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# 'I open the coffin and here I am': disability as oppression and education as liberation in the construction of personal identity

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**ABSTRACT**
This article presents a case study focused on the experiences of Rafael, a resilient young musician. The research is based on 180 records made through interviews, focus groups, observations and documentary collection, involving 190 informants. The data analysis shows that social systems create subordinated and stigmatised conditions of experience for people with disabilities which lead to social exclusion and reification. This understanding of disability as oppression (which is the 'coffin of the dead') can be combated by means of education, understood as resistance to inequality. This can be effected by questioning the social order and power relationships, thus striving to produce the possibility of being a subject. In this way Rafael has been able to construct his identity relatively autonomously, challenging social mandates that led him to exclusion and denied his existence as a subject. In his own words: 'I open the coffin and here I am'.

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Education; disability; identity; oppression; resistance; resilience

## Points of interest

- This article aims to present some of the analyses extracted from the research 'Education and Hope on the Frontiers of Disability', which has been recognised with the Disability and Human Rights 2013–14 Award by the Spanish Committee of Representatives of People with Disabilities.
- This single case study analyses the identity construction of the first person with Down's syndrome to complete a professional degree in music in Spain, which makes it unrepeatable; and the way it delves into the process – with the researcher being the brother of the subject of the study – reaffirms its uniqueness, ensuring an analysis from within the situation is carried out.
- The person studied has been recognised with the World Down Syndrome Day Award (2012) by Down Syndrome International (UK).

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## 1. Introduction

This article provides an analysis generated from the qualitative study entitled 'Education and Hope on the Frontiers of Disability'. The article is focused on the construction of the identity of a young musician, Rafael, with special reference being made to the socialisation and education processes experienced by an individual with Down's syndrome.

This is a single case study focused on Rafael, second author and brother of this article's main author, and therefore has been conducted with the researcher's full involvement. The analysis generated interprets disability as oppression, and education as a tool for liberation. It uses theoretical tools that are far removed from those normally used in special education. These characteristics took the research down some unorthodox paths, which gave rise to a new understanding rarely addressed by academia. These involve linking Disability Studies with the philosophy and pedagogy of difference, theories of reproduction, resistance and resilience.

The study dissects the collective and personal processes that have enabled the individual whose experiences are the subject matter of the research to develop his identity beyond the socially assumed interpretation of disability. It analyses the experience of a resilient person and his ways of challenging social representations, beliefs and stigma.

## 2. Disability, resistance and education as liberation

In critical studies on disability the emphasis is placed on disability as a social restriction (Oliver 1990). According to these studies, some people have the power to define the identity and the lives of others, and this disempowers, marginalises and creates dependency for people with disabilities (Barton 1993):

> To claim that disabled people are oppressed involves […] that […] can be regarded as a group whose members are in an inferior position to other members of society because they are disabled people. It is also to argue that these disadvantages are dialectically related to an ideology or group of ideologies which justify and perpetuate this situation. Beyond this it is to make the claim that such disadvantages and their supporting ideologies are neither natural nor inevitable. (Abberley 1987, 7)

This is an ideology that therefore mutilates people with disabilities and steals their humanity. According to Abberley (1987, 16), 'oppressive theories of disability systematically distort and stereotype the identity of their putative subjects, restricting their full humanity by constituting them only in their "problem" aspects'. Swartz and Watermeyer (2008, 187) and Goffman (1963) considered that at the heart of this discrimination against people with disabilities is the idea that they do not meet the necessary requirements to be considered fully human. In more general terms, Freire (1970) argued that the oppressed are dehumanised insofar as they are both reified and alienated, transformed into objects by the need of the oppressor to control them. The social model of disability emphasises something that has historically constituted a boundary: the humanity of people with disabilities, persistently denied by those who, from a position of privilege, define the identity and the lives of people with disabilities and radically separate them from their own. Obviously this oppression is neither natural nor inevitable, and the central element of educational analysis should be the unequal distribution of power with respect to ability (Slee 2011) in the case being discussed here.

From all this it follows that, if disability is actually the result of oppression, the main task of education is to accomplish the liberation of people with disabilities, their emancipation

(Calderón-Almendros and Ruiz-Román 2014). This is how individuals with disabilities and their families can be liberated from oppressive aspects of educational and social policy, according to Skrtic (1995).

Theories of resistance can be very useful in this endeavour, as we have postulated elsewhere (Calderón-Almendros and Ruiz-Román 2014; Calderón-Almendros 2011, 2014). According to Giroux (2001), the school has the power to transform a social problem into an individual problem. The discourse of 'resistance' rejects traditional explanations of failure at school and oppositional behaviour and redirects the focus of analysis: from the field of deviation to one of political and moral outrage; from psychology to politics and sociology. If we take into account that the social model of disability moves the emphasis away from the individual towards the context, from medicine towards sociology and politics, the connection is evident.

Gabel and Peters (2004) raised the possibility of building a praxis on disability based on theories of resistance, leveraging the knowledge thus produced. According to Susinos and Parrilla (2008), resistance theories recognise the ability that individuals have to resist dominant discourses. This is what Goodley and Runswick-Cole (2013) welcome as 'acts of resistance', which open a path for individuals to discover, analyse and question situations and recognises individual agency, paving the way for conducting research through their own voices. Where there is power, there is counter-power; resistance arises in the face of domination (Castells 2009). These – often informal – forms of counter-power decry the imbalance from which they emerge. This resistance involves understanding how conflict is eliminated and subordinate groups are silenced through the power relationships established during the educational processes. Therefore, bringing out the voices of the oppressed students and their families requires developing a policy of hope and possibility, while returning the conflict to the educational arena. These studies consider students as having individual agency, which is expressed through specific forms of resilience and resistance, thereby transforming the stigmatising social identity (Peters 2006). That is, people with disabilities and their families generate counter-discourses that can challenge the current order of things.

## 3. Methodology

The choice of a single case study as a methodology (Stake 1995) was made because in the study of the individual, social and cultural structures are present, filtered and reconstructed by the subject (Calderón-Almendros 2011). Not only is the subject of the case study analysed, but a broader social and cultural issue is also studied, which is 'metabolised' by subjects through their experience.

The study of the construction of identity of Rafael (co-author of this article) – the first person with Down's syndrome to complete a professional degree in music in Spain – renders its purpose unrepeatable. The circumstances involved in the process (with the researcher being one of Rafael's brothers) reaffirm its uniqueness and ensures that the analysis is conducted from within.

Two major processes were involved: on the one hand, beyond problematising the discourses around it, the study entailed unlearning one's own privileges, as noted by postcolonial critics such as Spivak (2006), in order to find the voice of the subaltern; on the other, additional efforts had to be made to ensure the credibility and validity of the study, based on the coherence of the argument (through the triangulation of informants, researchers and data collection methods), consensus and the instrumental usefulness of the study (Eisner 1991). This is why highly varied and numerous methodological strategies were used for data collection, combined with a great diversity of informants, as can be seen in the following:

- *Interviews.* Eight interviews conducted with Rafael (four of them by interviewers other than the main researcher); eight with his seven brothers and sisters (except for the researcher) together with their partners; two with his parents and two with four nephews; nine with Rafael's teachers at different stages of his education and at institutions in which he has studied; three with four of Rafael's friends, some with and some without disabilities; three with key informants in the neighbourhood; three with four parents of people with Down's syndrome; one with the Ombudsman; and eight interviews with eight Lecturers in Education at the University of Málaga who know Rafael.
- *Observations.* Nine recordings of Rafael's classes; two recordings of talks/concerts given by Rafael in different institutions; four concert recordings; recordings of references made to Rafael in different speeches delivered by the main politicians in the region, as well as in public official documents; and study of the most influential blogs in Spanish about people with Down's syndrome through the main social networks.
- *Group techniques.* Two focus groups conducted as established by Krueger (1994), with accompanying photographs to promote discussion (one was conducted with Rafael, his parents, brothers and sisters, and brothers-in-law and sisters-in-law; the other with a group of six students in their final year of teacher training); two group discussions in the form of 'Socratic Group' sessions (McKernan 2006, 170); and later assembly meetings of approximately 60 students who had recently graduated from secondary school.
- *Documents collected for the study.* Nine personal documents, 19 press publications and radio broadcasts about Rafael, 28 official letters, nine certificates and official reports, 16 academic reports and 40 photographs selected by the family of key moments in Rafael's life.

Each technique was chosen for its suitability in addressing the different informants, who were in turn selected by the information that they could offer about the family, the neighbourhood and the school contexts, and also about the political, educational, social and cultural context where Rafael lives. In total, there were 180 records, in which 190 respondents participated on 240 occasions, and their contributions were collected together in 1300 pages of text. The fieldwork took 14 months to complete.

In particular, the triangulation of researchers provided a much-needed counterbalance to ensure that a rigorous analysis was made of a situation which required a high level of personal involvement. The research was recognised with the Disability and Human Rights 2013–14 Award by the Spanish Committee of Representatives of People with Disabilities (which encompasses 3.8 million people with disabilities and more than 7000 associations). The full study has been published in Calderón-Almendros and Habegger (forthcoming) and Calderón-Almendros (2014).

All research has been conscientiously negotiated with each informant, and the general approach to the study was also thoroughly discussed with Rafael and his family during a focus group. The research dispenses with anonymity, following the wishes of the people involved. This is used as a mechanism to counter the invisibility of persons with disabilities and as a form of empowerment. The analysis produced two reports: an academic report, for which the computer software NVivo 9 was used; and an audio-visual report, a research tool which has enormous potential but is sadly absent in academic institutions (Eisner 1991). In our case this took the form of an ethnographic documentary (Calderón-Almendros and Sintes 2012), which was a key element in negotiating the report because it made the results accessible to people with cognitive disabilities or with reading/writing difficulties. All participating groups made criticisms and suggestions and endorsed some of the reports, and this served to strengthen the democratic value of the research.

## 4. Discussion of the results

### *4.1. The objectification of people*

The socialisation of people with disabilities is usually marked by beliefs, prejudices and expectations which are extremely difficult to distance oneself from. These social representations are embodied in the labels and stereotypes that limit the freedom of the individual. This happens, among other reasons, because it operates through a process of reification: when people with disabilities are named, catalogued and labelled, they are converted into objects. This process manifests itself in language and therefore in the structure of thought (Vygotsky 2012). Discourse is also a major instrument of power and control (Caldas-Coulthard and Coulthard 1996) which drastically limits freedom, as it is imposed on the subject. Therefore, taking into account its cognitive and social function, discourse plays a clearly ideological role (Fairclough and Wodak 1997; Van Dijk 1998).

One of the main features of social discourse and the ideology that surrounds the disabled person (in our case, Rafael) is a lack of confidence in the individual's potential abilities. Those around the individual tend to think he will not be able to do things, and so his chances of succeeding are greatly diminished:

> They think that the kid won't get any further … (Ángel, Rafael's brother, family focus group)
>
> Sure, and the fact that he has a disability puts you back slightly, to the extent of saying that he will not achieve the same as the rest of his schoolmates. (Daniel, primary school extra-curricular support teacher, individual interview)

This occurs because in this context there is a belief that, in the best case scenario, the individual with a disability is a subject who has something missing, who is incomplete. Thus, it is not rare to find statements in which the alleged deficiencies prevail, in which the actual person is replaced by these alleged deficiencies:

> I thought those with the syndrome had a disease. (Rafael, family focus group)
>
> José Luis: Yes, because for other people they never …
> Silveria: Never grow.
> José Luis: Never grow. (Rafael's brother-in-law and sister, group interview)

In this way he is perceived as infantilised and becomes, firstly, someone with a medical condition; and, secondly, a person. The lack of confidence in his potential turns into a label, and the label replaces the person. The expression 'he *is* Down's syndrome' appears repeatedly in the data and was very markedly stated by the family and by Raphael himself. Thus, Down's syndrome ends up replacing the person, and to a large extent is taken on by people with disabilities and by those nearest to them: 'he *is* blind', 'he *is* Down's syndrome', 'he *is* autistic', 'he *is* deaf', and so forth. All of these expressions in which the person is replaced by a label are very commonly used. The label covers the person, who is reified by the label. In this process, the person becomes an object, a thing, rather than a subject. In this way the context relates to the person by ignoring his personal abilities. Thus the wishes of the person with disabilities are overridden by the will of those who are with him:

> That is very difficult, because it is hard for me not to have complexes. Imagine they look at you every time they are going to serve you a coffee for example, and then instead of asking him, they ask you: What is he having? (Researcher, Rafael's brother, during an interview)

In this process, the objectifying person deprives the disabled person of his humanity. The 'wall' does not allow anything to be seen beyond appearance, thereby eliminating the inner person. Despite the fact that this is often not intentional, the truth is that a strong process of domination occurs – the speaker eliminates the ability for the other to be a subject:

> But in the end we are not within the subject, we are not inside of him, that's the big mistake. (José Luis, Rafael's brother-in-law, group interview)

The problem is not so much the inability to put ourselves in another's place, but rather to think of them as if there was no inner person, or perhaps a depleted interior: eternally innocent like children, incapable of taking responsibility for their actions, happy regardless of their circumstances, invariably good, and so forth. That is, fixed and determined; while indeterminacy is one of the main characteristics of human beings. Therefore, the individual is denied freedom, and his humanity is therefore rejected:

> A lady took her baby and it weighed less than mine, mine weighed 5 kg. or 4 kg. and a bit, and hers weighed less, and I said to the nurse …: 'Why … does her child weigh less than mine but with my child you can't tell? Why isn't it more noticeable?' She said: 'Because these children are called rag children. They are called rag dolls'. (Rafael's mother, group interview)

The metaphor could hardly be more expressive: children with Down's syndrome are as inert as a 'doll'; they are 'made of rag'. The term 'rag' ('*trapo*') is defined in the Dictionary of the Spanish Royal Academy (Real Academia Española 2014) as 'a discarded piece of cloth'. Whereas the term 'doll' ('*muñeco*') has the following meanings in Spanish: (1) no human being figure, (3) person of little character, (4) human cadaver. That is, 'rag dolls' look like children but they are not; they have little personality or are simply extinct as people, lifeless. They are made from waste, refuse, debris, slush.

The evidence provided shows how a professional reaffirmed prejudice. The child's mother asks why her baby seems to weigh less than the others, and the answer is 'because babies like hers are called rag dolls'. It is obvious that there is no explanation at all in that response. Probably because the nurse did not know the answer, she objectified Rafael, and dismantled the question of a mother at a time of great vulnerability (who then stopped asking), while stripping Rafael of life and abilities.

On many occasions professionals use this form of concealment of one part of reality in dealing with people with disabilities and their families. Their professional status allows them to create and impose a hegemonic interpretation of the situation of people with Down's syndrome:

> He was a doctor … And he was with another doctor. I had an interview with them … and they said, 'This child …' 'I see him just like all the others, just another child.' They said: 'Well, no, he is not just like any other child, this is a Down's syndrome child …' 'What did they say to me? That all of the parts of his body were different, that he was a completely different child.' I said: 'I do not see him in this way.' Boy, was I sad that they were saying that to me. When I left I was in tears … (Rafael's mother, group interview)

The paediatrician probably told her that every cell of his body had trisomy in the 21st pair, that 'all of the parts of his body were different', and that therefore 'he is not just like any other child'. The information was given to a person in a situation of extreme vulnerability and with little formal education, and therefore the message was unequivocal: he is completely different. Then the doctor went on to clarify that he was not just like any other child. That he was a completely different child. With these simple words, healthcare professionals began the process of Rafael's exclusion in his first days of life: he is 'totally different' (biologically), 'he is not just like any other child' (socially), he is a 'rag doll' (from a human point of view).

How could one feel like a subject when he is being treated by the environment as an object? How can the subject build his identity when he is not recognised as being a legitimate other? How can he achieve something when those around him manipulate reality according to personal interests contrary to his?

### *4.2. Resistance and educational action*

We will not go into great detail here about the collective processes generated to resist the various different processes of stigmatisation and objectification that besieged, and continue to besiege, Rafael. But there is a particularly representative aspect of how in his childhood Rafael began to interpret the oppression in the environment, which he had to address:

> Interviewer: When did you decide to become a musician?
>
> Rafael: When I was 9 or 10 years old, and when I saw the band members pass with their instruments … They were going with the band … [Rafael delays his response due to stuttering].
>
> Interviewer: Oh, sure, so you saw them pass by and you were jealous. And you said, I want to. I want to be in the band too, right?
>
> Rafael: No. No.
>
> Interviewer: Didn't you?
>
> Rafael: No, I'll tell you what I thought: Why not me? (Rafael Calderon, interview on Spanish National Radio (RNE), 15 September 2011)

Rafael explicitly said twice that saying 'me too' is not the same as saying 'Why not me?' He already sensed that he was denied this possibility, and generated his own resistance. His resistance was accompanied by his family, described by a teacher in the following terms:

> A modest family … And I want to highlight …, in general, they are a family of fighters … The neighbourhood … working class, a modest family, nine brothers and sisters … many of them went on to study, and they have been able to help Rafael, who is the youngest one. (Jose Antonio, Rafael's trumpet teacher, individual interview)

This section will be devoted to outlining some of the ways in which both the family – with their unconditional support in the struggle for equality – and the educational environment brought humanity back into the processes that conditioned Rafael.

(1) Extensive work has been done by the family, especially by Rafael's mother, which has served to reconceptualise his disability. This involves removing the generalisations through continuous and informal contextualisation of the usual concepts in the family's life; by eliminating prejudice through knowledge. By recognising the legitimacy of Rafael as a subject, new concepts are developed in his immediate environment. The clash between what the family is able to see and what society says Rafael is suggests a fundamental issue – that intelligence depends on the context:

> Antonia [a neighbour from Rafael's childhood] came and told me in a really mean way: 'Hey, they say your child is mongoloid. Is he or isn't he?' I said: 'Well, if you say so and people say so, then he must be.' She said, 'Well, is he or is he not mongoloid?' I said: 'To me he isn't, to me he

> is my child, but now I don't know … what people say or what you say … I guess it's quite right, what do you want me to say?' (Rafael's mother, family focus group)

The evidence is extraordinary, and illustrates perfectly Runswick-Cole and Goodley's (2012) necessary questioning of 'normative development': 'if you say so and people say it, then he must be'. Therefore, if you do not call him that, he must not be. Everything depends on what people say around him: the stigma, what Rafael calls 'the Down's'. This intuitive attitude is often what professionals want to eliminate, because it involves a denial of reality. However, what is not accepted is not so much the biological reality, but the social reality, the stigma. This is not accepted because everyone knows what this stigma means, because we have all been oppressors and have participated in it, we have all stigmatised others. Professionals (educationalists, teachers, psychologists, doctors) settle on the stigma, make it neutral and export it: we must accept reality. And the only reality is what the expert knows. Anything other than that, therefore, is pathological. In these terms, Rafael's mother is blinded (and therefore disabled) or affected psychologically (and thus requires psychological or psychiatric treatment). This is why the mother invites her neighbour to change. The logic of her statements is certainly not only an act of resistance to hegemony, but a strong argument against it. A mother does not give birth to a medical condition or a thing, but to a baby: 'To me he isn't [mongoloid], to me he is my child.' Professionals tend to counteract such a way of thinking and the behaviour that it entails, as it would enter into conflict with and destabilise the norm. However, the strength of the mother's thoughts initially causes some attitudes to be developed in other agents, as well as in Rafael. These attitudes often generate new schemas, which are positioned against the most widespread conception of people with disabilities, as a response to the aggression that the negation of humanity involves.

(2) A process of resistance was developed in the struggle for the recognition of educational rights. This was carried out through an action research study launched in 1998 and promoted by the main author of this article (Rafael's brother) within the family context. The action research started with the intention of accompanying Rafael in his school learning and was expanded in successive stages to build bridges with the school, prevent discrimination and exclusion, and 'rescue the humanising and educational function of the school, based on human dignity and respect for diversity' (Calderón-Almendros and Habegger forthcoming). The re-conceptualisation processes are one of these forms of struggle; they are complex and very precise. Let us now return to the period of 2001–2003, when a conflict took place with the school at the end of Rafael's compulsory schooling. It was the time when the school tried to segregate Rafael to a special-purposes centre. The family responded in three main ways:

(a) A petition was collected in the neighbourhood to support Rafael's right to continue to attend the same school, which helped to hold civil society responsible for the inclusion of each of its members.

(b) The family resisted the segregating diagnosis by obtaining an inclusive one to counteract it. This struggle for rights (widely described in Calderón-Almendros and Habegger, forthcoming) generated a series of counter-discourses that referred the analysis to the field of relationships, ethics and politics.

(c) For example, the designing, planning and writing of a psycho-pedagogical counter-report was key in challenging the one which had been compiled by the school, which sought to exclude him. This counter-report was drafted by a larger number of professionals; was based on more scientifically sound principles; had an ideological commitment to socio-constructivism and the social model of disability; and was fully supported by Rafael and the family. Disability was deconstructed in this way, by dismantling the faulty reasoning of the diagnosis (Danforth and Rhodes 1997). Throughout the process, Rafael was gradually empowered, as shown in a headline from a leading newspaper in Spain: 'If someone tells me that I cannot do something, this encourages me to do it' (Rafael Calderon, *El País*, 25 October 2010).

(d) Red lines were drawn that forced inclusive education provision. The main one involved not allowing the development of an individualised curriculum educational programme, the purpose being to demand that changes be made to the class group. It also entailed agreeing on some daily tasks with teachers to ensure Rafael's participation in joint academic activities.

(e) Written complaints were sent which were cross-addressed to the various agents involved in the excluding processes, and also to the press. This resulted in a bureaucratic struggle that made the concealed problems visible and the personal problems public, and also generated conflict between different public authorities.

(3) Other inclusive educational processes. As well as those activities carried out by the family in resisting the social conception of disability, other educational processes occurred which grounded the construction of Rafael's identity. The most remarkable ones were the activities of the local band, which succeeded in catering for his needs thanks to its various features of inclusiveness.

### 4.3. Identity construction as creative interpretation

It was within this harsh reality that Rafael had to build his own identity. It is easy to simply think that he has been successful in his career. Against all odds, he finished his secondary education, the Baccalaureate and the 10 levels that comprise the elementary and the professional music degree. For this he received the Gold Medal of Merit in Education in Andalusia, Spain (2010) and the World Down Syndrome Day Award (2012). This was all achieved without making use of significant individual curricular changes – and possibly also as a result of not having used them.

These achievements, as well as their social impact, are an example of the capacity for transformation that Rafael's experience had, and has, in today's society. In any case, despite the personal and social significance of these accomplishments, they mean nothing in themselves. They can only be understood as progress to the extent that Rafael managed them consciously and through his own free will; and to the extent that they have served him to build and realise his dreams. That is, insofar as they contribute to the construction of an identity that expands his ideal and material horizon and serves as a driver to improve his context. Also, to the extent that he continually opens up to new hope.

#### 4.3.1. Returning to the person

> At one point, Rafael says bluntly: 'The Down's is a nickname. I put it on one side, and then, I am me.' He impressed me. He was describing labelling theories in plain language, and how he has managed to survive despite the label. It has been a vital strategy that has allowed him to get to where he is … 'The Down's is another. I am Rafael.' (Researcher's journal)

In generalisation lies reification, stereotyping, stigma, prejudice. The loss of one's humanity. For this reason, in the discourses recorded in this study there is a persistent tendency to emphasise humanity and reclaim the person. Rafael and his family resist this reality continually by expressly stating his – often ignored – equal status. The word 'person' appears on 660 pages of the 1300 pages of data. This emphasis on his nature is an unconscious mechanism that constitutes a counter-discourse and helps him to contest the imposed reification; a requirement to be different. Only when a person is perceived as such can they begin to differentiate themselves from the rest and from themselves, as their educability is then recognised:

> I felt the same as everyone else. Part of the group. With what I have, which is Down's syndrome, which I have put to one side, because that is a label for me. Put aside. And I am another person. Another person. Same as everyone else. Part of the group. (Rafael, documentary interview; Calderón-Almendros and Sintes 2012)

> … [On] the one hand, Down's syndrome … I leave it aside as if it was a nickname. But I am just another person, just like all of you. That's what I feel. And with what I just said, I graduated from secondary school. (Rafael, concert/talk at the university, 2011)

Rafael has used this tool so as not to let prejudice and stereotyping dominate his daily life: by setting aside Down's syndrome 'I graduated from secondary school.' If he had not set this aside, he thinks (and 'feels') he would not have been able to do it, and reality confirms this; people with Down's syndrome do not usually finish their secondary education. He therefore used a strategy (putting the stigma to one side to interpret himself without it) which has certainly been useful, and which was not created by the family or professionals, but by himself. It would have been impossible to overcome the interpretation each and every one of the people around him has without such strategies, which helped him to block out a mistaken culture. But for this to take place socialisation itself needed to be questioned, because it is the individual himself who interprets the dominant culture as being wrong. However, professionals were entrusted with the role of making him part of a generalisation. They acted as guardians of normality, and tried to redirect him towards an unequivocal meaning of what it means to have Down's syndrome. What he says was seen to be obscene, and was turned into a pathology of sorts: he has to be considered to be sick, thus returning the analysis to the medical and biological field. An analysis which, as we have argued, is not neutral, as Down's syndrome does not exist in absolute terms, and entails the need for the individual to be conceived as inferior and non-human.

This is therefore a formula which, for those willing to listen to him and recognise his ability and dignity – as a person, and not for what he has done or for his attributes – is full of meaning. This is an interpretation of disability in social terms, a clear example of the social model of disability taken to its ultimate consequences, but without being aware of the theory of this model. It is an autonomous construction by Rafael, an interpretation that stops the social conception of disability from limiting his growth potential because the functional limitation (impairment) is also generated by social restrictions (disability) (Calderón-Almendros 2014; Runswick-Cole and Goodley 2012). Rafael learned to read and finished secondary schooling, against the rigid and immobile perspectives that determine people's fate. He managed to challenge and overcome the stigma. He reclaimed his status as a person, and this enabled him to grow and continue to improve as a project, beyond the set limits.

#### *4.3.2. 'I open the coffin, and here I am': resilience*

For Cyrulnik (2002, 23), resilience equals resistance to suffering; the ability to resist the bruising of psychological injury as a repairing force arising from this resistance. He makes a connection between life and death. Resilience for him is 'the escape from the basement', or 'the abandonment of the tomb'; the return to life after having been dead to humanity; after having been 'expelled from humanity', which involves having to re-learn how to live a different life. Quoting this author, one of the study's informants highlights this idea:

> It is as if we rescued Down's syndrome from the dead, as authors like Boris Cyrulnik say, from the dead … to return it to the world of the living. It's like taking that which is rotten from the stereotype of Down's syndrome, to dignify it and retain Rafa as a person. (Francisco, university professor, individual interview)

This idea could be very illustrative, as well as the metaphor used in it, because it coincides exactly with one of the two great metaphors that Rafael uses about oppression and his process of liberation:

> Someone hurt me [the teachers were against me]. Ok, I am injured, I have blood flowing all over my body, but the Lord pushed me forward. He said, 'You can do it. I have given you an ability, a gift that is music, fight against the school.' Ok, so the coffin that I was in – ok, it was only in my mind it wasn't real – I opened the coffin and I here am (Rafael, individual interview)

This willingness to fight enabled him to get out of the 'dead people's coffin' in order to return to the land of the living. A fight in which he was accompanied by his family and committed professionals, and which enabled the start of a process of liberation, a metamorphosis of his conception of himself and the context he inhabited. As we have seen, the stigma chased and will continue to chase Rafael, but his dreams and his faith allow him to take distance from it ('in my mind, it is not real'), to live without the continued weight of the gravestone, beyond the darkness.

His life experience cannot only be limited to trying to avoid conflict and suffering. This is a risk to be taken by people with disabilities in order to face their oppression and build resilience (Runswick-Cole and Goodley 2012). Avoidance means returning to the coffin, to death, to his objectification. The new interpretation that arises from the experience of suffering is the liberation process, the project and the projection, since successfully finishing secondary schooling was not enough. Then came the Baccalaureate and the Conservatory, the world of employment … and the minds of all who pass through his daily life, marked by prejudice. The stigma haunts people with disabilities throughout their life and in the majority of scenarios. It was necessary for him to have the interpretation that he was oppressed in order to leave the 'coffin', see the 'blood flowing all over his body' and to feel 'injured', in order to reconfigure the mind so that he did not just survive, but managed to live. The previous Rafael had to die, to find 'the light'; to survive and turn it into something positive:

> Diego: … of course he suffered. And the suffering or the capacity for endurance, what does it mean? That you fend it off as if you were made of stone and …? No …
> Alicia: Actually when he got out of the coffin it is that, right?
> Researcher: Sure.
> Alicia: Sure.
> Researcher: When he rose from the coffin and left the coffin …
> Alicia: The dead do not rise every day … And he was resurrected … (Rafael's brother-in-law and sister, group interview)

Being resurrected is not the same as only surviving. Resurrecting implies having been dead and having come back from the dead. Jorge Semprún talks about his experience in Nazi concentration camps as a 'death experience' because 'it is not something that we have been liberated from, as an accident from which came out unscathed. We've lived it … We are not survivors, we are ghosts …' (Semprún 1995, 104). Both somehow died because they stopped being (seen as) human. In that representation of reality in which Rafael imagined himself as being in a coffin, he died but not completely. When he saw the blood and felt injured – the suffering – he understood that the problem was not within him, but outside. One part died, which he discarded. The part created by others became an object, and with this act he re-released his individual agency. The part that died was the part that was not him; the part that did not let him be himself. It was a rebellion against objectification.

The metaphor finishes with him coming out of the coffin: 'and here I am'. It is actually a death that gives birth to the person, an attitude that allowed him to be born into the life he desired. His new life unfolds thanks to learning, when he moved away from all that is determined and conditioned by death. Suffering is an integral part of that life, and in the process of suffering he moves away from the inhuman condition. He already tasted his death to humanity when he was not recognised as someone with the capacity to learn, to grow, or to suffer. Learning, suffering and participating became time gained, instead of time lost: time for life.

He acknowledged that he had not had an easy ride:

> 'Problems? Of course I had problems, especially at first, because it wasn't easy, but just like any other music student,' he said. (Rafael Calderón, *La Opinión de Málaga*, 7 July 2010)

This is why he so strongly affirms his desire to learn 'even though I get tired, whatever the cost' (Rafael as quoted in Calderón-Almendros 2002, 32). This is the reason that continually invites action, forming what he calls 'the way of surprise'. Action breaks determinism and defies death; it brings life. A life based on music and confidence to protect himself. So this is not death, but an interpretative change for him to construct a life that caters to his needs and desires, with their complexity, fluctuations and difficulties:

> My body was empty, not wanting to study or anything, but as life goes on … and life goes on, well, I want to live a life. So I continue. (Rafael, documentary interview; Calderón-Almendros and Sintes 2012)

Therefore, he has chosen to live, not just any life but 'a life'. This change is an affirmation of his life, a project that is worth suffering for, as the lip callus that he proudly shows from playing the trumpet. Suffering is an integral part of anyone's life, and of the autonomous project he generated – the project for a life worth living:

> [B]ecause he likes it, because he puts in hours on end, and another guy might be doing something else or might be in a bar, or somewhere else … He has a genuine zeal to play. (Rafael Postigo, Rafael's neighbour, interview)

Thus, in some way, suffering ceases to be suffering when it finds meaning (Frankl 2006):

> Music is my life. Without it, everything would be duller. It wouldn't be such a happy life. Music supports me and I support it and I feel very comfortable with the trumpet in my hand. In the Miraflores band I am just like everyone else. There are no distinctions between the musicians who have Down's syndrome and those who do not have it. (Rafael Calderón, *La Opinión de Málaga*, 7 July 2010)

## 5. Discussion

Rafael's academic achievements suggest a resilient process that has been shaped by the subject, the possibilities offered by the environment, and the various contexts, as well as by the educational relationships generated between them (Ramognini 2008; Ungar 2015).

Resilience is often considered to be the same as adaptive capacity; however, this is not what we have discussed here, or what Rafael has done with his life. Following Runswick-Cole and Goodley (2012), our understanding is that this interpretation is based on the same normality that excludes people with disabilities: maintaining what is understood as normal and abnormal, and the (hegemonic) social and life mapping of people with Down's syndrome. The process discussed in these pages has been exactly the opposite: a human transformation of the context, rather than an adaptation process. A questioning of socialisation, rather than a mere adaptation to its rulings. A process in which the individual transforms reality and is then transformed by it. What is necessary is not only a change in the individual, but a change in our patterns of interpretation of reality.

This capacity to transcend social conditions has fundamental implications for the processes of identity construction. As human beings, we have the capacity to decipher the codes of the contexts in which we live, while building ways of projecting ourselves relatively autonomously from our interpretation of reality (Calderón-Almendros and Ruiz-Román 2015). However, this is very unlikely to happen if there is no assertive mediation within the context. That is, the individual is conditioned by the environment, and there are collective identities which facilitate personal emancipation. Castells (1997) calls them 'project identities' and they are produced by social actors 'that redefine their position in society and, by so doing, seek the transformation of overall social structure'. This collective identity is in keeping with what we have called 'individual interpretation identity' (Calderón-Almendros and Ruiz-Román 2015), as it represents an elaborate form of promotion: people strive to place themselves with regard to the socialising power of the cultural communities by understanding the conflictive situation.

This is precisely what has been analysed in these pages: a family and other social and educational agents generated a platform of meanings to contest some of the main excluding processes created by school and social cultures. The weaving of cultures based on affection (as opposed to rationalism), knowledge (as opposed to the rationalist prejudice of generalisation) and the recognition of legitimacy (compared with the previous subordination) means that the disabled person can think of himself in a way that is different from the hegemonic. This collective resistance takes the silenced conflict back to the institutions (e.g. in the struggle for the recognition of educational rights), questions structural barriers, and also emerges in the personal arena, allowing the individual's cognitive conflicts to be resolved through impertinent questions: 'Why not me?' Therefore, collective identities and counter-cultures represent a springboard for the transformation of personal situations, especially when they are so conditioned by the environment as in the case of disability. All this leads us to conclude that people can transcend, and in fact do transcend, the structural frameworks within which they are located, although these substantially determine their identities. This allows the reconstruction of life and social maps, because reality is not already made, but is constructed by us. As shown in the present case, impairment is also influenced by disability. This relationship is particularly strong in the field of cognitive impairment, where educability is denied, and along with it the option to develop intelligence outside of the mould.

In the case under discussion here, the structure so strongly conditions people that they may even feel dead. Only in the process of feeling accompanied and legitimised can oppression be questioned and transformed. It is not a heroic act. It is not a tragedy either. It is a complex process of resistance in the most profoundly educational sense. Because if the stigma ('the Down's') kills, it is necessary to become empowered against it. In that empowerment above the stigma, by being accompanied and knowing that the enemy is a barrier located outside the body, Rafael's fight was not against himself, as claimed by the school and professionals, but against those who tried to take away his freedom to the point of killing him and reducing him to a thing. There is certainly hope in those educational processes that break moulds and challenge the hegemonic interpretations of reality:

> It was as if the Down's was a murderer at that time. What did the Down's do? It made me feel alone, it discouraged me, made me miserable. The Down's was different [when I was] with them. When I was with them it was as if I didn't have Down's. There I became a policeman, and got the Down's out of the way. And I (mentally) asked the others to support me. And I caught the Down's, left it in jail and I was free … By being accompanied, I was freer. (Rafael, individual interview)

The case presented is not intended to represent the world, but it serves as a mirror in which other people may be reflected. Educational support in personal construction, the commitment to the fight against stigma and resistance to inequality in schools today can challenge oppressive structures of disability, re-humanise institutions and transform their influence on impairment. And above all, it can help restore people's control over their lives.

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