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Self-determination and adults with intellectual disability

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Abstract

The concept of self-determination started to be used in our country a few years ago as a basis (reference) in the services and programs directed at the mentally handicapped. The concept of self- determination is about the urgent need and the right of the mentally handicapped to have more control over their lives. However, although this concept has been rapidly and easily assimilated as part of professional jargon (a good example is all the papers that have been published on the theme), and the unanimity that seems to exist around the necessity to ensure its development, in many cases it ends up converting itself into a collection of abilities that need to be developed in the person with the mental handicap.

In this way, as occurs with other concepts that come for Anglo-Saxon culture, for instance «empowerment» or «self advocacy» it is forgotten that their strength resides in their very nature. That is to say, the recognition of the possibility and the need of the mentally handicapped, to take control over what happens to them.

Keywords: Ordinary contexts. Positive personal identity. Rights. Self-determination. Supports.

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Defining "self-determination" is no simple task. As the term has become more widely used, new definitions have come about that have not always aided understanding. Self-determination — as opposed to "determination", understood as all the causes external to an individual that precede a phenomenon, enabling it to take place — allows each person to control events in their own life. Hence, in terms of the individual, we say that a person is self-determining when what occurs around them is a consequence of their own actions and decisions. So, in the context of everyday life, expressing our emotions and thoughts, accepting the responsibilities that arise from the decisions we make, and assessing the outcome of our actions are all instances of self-determination.

Additionally, the term "self-determination" has been used by some minorities, including people with intellectual disabilities, as a strategy for claiming their group identity and the right to be respected and decide on what is best for them. Whereas we may say that an individual is self-determined when we view them as responsible for the consequences of their own actions, when such action is aimed at common well-being, self-determination becomes a desirable sociopolitical goal. The emergence and progressive consolidation of 'self-advocacy groups' in Spain conveys the claim collectively staked by people with disabilities to the right to manage their own lives (Goodley, 2000); that is, to self-determine.

Self-determination can therefore be expressed individually and collectively. Individually, it can be easily identified with a constant, ongoing process of gaining the confidence and skills to make the best self-benefiting decisions. Collectively, the term denotes a new social movement spearheaded by people with disabilities and concerns their well-being or satisfaction as a group. However, it is important to note that both approaches recognize and underscore the right of the person with disabilities to take control of their own life, a key element in uncovering the true

meaning of this term and discerning some of the misunderstandings surrounding it. As opposed to the traditional idea of the person with intellectual disabilities as incapable, dependent or handicapped, the term "self-determination" embraces the possibilities, respect and worth of all people, including those with disabilities.

However, this has not always held true when the concept of self-determination has been applied to programs and services geared towards supporting people with intellectual disabilities. The meaning of the term has become obfuscated by attempts to define it (Wehmeyer, Sands, Doll and Palmer, 1997; Wehmeyer, Agran and Hughes, 2001) and, as a result, narrow it down to a series of characteristics, skills and attitudes. What is worse, it has actually ended up being used in a sense that contradicts its core meaning. Thus, some approaches have aimed to help people with intellectual disabilities learn to make choices or solve problems in controlled environments – similarly to other, earlier skills training programs – because such learning will supposedly bring them closer to the sought outcome (self-determination), so they require less support and become less dependent (though never independent enough, as adults, to decide whom to be friends with or when to leave and return home). At times we have also seen the ideological dimension of the term fade into the background, so that the need to develop it and flesh it out in technical terms has taken us right back to a traditional model of disability, with rehabilitation and training at the heart of the program or service. These interpretations overlook the fact that the defining characteristics of self-determination are mere approximations that can neither explain nor predict the complexity of the human being and, above all, tend to downplay the structural conditions (Oliver, 1992, 1998: [Barton, 1993; Barnes, 1992, 1998; Drake, 1998; in Rojas, 2004]) that have prevented and continue to thwart the overall development of people with intellectual disabilities and their participation in society as individual citizens with full rights.

Unarguably we must start by acknowledging that people with intellectual disabilities can be, and have the right to be, causal agents for the events in their own lives (or, to paraphrase Wehmeyer et al. (1997), to make things happen in their life). Awareness of the prejudices and stereotypes that surround people with disabilities is therefore a priority, since it is only by debunking some of these notions that we shall be able to counter the dominant discourse that emphasizes shortcomings and limitations. It is bold indeed to suppose that a person who is constantly receiving negative messages from their environment about who they are or what is expected of them can build a positive personal identity and find enough confidence to express feelings, thoughts, desires and fears, and change their lifestyle; that is, to be self-determining (Peters, 1998; Shakespeare, 1998; Goodley, 2000).

Similarly, for people to be able to make choices or set themselves goals, their environmental conditions must be ripe to enable this. And let us not forget that changes are required at various levels (political, professional, cultural and personal) and that these changes go beyond our own powers of mediation. In day-to-day life, the fact we must acquire certain skills, learn a number of strategies and develop certain attitudes means that life choices must be broad-ranging and arise in numerous (necessarily complex) contexts, in which the person with intellectual disabilities can weigh up various alternatives and come to feel that their decisions are supported. Concretely, as described by Bambara et al. (1998), three factors are fundamental to promoting or developing self-determination: fostering a lifestyle that is valuable to the person himself, understanding or knowing the person with intellectual disabilities, and creating social support contexts (Figure 1).

The first requirement, valuable lifestyles, refers to contexts in which the values and preferences of the person with intellectual disabilities are respected and which allow them to learn, make mistakes or give way to others. Most people without disabilities learn many of the skills and attitudes that convey self-determination from a very young age, and go on progressively acquiring them in informal learning situations. Over the course of a person's life, the experiences they

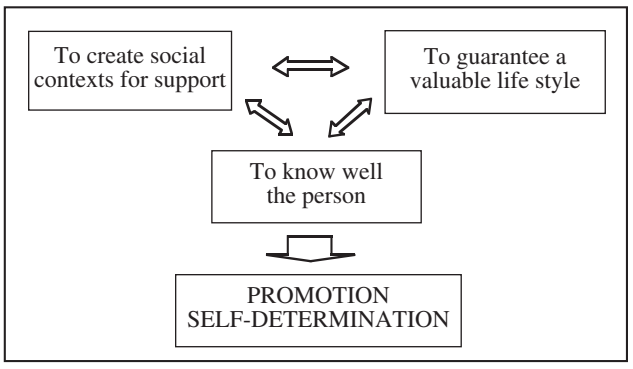

Figure 1. Conditions for the development of self-determination.

come up against and react to allow them to build their own identity and create a space in which they can be respected and valued by others. Thus, regardless of the skills they actually display on reaching adult life, they are assumed to have a series of roles, and their family, sexual, working or leisure life is not challenged. By contrast, deprivation from experiences (and from the contexts in which they take place) condition much of the learning done by many children and young people with intellectual disabilities, and have a bearing on their adult life. This is not only because they do not know how to handle situations, but because they are seen as incapable of doing so, which has a negative impact on the possibility of new learning. Therefore, those who give support to people with intellectual disabilities must ensure they obtain increasing control over their daily routines and activities whilst also giving them access to new experiences relating to their own interests and concerns. The idea is that the more independent a person is, the more opportunities they will have to exercise control and the more they will want to do so.

Clearly, an interest in facilitating new learning situations consistent with individual preferences and values requires a profound understanding of the person with intellectual disabilities, beyond merely meeting their most evident needs (food, hygiene and personal care) or their most basic preferences (types of activity) plus whatever third parties deem appropriate or necessary. In other words, this knowledge must inevitably come from the person with intellectual disabilities, must necessarily embrace the whole array of social environments in which an adult person is active (family, friends, couple, etc.) and must take on board material factors that are usually important to that person (work, education, leisure, accommodation, etc.).

Furthermore, and bearing in mind that many people with intellectual disabilities may utilize alternative communication strategies, support providers (both formal and informal) must ask, listen, observe, accompany and spend time with the person in order to ascertain what is important to them, what is the significance of their body language, their facial expressions, the relationships they strike up, the spaces they make use of and the decisions they take. It is this approach that enables us to find out how a person learns and with what skills they need help (e.g. communication, decision-making, problem-solving, risk-taking, etc.); thus can we find out how to mediate in their learning. It also allows us to understand the barriers put up by other people that hinder the development of some skills and attitudes, and to ascertain the extent to which the person with intellectual disabilities needs support or monitoring from other people to carry out specific activities.

Another point is the need to create social support contexts in which the person with intellectual disabilities has the security and confidence to refuse decisions made by others or negotiate according to personal interests, in addition to finding emotional support when needed. Conversely, 'support' persons who impose routines, strategies or activities, or are indifferent (e.g. to individual wishes, concerns or emotions) will not only fail to aid development of greater self-control or control over personal surroundings, but may induce attitudes and behavioral patterns currently deemed maladjusted. Both the formal professional support givers who provide their services to people with intellectual disabilities and informal support givers – relatives and friends, in particular – must act as mediators, and consequently must listen to the demands made by the person with intellectual disabilities. These people must help them cope with loss or grief and encourage them to take risks, foreseeing the outcome of their decisions. In other words, over the course of their life, people with intellectual disabilities must be able to strike up and maintain emotional relationships that bring them stability and security.

The three factors discussed briefly here highlight the importance of the most immediate supports and contexts experienced by people with intellectual disabilities in terms of developing and consolidating some of the skills and attitudes that reveal self-determination (Wehmeyer et al., 2001). They also help to challenge or call into question the essentialism of programs that focus on changing the person with intellectual disabilities and on acquiring strategies that largely teach them to see what the target is and how to attain it, as if that were possible. Thus, failing to take into account that self-determination is a process – and a possibility -, ignoring the fact that the decisions people habitually take over the course of their life are not devoid of fears, doubts and uncertainties, or overlooking the fact that life, by definition, is not static, is a simplistic or reductionist take on the human being. Denying people with intellectual disabilities this complexity is therefore denying them the right to live their life to the full.

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