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PSYCHOLOGY DEALING WITH THE QUALITY OF LIFE AND SOCIAL INCLUSION OF PEOPLE WITH INTELLECTUAL OR DEVELOPMENTAL DISABILITIES

Javier Tamarit Cuadrado

Plena inclusión¹

Desde una perspectiva narrativa participativa se describen procesos de avance desde hace cincuenta años hacia la mejora de la calidad de vida y los derechos de las personas con discapacidad intelectual o del desarrollo, y el avance hacia una plena inclusión social. Estos procesos conllevan también en el curso del tiempo otros procesos de redefinición y transformación de los servicios de apoyo y de los roles profesionales de psicólogos y psicólogas. En este escenario, se va siendo consciente de que los campos tradicionales de la Psicología no son los más apropiados para las funciones que los nuevos modelos de apoyo requieren. La Psicología de la Intervención Social puede ser un elemento importante para avanzar en la construcción de apoyos y recursos para la calidad de vida y la inclusión social de las personas con discapacidad intelectual o del desarrollo.

Palabras clave: Discapacidad intelectual, Discapacidades del desarrollo, Inclusión social, Calidad de Vida, Transformación de rol, Psicología de la Intervención Social.

Based on a participatory narrative perspective, processes are described of the last fifty years' progress towards the improvement of the quality of life and the rights of people with intellectual or developmental disabilities and towards full social inclusion. These processes also involve, over the course of time, other processes of redefining and transforming the support services and the professional roles of psychologists. In this context, it is becoming evident that the traditional fields of psychology are not the most appropriate for the functions that the new support models require. The psychology of social intervention can be an important element for progress in the construction of support and resources for the quality of life and social inclusion of people with intellectual or developmental disabilities.

Key words: Intellectual disability, developmental disabilities, social inclusion, quality of life, role transformation, social intervention psychology.

“What is that, mom?” The city had not yet expanded on the other side of the river, where, in the early sixties, we were going for a walk. The sounds that we heard were halfway between laughter, screams and moans. A little further on, at the tall, barred windows of a building in the middle of the solitude of the moor, arms and legs appeared, among white cloths, of the people –their faces barely seen– who were uttering those sounds. “Don’t worry, son, it’s ok. They are the crazy people from the mental asylum.” In that social landscape of my childhood it was not unusual to see people begging or asking for alms at the doors of churches, people lacking a limb or who had serious physical or sensory problems and problems of mobility.

Adults with intellectual disabilities, at least some of them, ended up in those years, when their relatives could not care for

them, in the most isolated rooms of those buildings called mental asylums or in other large institutions also far removed from everyday life. This did not only happen in Spain. Robert Martin, currently an Independent Expert of the United Nations Committee on the Convention on the Rights of Persons with Disabilities, recently stated (Martin, 2017):

Living in an institution taught me that I was a nobody – that my life did not really matter. Many of my friends lived with me in the institutions, and many died there. Their names are not on any graves. Living in an institution, I realized that I was actually being punished for what I was (p. 7).

Robert Martin is a person with an intellectual disability due to brain damage at the moment of his birth in 1957. He lived his childhood and adolescence in psychiatric hospitals and other institutions. As an adult, he reported abuse practices in these institutions that led to their closure.

Since the second half of the fifties, a group of parents from different cities in Spain had begun to join together to provide a response to their children with intellectual disabilities, to avoid this situation of institutionalization. Through advertisements in

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¹ <http://www.plenainclusion.org>

the local newspapers they called meetings with other families who had “subnormal children” in order to be able to respond to their wishes, together, for a better life for them. These parents wanted their children to have an education similar to that received by their other children without disabilities, but the law, as well as prohibiting them from associating with others –it was a time of dictatorship–, did not allow teachers to attend in their classes to boys and girls who were not “normal” (López, 2014). It was a punishable offence. In fact, some schools, including the one I attended, used some of the spaces furthest away from the center to start a special education there, but only temporarily while their families were arranging to have their own center. One day, in those same times when I discovered the mental asylum, three companions and I (every day it was a different group’s turn) were taken to the end of a corridor that we never went to, to spend the morning in a classroom with four children who we had not seen until then and who, for us, from that day on had a name. It was truly a practice ahead of its time and a curious paradox now that we are in processes of specific classrooms within ordinary centers.

Those families that began to unify and build resources for the children with intellectual disabilities, with hardly any means or help and in a sociocultural environment of often hostile attitudes, were –without knowing it– making history, transforming society. In the present day, it is hard to understand the harsh social and cultural conditions that they had to face, caused –not necessarily consciously– by their own neighbors and even by relatives, due merely to, for example, daring to go out to the street with their “subnormal” son or daughter, when it was socially expected that these situations were better off “hidden” at home or in an institution. These pioneering, courageous and fighting families carved a path, still unfinished today, to achieve the social inclusion of all the people who were not only excluded but sometimes imprisoned for life for the “good” of society. And it did not take long for the professional figure of psychology to become incorporated on that path.

Jack Tizard, a New Zealand psychologist based in England, was one of the pioneering figures of our profession to see the situation of people with developmental disabilities in a new light. In August 1964 an International Congress on the Scientific Study of Mental Retardation was held in Copenhagen and Tizard (1964) exposed the daily life of children in hospital wards of up to 50 beds, who were passed from one to another different professionals of the hospital who rarely established a relationship or carried out play or educational activities with them, concentrating on performing the tasks of dressing, hygiene, feeding, bathing... as if it were an assembly line. The activity of the professional nursing team towards the children, as of that of the rest of the services, was of mere passive observation that had no consequences except in the case of situations of non-compliance with the rules and discipline.

Tizard denounced this situation to his colleagues around the world, lamenting that these children were treated as objects, without any type of program or expectation of progress in their different “medical” conditions. At that time, the interest of the professionals focused, in the immense majority, on describing new syndromes or discovering and revealing new biological characteristics. Tizard’s view of personal and social well-being was unusual, as was his denouncement of the conditions of maximum institutionalization that clearly, in his opinion, did not provide the children who were there with any opportunity for current or future progress.

In a way, in the 1960s, a first paradigm shift began to be glimpsed in the models of knowledge and intervention in the field of developmental disabilities. The transition was initiated from an institutional model based on clinical and biological models to a model of integration (not yet inclusion, rights, and full citizenship) (Bradley, 1994), in which it was considered that the person was not ill, and they could learn basic skills in order to function better in their daily life. This was a model in which the decision-making power about the practice to be developed ceased to be exclusively in the hands of clinicians and transferred to professional teams of psychology, pedagogy, and social work. It also coincided that the knowledge and intervention resources derived from the theory of learning were beginning to be considered as valid tools to favor the education and progress of the group of people with intellectual disabilities or other developmental disabilities, such as what is known today as autism spectrum disorder. However, while that current “teacher/rehabilitator” emerged, moving away from the “therapeutic” view, the reality in the care services for this group of people still had embedded signs of a clinical culture, as observed for example in what are known as “clinical records” (still in existence today) and intervention proposals that attach the suffix “-therapy” to their names.

And so this social and cultural territory is what awaits in our country the incorporation of psychologists who wish to guide their profession in the field of disability. In the seventies and eighties, when a powerful social and political commitment emerged in Spain in psychology as a committed profession as well as with the well-being of people with social transformation, there was an explosion, the fruit of the efforts and activism of the already numerous associations of relatives that spread over a large part of the country, of specialized services (special education centers, sheltered workshops occupational centers, day care centers, residences, early intervention, etc.) that require professionals of very diverse disciplines, including psychology. Paradoxically, in a very generalized way, in the Spanish psychology faculties, there was a lack of knowledge about the different disabilities and the most appropriate intervention models to approach their intervention. It is not strange, then, that at a time when psychology seemed to exist



only within the borders of the educational, the clinical and the organizational, the set of professionals that had to begin to practice its activities, based on a powerful professional commitment and the best of wills, was naturally inclined toward the clinical and focused especially on the pathology, on the processes of limited human functioning and on how to increase personal competencies and/or reduce the behaviors that may interfere with the development of those competences. This, at that time, incidentally, was already creating a better life expectancy for people with developmental disabilities who until very recently had been considered uneducable, and a group of them with greater needs that were not even considered “trainable”.

However at the end of the 20th century another paradigm shift was to emerge. These were times in which in a large part of the world of people with disabilities (usually those with a physical disability not affecting their intellectual or adaptive functioning) publicly expressed their oppression and fought to make society see that their disability was not reduced to their deficit, but to a large extent it was a social and cultural construction that condemned them to exclusion and discrimination. The struggle for the rights of people with disabilities, with the individuals themselves as the protagonists demanding the power that corresponds to them to design their own life project, had repercussions in the academic and professional spheres. These spheres began to strengthen the idea that a disability was not something that the person was (i.e., “disabled”) but rather that it emerged in the daily processes of interaction between a person who has certain limitations in their functioning (whether intellectual, social, physical, sensory, or other) and the environment in which they live. Therefore, in addition to initiating a substantial change in the story (“person with a disability”), the proposals that were derived from these approaches for intervention were now more than just those focused on the deficit or the disorder, and a range of proposals opened up for intervention on the environment, to increase the opportunities for people to participate effectively and without barriers in all normal areas of daily life. In 1992, the then American Association on Mental Retardation (Luckasson et al., 1992) presented the new conceptualization of what is now known as intellectual disability. Among other revolutionary considerations, it opened the door to the concept of support, as the essential element (without forgetting competences, and adding opportunities) in planning and implementing the intervention. It was an intervention centered on each individual that is based on an essential axiom: every person can progress if they have the appropriate support, so if a person does not advance in their competences and their functioning on a daily basis, we could no longer shield ourselves with the limitations generated by the specific deficit or disorder but rather we directly turned to our professional action “*What must we do to*

make the person progress?”. In addition, prior to the formal birth of positive psychology, we were alerted to consider not only the limitations of a person but also their strengths.

This new narrative of intellectual disability became linked in a very short time with the narrative of quality of life as an essential mission of professional interventions (Schalock & Verdugo, 2003), a quality of life that has subjective and objective components, and that, while considered a universal concept, is also mediated by cultural components. It is interesting to note how in some of the definitions used of quality of life, the need for adherence to human rights was now included (Wallander, Schmitt, & Koot, 2001, p.574, quoted in Sabeh et al. 2009). Quality of life is, for these authors, the “combination of objective and subjective well-being in multiple domains of life considered important in one’s culture and time, as long as it adheres to the universal standards of human rights” (p.11). It was only a few years before the paradigm of the rights of persons with disabilities emerged, expressed in the Convention on the Rights of Persons with Disabilities, to which our country adhered fully (Boletín Oficial del Estado [Official State Gazette], 2008).

And, also at the beginning of the current century, the very organization that created the paradigm shift (Luckasson et al., 2002), was beginning to talk about the need to rethink the professional role, as a result of the transformations generated (Table 1).

This proposal clearly shows the professionals in this field the urgent need to reflect on the transformation of their role. It is a transformation, because it is about the emergence of a new professional “culture”, it is not simply a matter of improving the existing role. In short, in the face of the emergence of this new conception centered on the person and their well-being, where the power to make decisions about their lives resides with the individuals themselves and where the success of the interventions must be assessed in relation to the achievement of personal results valued and significant for each person, the professional

TABLE 1
PROFESSIONAL ROLES
(LUCKASSON ET AL., 2002, PAGE 198 OF THE SPANISH EDITION)

Planning role	Responsible for analyzing the services the person is looking for and helping him develop a plan to achieve the desired result.
Role of community resource	Responsible for knowing the resources of the community in order to help the individual to access and obtain natural support from the services.
Consultant role	Responsible for being involved in a consultative relationship with the person and offering recommendations based on their knowledge and experience.
Technical role	Responsible for keeping up on technical aids and strategies to ensure the acquisition and maintenance of skills.



culture focused on the deficit ceases to make sense. And this points specially to psychology.

Bushe and Marshak (2016) point out three central transformational processes for the success of a cultural transformation: emergence, narrative and generativity. They speak of emergence when a disturbance that breaks down the previous patterns of relationships and activity is introduced into the established culture. In this case, the disturbance came from a new conceptualization of disability and the increasingly loud voices of people with disabilities themselves, demanding models of intervention focused on the quality of life and equal opportunities with others. The new narrative (support, quality of life, self-determination, inclusion, full life, dignity, etc.) is opposed to the previous one, organized around concepts such as deficit, disorder, pathology, isolation, and therapy. As for generativity, it refers to the introduction of generative images, symbols of the new situation that confront the symbols and images of the culture that had prevailed until then. Thus, in contrast with images that express institutional solitude, syndromes and their characteristics, images that focus on pathology, intelligence tests, clinical records, etc., now images of people with intellectual or developmental disabilities are introduced in the community, contributing to the well-being of others (for example, through volunteering actions), living independently, forming families, enjoying leisure, participating in public life, and so on. In this sense, therefore, a new culture that is going to be inoculated into the previous culture is beginning to demand inexorably a new professional role.

And in the process of the appearance of a new role, these transformational central processes (emergence, narrative, generativity) are also detected; emergences that disturb what is established (for example, the need to address interventions in the natural context versus the interventions focused on offices, the need to assess the support needs, quality of life versus/together with the valuations focused on intelligence and skills); new narratives are generated (empowerment, emotional well-being, social inclusion, etc.); and new images and symbols are produced (for example, leaving behind the traditional symbols of the clinical office, for example the symbol of the "white coats", moving on instead to contexts of "round table", processes of equality of participation, oriented to generate models of collaborative relationship and symmetry). It involved a truly complex process of transformation, because when after a few hard years of building functions and role to meet the needs of people with intellectual or developmental disabilities, perceiving little support from the collective of psychology, what has been built begins to fall apart again and we find ourselves in a new process of determining our role.

It is also worth noting that a new stage had appeared for a large group of colleagues, especially those who had struggled the most to advance the profession in this field, training,

participating in work and innovation groups that were already incorporating the emerging models; models in which the knowledge and resources proposals promoted by INICO, the Institute of Integration in the Community of the University of Salamanca, have been and continue to be a fundamental support, under the leadership of Professor Miguel Ángel Verdugo, the first Professor in Spain on Disability. This scenario was the result of the development of new services throughout the country, the need for qualified people for the management of services and organizations. And there entered colleagues who, whilst competent to address the intervention considered most appropriate for people with intellectual or developmental disabilities, still with the models of the time, and although they had shown commitment and innovation (perhaps because of that they entered), they had not received the preparation required to manage management processes and team leadership in increasingly complex services and organizations. Thus we have the paradox that our colleagues, with an important participation in the collective construction of the profession in this field, saw themselves on an uncertain pendulum in their professional itineraries, which took them, without them being very aware of it, from clinical psychology to organizational psychology, when neither branch considered that they provided the knowledge and resources necessary for the exercise of their professional mission, increasingly oriented to quality of life, personal well-being in contexts of social welfare and social inclusion of the people for whom they worked.

As indicated above, the almost global agreement on the Convention on the Rights of Persons with Disabilities (Organización de las Naciones Unidas [United Nations Organization], 2006) definitively brought about the urgency of the transformation of services (Tamarit, 2015), demanded based on those rights –achieved mainly by the active fighting of people with disabilities themselves and their representatives around the world– but also based on the scientific knowledge derived from the paradigm of support and quality of life. Furthermore, it consequently triggered the urgency of the transformation of the professional role, indirectly demanding a more activist role in the set of professionals, in a way that evidenced, together with their knowledge, their commitment to defend those rights, putting themselves on the side of the individual, constituting a true human alliance in equality and in collaboration, compared with the previous styles closest to the subtle division between "us" (the professionals) and "them" (the people with intellectual or developmental disabilities). This prompted the emergence of ethics in the arena of professional intervention.

In the latest edition of the American Association on Intellectual and Developmental Disabilities - AAIDD (Schalock et al, 2010), the debate emerged between the vision of professional action



from the perspective of neoliberalism versus the vision from the perspective of professionalism (Reinders, 2008). This emerging process is crucial in the advancement of the profound application of the quality of life model and the support model and in the construction of a different role. One of the main issues raised is this function of defense and activism in our professional action. We could say that rather than a “loyal” role to the organization a “loyal” role is imposed on the defense of the rights and dignity of the person whom it supports, a defense accompanied by a precise knowledge based on evidence and ethics. The AAIDD also advocates that teams and organizations should consider an organizational transformation, moving away from vertical hierarchical proposals and moving towards horizontal proposals with self-managed teams that have the necessary knowledge and a strong anchoring in values and rights. In this scenario, the role of the psychologist should be geared towards the strengthening and positive supervision of the direct support teams, being at their side in natural contexts, thus moving away from the offices. In turn, psychologists must ensure the empowerment of the people to whom a support system is offered and collaborate in the construction of a fairer and more inclusive community.

How should professional excellence be understood from this perspective? I have proposed a formula that combines ethics (what should be), technique (know-how) and empathy (knowing how to be) (Tamarit, 2005). Authors such as Gardner (2011) consider it from the perspective of combining excellence, ethics and engagement (participation or involvement). Also other authors (Wilson et al., 2008) point out the relevance of ethics in the construction of good professional practice. Similarly, Rappaport (2005) states that the role of science should not be limited to science but rather should be something more than science, including critical awareness that enables the construction of a better society, that is, the professional should be involved, should be aware of the situation of the person he or she supports and should stand beside them. Finally, Reinders (2010) argues that for an excellent provision of care it is necessary to establish high quality relationships between the professional and the person that he or she supports.

The intervention process in the field of support for people with intellectual or developmental disabilities includes many moments of high uncertainty (precisely that which the evidence-based practice seeks to lessen) in which the professional does not have, largely because it may not exist yet, the precise knowledge about how to act and yet is urged to do so, from the responsibility that comes from professional ethics. Schwartz and Sharpe (2006) point out that complex problems occur to a great extent under particular conditions, in which the rules and standards that may exist, while useful, are not always the sufficient answer (good judgment is also required) to complex circumstances such as those that are expressed, in many cases,

in the ongoing relationship between professionals and people with developmental disabilities. In these situations there must be, they say, an executive decision system (*phronesis*) that ensures that things are done right, in the right way and at the right time. These authors point to practical wisdom as that which can provide a better answer. Practical wisdom not only makes it possible to know what it is right to do but also impels one to want to do it; there would be no practical wisdom if one only knows what should be done but lacks the will to do it.

With these approaches, the role of those who practice psychology in the field of developmental disabilities seems to me to combine, without neglecting any of the components, an ethics and evidence based-practice which is person-centered, an active defense of the rights of the people whom it supports, a symmetrical relationship based on trust and collaboration both with the person and with their loved ones and other professionals and people in their environment (therefore working with cross-disciplinary teams with different knowledge –scientific knowledge, technical knowledge, life knowledge– all of them essential), impeccable ethical behavior, especially in situations of uncertainty in the face of the insufficiency of existing knowledge, a high sense of responsibility and social justice toward the inequalities, discrimination and stigma that these people still face, an unwavering commitment to the wellbeing of each person and to the social welfare of the communities in which they live.

This set of characteristics is clearly differentiated from those that in the beginning were linked more to a rehabilitating clinical psychology. However, currently, there is a specialty of psychology gaining significant strength that does seem to “marry” well with all of them and therefore can serve to accommodate the necessary development and collective strengthening of this role. The aforementioned characteristics fit very well with the current emerging approaches promoted by the conceptualization of the psychology of social intervention (PISoc, in Spanish). Sánchez and Martínez (2017) remind us that in 2015:

It was agreed that the mission of this specialty was to promote the psychological and social well-being of individuals, groups and communities, especially those who are at a disadvantage, through changes that lead to a more just society, establishing networks and social interactions that facilitate their empowerment, and using the models and methodologies of psychology. Likewise, PISoc must influence social policies as part of the processes that generate normative change (p.20).

And today, López-Cabanias, Cembranos and Casellas (2017), while recognizing its current weak identity together with scarce knowledge and recognition, due to its short history, and aware of the blurred boundaries existing with other disciplines, define PISoc as:



a set of knowledge and practices based on the science of human behavior that are applied to the interactions between people, groups, organizations, communities, specific populations or society in general, in order to achieve their empowerment, improvement in their quality of life, an inclusive society, the reduction of inequalities, and social change. All this occurs through proactive and preventive strategies that stimulate and favor the participation of people and communities and take into account human diversity (p. 10).

Today, assuming this professional perspective, in my opinion we face another critical challenge in order to continue building our profession in this field: the need to advance in the conceptualization of social inclusion, recognized as a fundamental right in the Convention on the Rights of Persons with Disability, and therefore one of the critical objectives that we must try to achieve. Social inclusion does not have this conceptualization and is generally defined more by describing processes of social exclusion. And if there is no clear definition, progress is hindered in the planning and development processes of the services and resources necessary to advance its achievement (Cobigo et al., 2016). Among the most interesting proposals to advance in this conceptualization is the one developed by Simplican et al. (2015) that articulates social inclusion through the interrelation between processes of community participation and processes of interpersonal relationships, advancing the idea that social inclusion is a path rather than a goal and that it can be walked with multiple steps if one has an appropriate theoretical framework. Other authors (Cobigo et al., 2016) propose a framework for social inclusion, understood as the product of complex interactions between personal characteristics and the environment, finding four aspects common to different definitions of social inclusion: belonging to a group; having interpersonal relationships; being accepted as a person; and having reciprocal relationships. On the other hand, Cordier et al. (2017) highlight three general domains of social inclusion: 1) participation; 2) connection and a sense of belonging; and 3) citizenship and rights. In any case, all of these incipient proposals are clearly aligned with the focus of the psychology of social intervention. Its future developments will be very relevant.

In this article we have tried to describe a narrative journey from the beginning, in the fifties, in reference to the role of psychology in addressing the challenges faced (both in the past and today) by people with intellectual or developmental disabilities and their families. Initially there was a long period of an apparent lack of definition of the role of psychologists and a situation of unintended detachment from their activity, in relation to the traditional disciplines of psychology. Now, having advanced the professional action clearly towards intervention models centered on the person, oriented to their personal well-

being in an environment of social welfare and in the construction of fairer and more inclusive communities, a period of opportunity is opening up thanks to the recent strengthening in Spain of the psychology of social intervention. This can generate a stronger professional identity and, with it, the possibility of the collective construction of knowledge and resources necessary to ensure the advancement of the quality of life and full social inclusion of people with intellectual or developmental disabilities and their families.

CONFLICT OF INTERESTS

The author states that there is no potential conflict of interest of an economic nature or of other relationships with individuals and organizations.

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