

Decision-Making, Expectations and Life Project in Dependent Adults Due to Disability

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Abstract : People are not completely autonomous, as we live in society; therefore, people could be defined as relationally dependent. The lack, decrease or loss of physical, psychological and/or social interdependence due to a disability situation is known as dependence. This is related to the need for help from another person in order to carry out activities of daily living. This population group lives with major social limitations that significantly reduce their participation and autonomy. They have high levels of stigma and invisibility from private environments (family and close networks), as well as from the public order (environment, community). The importance of this study lies in the fact that the lack of support and adjustments leads to what authors call the circle of exclusion. This circle describes how not accessing services - due to the difficulties caused by the disability situation impacts biological, social and psychological levels. This situation produces higher levels of exclusion and vulnerability. This study will focus on the process of autonomy and dependence of adults with disability from the model of disability proposed by the International Classification of Functioning, Health and Disability (ICF). The objectives are: i) to write down the relationship between autonomy and dependence based on socio-health variables and ii) to determine the relationship between the situation of autonomy and dependence and the expectations and interests of the participants. We propose a study that will use a survey technique through a previously validated virtual questionnaire. The data obtained will be analyzed using quantitative and qualitative methods for the details of the profiles obtained. No less than 200 questionnaires will be administered to people between 18 and 64 years of age who self-identify as having some degree of dependency due to disability. For the analysis of the results, the two main variables of autonomy and dependence will be considered. Socio-demographic variables such as age, gender identity, area of residence and family composition will be used. In relation to the biological dimension of the situation, the diagnosis, if any, and the type of disability will be asked. For the description of these profiles of autonomy and dependence, the following variables will be used: self-perception, decision-making, interests, expectations and life project, care of their health condition, support and social network, and labor and educational inclusion. The relationship between the target population and the variables collected provides several guidelines that could form the basis for the analysis of other research of interest in terms of self-perception, autonomy and dependence. The areas and situations where people state that they have greater possibilities to decide and have a say will be obtained. It will identify social (networks and support, educational background), demographic (age, gender identity and residence) and health-related variables (diagnosis and type of disability, quality of care) that may have a greater relationship with situations of dependency or autonomy. It will be studied whether the level of autonomy and/or dependence has an impact on the type of expectations and interests of the people surveyed.

Keywords : life project, disability, inclusion, autonomy

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