Necessarily, this research will question the functioning of organizations, the traditional distribution of supports and an institutional culture based on relations of power in which professionals make priority decisions. In this context, the denial of access may be due to the will to silence potential participants to avoid criticism of the service and its professionals, and to avoid having to make decisions regarding the management of organizational, relational or professional problems linked to the results of the research. Indeed, as Williams puts it, the fear of being judged by researchers is common to all research,

but when this fear involves silencing the voice of people to whom direct access is difficult; or to filter and select the participation in the research of those voices whose discourse agrees with the institutional message, the fact is even more serious and is ethically questionable.

Faced with this situation, our responsibility as researchers forces us to focus our research on topics that interest people with learning disabilities and with results which can significantly improve their lives; to provide accessible information to both gatekeepers and people with disabilities about the objectives and methodology of the research; and to commit ourselves to carry out an appropriate dissemination of the results that ensure that these actually affect the improvement of professional practices and contribute to improving people's living conditions. This dissemination entails the return of the resulting information to the participants and to the people who have provided their contacts. It is necessary for researchers to make concerted efforts in establishing synergies with organizations, promoting the transformation of professional practices through the collaboration of people with learning disabilities, but also with professionals. The involvement of professionals and informal supporters in some of the phases of the information can constitute a training opportunity that contributes to the change of perspectives based on the authority of the professionals, advancing in the transformation of the institutional practices of control based on relationships of power. In addition, in order to promote a real change in practices of support, it is also necessary to establish synergies with those responsible for social policies. If the research participants and the people offering formal and informal support can positively value the results of the impact of research on social policies and generate positive, desired changes for people with LD, they will possibly have more interest in being part of them. The advance in the real participation of people with LD in research is therefore a challenge in which, as researchers, we can and should contribute through actions aimed at the institutional and political framework in which support is organized.