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Life Stories on the Social Image of Disability. An Educational Outlook

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Abstract

This paper forms part of the results of the ongoing doctoral thesis with the title Resilience and intellectual disability in residential environments using life stories. From a narrative and inclusive biographical approach, we delve deeper into the life history of four people who have been diagnosed with intellectual disability and who live in a residential environment in the city of Malaga (Spain). The field work was carried out using semi-structured and in-depth biographical interviews. The analysis reveals one of the conceptions that is a priority in this paper: the “social image” of disability, structured in three main areas for the purposes of this article: “the image of disability from social culture and identity”, “the image of disability from close contexts” and, lastly, “subversive experiences to the image of disability from inside”. In conclusion, there is a commitment to continue generating another social image of disability based on a more social and inclusive paradigm.

Keywords: intellectual disability, social image, education, social exclusion, culture.

Relatos de Vida sobre la Imagen Social de la Discapacidad. Una Mirada Educativa

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Resumen

Este trabajo forma parte de los resultados de la tesis doctoral en curso con el título Resiliencia y discapacidad intelectual en entornos residenciales utilizando historias de vida. Desde un enfoque narrativo y biográfico inclusivo se profundiza en la historia de vida de cuatro personas a las que se les ha diagnosticado una discapacidad intelectual y que viven en un entorno residencial en la ciudad de Málaga (España). El trabajo de campo se llevó a cabo mediante entrevistas biográficas semiestructuradas y en profundidad, entre otras estrategias. El análisis revela una de las concepciones prioritarias de este trabajo: la "imagen social" de la discapacidad, estructurada en tres grandes áreas para los propósitos de este artículo: la "imagen de la discapacidad desde la cultura e identidad social", "la imagen de la discapacidad desde contextos cercanos" y, por último, "las experiencias subversivas a la imagen de la discapacidad desde el interior". En conclusión, existe el compromiso de seguir generando otra imagen social de la discapacidad basada en un paradigma más social e inclusivo.

Palabras clave: discapacidad intelectual, imagen social, educación, exclusión social, cultura

People with an intellectual disability (PWID) have an objectified significance at a cultural level in Spanish society, which is evident in the perspectives, representations (Celada, 2015) and social images of this collective; a clear example of the latter can be seen in the data from statistical sources provided by the state disability observatory¹ (2018), in which 3,787,447 people are registered out of a total of 47,100,396 inhabitants². Nevertheless, these figures are offset with the lack of interest and media, political, social and public presence³, a matter that, as pointed out by Aparicio (2009), is a historical problem.

The definition we are currently following and using as regards intellectual disability (ID) comes from the American Association on Intellectual and Developmental Disabilities (AAIDD, 2011), which refers to ID as a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills (Schalock, et al. 2010). Likewise, we understand it is essential to follow the WHO's guidelines (2011)⁴, recovering what the Convention on the Rights of Persons with Disabilities (United Nations, 2006) states, which establishes it as a complex phenomenon that is not perceived in the person individually, but in their interaction with their environment.

The dominant social and scientific cultures have generated an undervalued vision of PWID, based on the medical-rehabilitation paradigm that pursues "standardisation", and which defines, stipulates, and in many cases, confines the perspective other people have of this collective.

Moreover, we know that this dominant view has had a huge influence on the representation that PWID have of themselves. In many cases, these social images have contributed to social exclusion in the way of employability and educational restrictions, limits to rights to leisure and other facets of social life. This is accentuated in situations in which the diagnosed people live in residential or institutional environments (Martínez & Planella, 2010). On the other hand, the stigma from a social point of view has degraded them to a deeply segregating attribute that sets them apart on physical, psychological or identity grounds (Goffman, 1963; Manzo, 2004). This has been evident in the characteristics and adverse distinctions attributed by the others (Beart et al., 2005; Barton, 2008).

We find an important conceptual evolution in Spain and internationally, regarding the consideration of people with intellectual disabilities (Egea & Sarabia, 2004). These conceptual changes meant a considerable advance as

far as the social image of disability is concerned, but they were not enough. Even the voices of the people diagnosed (as entities that contribute to the construction of the social image) are not very present (González Luna, 2013; Haya et al., 2014; Parrilla & Sierra, 2015; Pallisera et al., 2017).

For this reason, it is currently necessary to back a more human level of research into and with PWID, contrary to what has been the research tradition for decades, which has been developed without the contribution of people with disabilities (Goodley & Moore, 2000) generating a perspective that has underscored a closer promotion of a social image of disability from a point of deficit.

The Social Image of Disability

The social conception hanging over PWID can be studied from three different areas (Pintos, 2005): (1) social systems (policy-making, law, science, education, etc.); (2) organisational systems (institutions for people with disabilities); and (3) within a more relational level, we find the interactive systems that arise amid the diversity of conceptions and self-perceptions about PWID. More specifically, the concept of a social image of disability is structured from a wide range of scenarios and actors, such as the press and media, scientific productions, literature, legislation and regulations, etc. (Mitchell & Snyder 2001). These are conditioned by various elements that, according to the CIREM foundation in Spain (2004) and authors like Vander (1995) or Barriga (2008), can be listed as the following: information available regarding the individuals and/or collectives; the values or axiological universe of the observer who is constructing the image or making the perception; the direct relations between the diagnosed individuals and society, and stable features and permanent dispositions.

Considering this, we propose the definition formulated by CIREM (2004, p.38) that says the social image of disability is “based on assumptions and valuations about the appearance, apparent behaviour, positive and negative aspects, priorities regarding how to treat someone or something, etc.”

In relation to this, the image that the public used to have⁵ about people with a disability was legitimised by a balance of power between the norm and the diverse. This legitimisation was based on a presumption of inferiority (Hahn, 1986) of the damaged individual and a denatured view of human beings, focusing exclusively on the pathological as something that had to be

cured. The eugenics movement and the medication-rehabilitation model played a crucial role in the construction of this view of PWID (Mitchell & Snyder, 2003), and which shaped the care given to these people up until the end of the 20th century (Rodríguez Bausá, 2003).

In this attempt to understand the portrayed social images, we must understand the evolution that has taken place, in parallel, of the different social, political, cultural and scientific models that have governed and influenced both the conceptual design and the care and attention given to disability. These representations have traditionally placed disability at the boundaries of social and cultural disadvantage in which their pathological nature is highlighted (Rodríguez Bausá, 2003; Richardson, 2005).

In this respect, on one hand, in early studies into the social image of disability, an analysis of the media was shown, as the media have played, and still play, an essential role in conveying a specific image of PWID (Soto, 2015). These were undertaken in the 1950s, a period which Barnes (1992) called less illuminated, and which shed a simplifying, stereotyped, mythicised, superficial and/or mistaken perception on people with a disability, which evidently had an influence on the popular consciousness at that time (Carrillo & Madrigal, 2013). This stance maintained the biased, negative image of disability within an illusory correlation⁶ (CIPS 2015), projecting approaches and views that kept them as the oppressed group, restricting their possibilities for social participation (Oliver & Barnes, 2012).

On the other hand, around the 1970s and 1980s, a period of integration and recognition of people's rights (Barriga, 2008) started to bring about a change in perceptions of PWID. A period of deinstitutionalisation began in Spain (Huete et al., 2015; Muyor, 2019) that, albeit not in a particularly clear manner, revolved around the push that came with the Warnock report (1978) and what this meant for people with a disability. The associations in which they had been confined gradually abandoned the undervalued and dehumanising views that had been aimed at them, spurred on by the international movement and drive in the need to see their rights reflected in social and healthcare policies, which led to the rise of the social model (Oliver, 1990; Shakespeare, 2013).

This development endeavoured to present a perspective that took the focus away from the merely pathological aspect to focus more on understanding that the person formed part of a social, legal and cultural

framework in their own right. This directly affects the social image of the PWID.

Different milestones and official documents in Spain show the attempt to raise awareness of the situation and encourage a change in the social image surrounding PWID. In this sense, we would like to highlight the following, according to the *Plena inclusión* collective⁷:

<i>Date</i>	<i>Event</i>
1998	The pilot programme of Self-advocate groups was created in 5 associations.
2008	A study of the Financial Burden that intellectual disability causes families in Spain was carried out (FEAPS sponsored by ENDESA, with the collaboration of Antares Consulting).
2012	A research study was carried out on the Quality of Family Life Scale (INICO).
2013	A research study was carried out on the Quality of Individual Life Scale (INICO-FEAPS).
2013	<i>Guide of good practice regarding people with a disability for media professionals (2013) (Department of health and social welfare, Regional Government of Andalusia)</i> . This document offers a brief analysis of the background situation and goes on to deal with subjects related to language, message and image of people with a disability.
2013	<i>Comprehensive Plan of Action for Women with a Disability² (2008-2013) and II Comprehensive Plan of Action for Women with a Disability (2013-2016) (CERMI 2013)</i> . These documents discussed the need to improve the image offered, among others, by the media regarding women with a disability. In particular, we should highlight one of the three general objectives of this plan: "Eradicate gender stereotypes, promoting the transmission of a non-discriminatory social image of disability, which makes women with a disability more visible and enables processes to improve their self-esteem and revaluation of their abilities". (20)
2014	
2015	
2016	
2016	A study was submitted on the Transformation of services to services focused on people and implementation on a prototype scale (Ministry of Health, Consumer Affairs and Social Welfare).
2016	Research was carried out with the University Institute on Community Integration (INICO), and campaigns such as <i>Todos somos todos</i> (2016) [We are everyone] were also launched.
2016	The POMONA-ESP project, studying health indicators in people with intellectual disability, funded by the Health Research Fund of the Carlos III Health Institute (Ministry of Economics and Competitiveness) and coordinated by <i>Plena inclusión</i> in conjunction with the <i>Fundación Villablanca y Sant Joan de Deu</i> .
2017	Research was carried out into the quality of service from the point of view of people with a disability, led by Vicente Martínez-Tur (IDOCAL – University of Valencia).

Figure 1. Prepared by the authors, content extracted from www.plenainclusionandalucia.org

Through the Independent Living Movement and changes in legislation, the social image surrounding people with a disability is changing over time, from the previous situation of exclusion and charitable attitudes, to the current point of inclusion, or at least the intention to achieve inclusion. These changes encouraged a greater awareness of the repercussions and degree of influence that these images can have on people with a disability, and they

endeavoured to break that historical burden that has accompanied them for decades, and in the words of Barron (2002), has generated a reconstruction of the labelled identity.

Methodology

The methodological approach that we put forward with this project is, on one hand, based on the approaches of inclusive research (II) (Apple, 2012; Griffiths, 1998; Nind, 2014; Nind & Vinha, 2014; Parrilla & Sierra, 2015; Strnadová & Walmsley, 2018; Slee, 1998), understanding that research studies must be carried out by, with, and for the participants. On the other hand, this research comes under the biographical-narrative paradigm (Bolívar, Segovia & Fernández, 2001; Rivas, 2007; Cortés, 2019), through reprocessing fragments of the individuals lives and their life experiences (Cortés, 2011); ‘the idea of the “biographical approach” asserts the need to always see individual and collective actions in a relational way, where “belongings” are temporary, plural and multiple’ (Aceves Lozano, 1997).

In this sense, we are not searching to understand a social phenomenon by repeating social manifestations, but rather we aim to go deeper into how the individuals of the study live and feel their reality under the predominant social image of the disability.

This text is part of a doctoral thesis project, mentioned above, which focuses on studying the life histories and their resilient processes of subjects diagnosed with intellectual disability. It consists of three empirical phases: (1) exploration of the study context (direct observation in the therapeutic center of residence of the participating subjects, documentary review, interviews with professionals and families); (2) deepening in the life stories of the subjects (biographical interviews); and (3) the inter-subject discussion (reflection and discussion groups).

Objectives

The main objective of this study is to view and analyse the common characteristics that have led to the exclusion of people identified with an intellectual disability, clearly ‘marked’ by a segregating label (Goffman, 1963; Manzo, 2004; Becker, 2009), based on an image that is socially removed from the features with which they, themselves, identify.

The specific objectives that we have set in this article are:

- To tackle the ‘image of disability’ concept from the accounts given by the participants in our study.
- To delve into the different processes of subversion against this predominant social image.

Ways of Compiling Information, Analysis Procedure and Rating Strategies

We propose biographical interviews for collecting information related to the results of this text. We developed them from a semi-structured design and carried out from a non-leadership procedure (Flick, 2004), with questions of the type: What would you like to talk about? Do you want to tell me anything? and such like.

We also used targeted interviews (Merton & Kendall, 1946), in which we gradually introduced a greater level of structure to provide a more specific view of the particular topic we manage, some examples are: Tell me about your family / Tell me about school / What was lifelike at home? / How did you get on with your brothers and sisters? among others.

Next we offer some more detailed information about the outlined biographical interviews and its participants:

Table 1.

Methodological strategies and sources. Prepared by the authors.

Formal individual interviews	18
Age of the individuals	27-45 years
Timing of field work	5 months
Informal interviews	13 Aprox.
Participants (Teresa, Julio, Carmen and Miriam)	4

It should be noted some issues of interest of field work. We plan to carry out the interviews according to the needs and reality of the subjects; for example, understanding their possibilities of concentration, in order to facilitate the meeting. Also, it was important to resort to paraphrasing, in order to follow the discursive thread, conduct brief interviews and be flexible to the moments of interviews, since they had to be carried out in a quiet and

calm moment. Therefore, the process of observation and prolonged stay in the center was necessary for such a methodological strategy.

As regards the analysis of the information, we have based our work on the interpretative method of the life stories (Creswell & Poth, 2007), which was carried out, first, using an open thematic coding process (Gibbs, 2012), differentiating units of meaning or themes that have been categorised in branches to be able to comprehend and interpret them. From this strategy, issues such as sexual abuse, social distancing, labeling, among others, appeared. Secondly, we use an axial encoding (Strauss & Corbin, 2002), through (1) a word count technique, which made it easier to examine which experiences, situations or words were most repeated in the stories and which could warrant further analysis, and (2), coded analytic induction (Ryan & Bernard, 2003) for the elaboration of interpretive categories. Important issues of this strategy were resilience, the social image of disability or risk and protection interpersonal mechanisms.

On the Choice of Participants and Ethical Aspects

It is important to highlight one of the researchers of this study is part of the team of educators at the center in which the participants live. Therefore, one of the essential aspects is the trust, closeness and recognition that they have for each other due to a previous relationship already established. On this basis, four people out of a total of 123 possible were identified, within a process of "intentional sampling" (Portney & Watkins, 1993), and through criteria specific (Goetz & Lecompte, 1988), such as having demonstrated / remarkable linguistic ability and understanding, having availability, willingness and interest in research and the possibility of accessing them.

Also, the protection and ethical inclusion of the participants in a research study, and the handling of ethical codes within the inclusive type of research that we are engaging in, is a matter that we must bear in mind at all times. This study follows the Code of Good Practice issued by the CSIC (2011), we secured the necessary consent and permission both from the participants and their legal guardians. At the same time, we felt that it was vitally important that people were aware of the nature of the study, its purpose and the topics that would be discussed in the interviews, as well as keeping a record at all times of the relative purposes and development, which is in keeping with the principles of inclusive research.

Results and Discussion

We focus on presenting the results obtained in the three emerging analytical themes that have come out of this study, and which are discussed in depth in the following sub-headings.

The Image of Disability from Close Contexts

At this point, we prioritise listening to the voices of those who were invited to participate and who will go by the names of Julio, Teresa, Carmen and Miriam in our text.

We observe that the labels imposed on the PWID in our research study have stayed over the years, in social, family and school contexts, which has had an effect on their identity as regards their disability. In the first of these, the social context has maintained a biased image of disability in which PWID were the bearers of pathologies, weaknesses, medical conditions, etc.:

When I would go out for a walk, people would stare at me, they used to say things to me and laugh at me, but I can still sense them looking at me a certain way. (Julio)

Julio's words reflect the reality of how the difference is still stressed on a social level, and consequently the stigma associated with everything about the individual in question continues, with that person being perceived as being out of place. This fact generates a change in the others as far as attitude is concerned, entailing rejection and mockery:

Everyone used to say things to me, they laughed at me and that. (Teresa)

These situations still exist, from a viewpoint of social image, in a traditional paradigm of ID associated with the unknown, the different, and even, at times, with madness:

They always picked on me, everywhere I went; they must have seen something odd in me, in the way I am, the way I talk, I don't know." (Miriam)

In fact, they always called me the village loony, as if I had something weird.” (Carmen)

From their voices we perceive as the social image materialised in the form of insults, discrimination, etc., and so on, forming an *attributed identity* that was *deteriorated* (Goffman, 1963; Barron, 2002; Sen, 2007), which induced them to the process of *reification*⁸ that minimised the individual as a whole, reducing them to mere negative attributes that objectified them.

We have seen how the second context, family, is very much linked to the cultural input of the environment or the image of the social culture of disability. The family has had a significant influence as regards limitation, undervaluation, discrimination and, on many occasions, humiliation. This is the context that is most influenced from outside, while at the same time it has the most repercussion on the members of the family. Thus, a vicious circle is created, which reproduces the violence/discrimination/neglect that they receive in other contexts, becoming a reality that accompanies them throughout their days:

My husband used to say I was crazy, but what about him? He also used to tell people in the village that I was crazy, that I was ill (disabled) and people who didn't know me at all would look at me oddly in the street. (Carmen)

These power relations subject to imposition are given in the other stories as well:

(...) my adoptive mother had a brother who was schizophrenic and he used to hit me, he treated me really badly, I had to do whatever he wanted, I would go to the flea market and he would take all the money I had earned off me (...) So, what I was telling you, he would take the money from me and give it to my mother, because my mother told him to, and if I didn't he would hit me, he took advantage of me, because he said I was disabled and other things that were even worse (...) My mother and her boyfriend always wanted my money, that's why they would come to see me at the centre. (Julio)

With my father it was bad, in fact it was him who used to hit me, and I didn't get on well with him; he hit me once and the monitors at school noticed the marks, and that's when it all stopped; I've been in centres since then. (Miriam)

This family context became more and more violent and aggressive, falling into patterns of dehumanisation and objectification of the PWID themselves, which is always reflected, as Calderón (2014) mentions, when it comes to naming them, labelling them, cataloguing them and restricting their freedom as people, confusing the responsibility of care or dependence with subjecting them to violence and to the family beliefs, rituals and/or expectations.

The family context is where they experienced the most humiliating and degrading situations; different phenomena coming under (1) the condition of being PWID and being women -*double stigma*- (David, 2004; Serra, 2017), (2) but also affected by a deteriorated social image of them, they were at greater risk of suffering sexual abuse, as covered by Hollomotz (2011) and Stefánsdóttir and Traustadóttir (2015), among others.

As regards the school context, it remained *inactive* for the participants, they did not have sufficient impact on the school context to break away from the indifference and neglect insofar as to diversity are concerned:

And because I thought they were going to laugh at me, I didn't speak to anyone at high school, I was almost always on my own (...) in the end they had to take me out because of that. I didn't understand why they laughed and it stressed me because they would tell me that I couldn't do stuff, that I wouldn't know how, and I left because nobody helped me at school to do anything, the teachers couldn't be bothered with me. (Miriam)

This school context was yet another point of contact with the stigma and its ramifications that are based on *structural discrimination* and which caused a more closed vision of the outside world, which holds them back and disables them, through deficit-based language:

You can't"; "you've come too far... (Teresa).

As claimed by Parrilla (2007), these school experiences (mockery, insults, etc.) merely added to a long list of institutionally generalised and assumed

(and we dare say permitted) situations of segregation and spatial and social exclusion in the school set-up; this structural exclusion was what made change impossible.

I wanted to learn more things, but they didn't let me. They always put me at the front of the class and gave me stuff to draw while the others were doing maths and other things. They didn't teach me anything. (Teresa)

The long-awaited contexts of inclusion were transformed into contexts of *immersion* (Jollien, 1999), in which the two, clearly differentiated, groups⁹ kept a comfortable distance by mutual agreement, without contact or communication between them.

They gave me easier, more basic material than the rest, because they said that, seeing as I had a disability, that was the way it had to be, but I still failed and that was that, nobody helped me at all. I left the education system at the age of 18 because I couldn't stand it any longer, and the fact is that I don't even remember the names of my classmates or the teachers. (Carmen)

These situations kept them in the assumption of biological or physiological inferiority (Hahn, 1986), following Freire (2002), developing a resulting behaviour that is based on patterns that are beyond them and following the patterns of the oppressors, which did not let them grow in an educational sense:

They put me right next to the teacher so that I could pay attention, because they said that if I didn't, I wouldn't do anything. (Miriam)

My parents used to say: The truth is that I did very little at school (Julio)

I used to get zeros or really low grades, I don't remember, I didn't care, what was the point? I didn't study, a school I used to fall asleep there and nobody would say anything, they would just leave me sleep. (Carmen)

These situations that they experienced compelled them to an identity construction that was deep-rooted in guilt-ridden, undervalued and negative self-perceptions, giving in to a "disabled" image of themselves, as we will see below.

The Image of Disability from Self-Perception

The image of disability, as a social construct, has negative connotations that can find their way into the perceptions that PWID have regarding themselves.

In the specific case of the four people participating in this study, the social image that hung over them kept them *bound and subjected* (Celada, 2019) for many years, which only served to increase the existing separation between them and the rest of society.

This was one of the reasons that led to participants being associated with other people in accordance with this disability, and kept them distanced from *the others* (Beart et al., 2005; Barton, 2008), self-attributing the fact of being and referring to themselves as "disabled" (in the sense of attributed identity) (Barron, 2002; Sen, 2007).

The undervalued and projected image of disability, from which PWID were discriminated, was imposed on them by a context that made them see themselves as disabled; they were kept in a categorical logic that was socially asserted, and which continues to the present day, blaming, nominalising and individualising the problem (Calderón, 2014), focusing it exclusively on the PWID themselves. This generates an altered and assumed image of themselves that is based on labels that are imposed on them by others in society, that have made them believe and feel like they are disabled, and one which has justified everything that happened to them.

I was with the owner of the bar, she was the same as me; I mean, she had a disability. Seeing as she had a disability, mostly physical, in her hand, my mother put me in school, precisely for that, because of my slowness, you know? Because of my disability. (Teresa)

Because I guess that my disability was more obvious before, that's why they picked on me. (Miriam)

From their words we can see a sympathetic self-perception, as a result of a negotiated identity in the interactions that made up the nearest context and that was based on criteria of inferiority, limitations, pathologies, etc. This identity *darkened* (Becker, 2009) all the other identities, submerging the PWID in the impossibility of not relating with any interpretation of themselves other than that which was imposed on them from the others (Kittelsaa, 2014). This leads to a sentencing of the self:

They laughed a lot at me. At that time, I had burns; I've had 6 operations on my burns¹⁰ and they laughed at me because I didn't walk properly and I had a disability. (Teresa)

The impact of disability does not differ from one situation to another; regardless of the situation, the disability transforms into a justification for all things negative, which ends up leading to a process of repulsion and struggle against everything that had been established without their say.

Subversive Experiences to the Image of Disability

Lastly, we have found subversive experiences from the inside; people and contexts that have said “enough” to those realities that had been imposed on them, and from which they managed to generate a vision of themselves in opposition to that social image of disability. This is the case with Julio, and what this fragment of his story reflects:

I remember the binding module, which I actually liked (...) and also I was already there in the hood doing nothing, because that guy didn't want me to do anything because he said that I was sick and that I couldn't do those things because I was 'disabled', well obviously he didn't want that, but I did it because I knew I could and above all, because I wanted to. I signed up for a binding course and I used to sleep there at nights in the centre where I did it, and I stayed the whole course. I did it because I wanted to, and because I knew I could finish it. (Julio)

My mum spent the whole day telling me that I was disabled, that I couldn't do this or that, that if I didn't know now I'd never be able to learn (...) and I just didn't see myself like that (...) I'd like to meet

someone special, get married and start a family. Get married, have a job, a car... I can do that and I could have my children; I'd also like to train to be a childcare assistant and work in a nursery. (Miriam)

Julio and Miriam's case clearly contradicts and claims back this 'marked' social image of disability, fighting against the accumulation of "name-calling" (Butler, 2002) such as '*disabled*', that prevented them from being, doing and being able, and on which efforts are made to claim it back in a reaction (Cortés, 2011) against the stipulated norm.

Albeit in a less head-on way, the generalised stigma that was attached to PWID was sometimes offset with the accounts they gave of themselves, both in the school environment, in the family and in a contextual sphere, with that fighting nature and will to overcome obstacles that has characterised them throughout their life shining through:

I don't want to see my family, I feel bad, I'm positive I don't want to, because the truth is, since I've been here in this centre and I don't see them, I feel a lot better and then they come and they think they can tell me what I have to do, and they give me orders as if I were their maid, and all that because they still believe that, seeing as I have a disability, they can do what they like with me, they are wrong. (Teresa)

On occasion, the subversion comes with the break-up that is produced when a person does not recognise themselves in the diagnosis imposed on them from outside, in "*what they say I am*", but they are still aware of their possible limitations. Consequently, we find ourselves facing the need to recognise PWID in a multi-factorial, varied, open and empathetic manner.

I'm not like this, like others I know, there's no understanding them, I'm not the same, I mean, I don't know to what extent I have a disability because I wash myself, I shower, I get dressed by myself. I don't really have a disability, I get given 20 euros and that's it. I'm not the same as them, because I do things by myself, I don't see myself the same as them, that's why I don't want to stay here. (Carmen)

All this leads us to recover the three dimensions put forward by Jo Rowlands (1997), on which we understand the acts of internal subversion, of change and break-away from the stipulated norm¹¹, expressed by the individual subjects in the study.

Therefore, we find ourselves with the personal projection that empowers them before the circumstances and boosts their strategies to counteract and improve their self-esteem (Crocker et al., 1993), generating a categorical identity (Taylor, 1998)¹² which is immersed in a deep-rooted cycle of change, something that Giddens (1991) called the continual reflection of identity development.

This reflection leads to a self-identity (Barron, 2002; Sen, 2007) that is more based on principles of trust, self-confidence, etc.:

They have always made me believe that I couldn't do these things, but I can, I have certain difficulties, but not as much as they say. I think that studying in a normal school is harder for me and if I don't pay attention I don't understand things, but not like my mum says that I don't know anything. (Miriam)

According to the author (Sen, 2007), these exercises come with an openness to the world that has been closed to them for years, implementing a political and mobilising stance and enabling a change on a large scale. We understand that these changes go hand in hand with a gradual raising of awareness about their situation, and that emphasising them can mean they seep into the different political and institutional contexts, impregnating their entire daily life (Lagarde, 2000).

In summary, these three topics of discussion contributes to raising some broader questions that coincide with proposals by authors such as Barron (2002) or Crespo (2019), who hold that identity development goes through three different forms:

- The first of these, in which identity is legitimised, in our cases, is in favour of the dominant institutions in society, which corresponds to the development of a biased self-perception based on a deteriorated social image and on abuse from close contexts (Gomiz, 2016).

- In the second form of identity process, these same authors (Opus Cit.) argue that the actors build resistance trenches based on opposite principles, in what we have presented as the subversion.
- Thirdly, we have found a working identity that breaks away with the stipulated norm, as we have seen, and on which we have found that, through activity, insight, intentionality and a conviction to be able to live and be in another way is possible, aspects that have also been shown by authors such as Goodley (2000), Kittelsaa (2014), Stefánsdóttir and Traustadóttir (2015), among others.

Conclusions Based on a View to the Future

Understanding the reality of PWID first-hand is an enriching learning experience in every area, both for the people who are researching or working with them, and for families and loved ones. Thanks to this, we can delve into and expand our understanding about their realities and challenge the detrimental notions about who they are, and which are deep-rooted in us and have been for decades. In this research study we have been able to work with PWID, breaking the established custom in society, as mentioned by Schormans (2014), of talking about their visual representations but without them, themselves.

The research process that we have handled has contributed to make visible the negative attitudes and low expectations towards the participants due to their diagnosis and to resume the discourse on the necessary implementation of a new order of coexistence, both in the educational, health and political fields. It requires the modification of these prejudices and stereotypes that hinder the personal and social acceptance of PWIDs in our day-to-day lives.

In general, the research approach towards PWID has been contained in the attempt to discover the social construction of identity (Barron, 2002; Zárate, 2015), bibliographical reviews about it (Beart et al., 2005), learning problems (Goodley, 2000), and, in most of the cases, from a highly generalist approach to the world of disability (Murray & Fox, 2002; Zhang & Haller, 2013). At the same time, this study presents evidence of the close correlation between that popular consciousness and the social-educational exclusion, an aspect which fits into the subject raised in other studies (Macrae et al., 2003).

Having retrieved the testimonies in the first person has made us question the role played by the social organisations and agents when it comes to

supporting and counter-supporting the social integration of PWID, from a micropolitical-hegemonic viewpoint. In the same way, like the established image of them, from what was put forward by Pintos (2005) and Cobeñas (2015), i.e. from the social and education system, the organisations and institutions and the development of the different interactions, have continued to be laden down with negative ideas and perceptions, and very low expectations regarding PWID because of their diagnosis or diversity (Díaz-Alzate, 2020; Rodríguez Bausa, 2003). This is shared by studies such as that presented by Gillman, Heyman and Swain (2000), which shows that the imposed labels are constitutive in people's lives and, as Polo, Fernández and Díaz (2011) point out, they still constitute one of the main obstacles to their inclusion and integration.

To conclude, on the one hand, in reference to the possibilities and transferability of this study, we can say that the self-perceptions from a perspective established in PWID, and from a narrative approach, has not been dealt with sufficiently frequently in the international research panorama (Kittelsaa, 2014).

On the other hand, we think that the results are sufficiently insightful regarding the personal perspective and self-concept that PWID have of themselves, and in the convergence with the popular consciousness opinion of them. A change in the popular consciousness regarding PWID is clearly necessary, moving from an image of 'invalid', 'inhuman' or 'disabled' (Cobeñas, 2015; Hahn, 1986; Rodríguez Bausá, 2003), to the image of possibility and, in this way, have a bearing on more favourable attitudes and fairer and more democratic social practices that entail greater togetherness (Barr & Bracchita, 2008), which generate a social change regarding PWID. This will encourage 'the development of new theoretical frameworks that act as a base to improve the support given to this collective' (Barquín 2015, p. 113).

Notes

¹This data can be found at: <https://www.observatoriodeladisapacidad.info/tag/estadisticas/>

²Data obtained from the national statistics institute on 2-3-2020.

³Data reflected in Google Trends, which show that, between 14 July 2019 and 23 November 2019, only 3-4 searches per day were made in Spain related to disability, compared to other topics, such as: football 30-50, Big Brother 10-12, Politics 10-15, and Employment 20-30.

⁴World Report on Disability (WHO - World Bank).

⁵It is important to stress the perspective in the past, supported by the approaches put forward by Barriga (2008) of the Social image and visibility of disability, as something from which we have now moved on. We will endeavour to maintain this stance throughout this article.

⁶Associating a person with a disability with negative events or behaviour.

⁷Plena inclusión is a network of organisations that safeguards the rights of people with intellectual and developmental disability in Spain, ensuring their rights are respected. It is a non-profit entity that is made up of over 880 associations that deal with people with intellectual or developmental disability. Plena inclusión was founded in Valencia on 26th April 1964. Its original name at the time was FEAPS.

⁸This term was used by Jollien (1999) in his work in praise of weakness, and has its origins in the works of György Lukács and Jean Paul Sartre, in which the conduct of reducing a person to a simple attribute, seeing them as just one quality or characteristic that is taken to define them, not allowing anything else to be seen, and reducing that person to the category of ‘thing’ or object.

⁹Separation in the classroom, different career guidance, different material and subject matter, etc.

¹⁰Burns that occurred resulting from a fire at her home when she was only 8 years old.

¹¹We can unify these concepts under the umbrella term of Empowerment.

¹²We understand that, from the author’s perspective, that identity can be chosen by the person to develop their own empowerment before the vulnerability of their rights.

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