

# Disability, stigma and suffering in schools. Emerging narratives for the right to inclusive education

## *Discapacidad, estigma y sufrimiento en las escuelas. Narrativas emergentes por el derecho a la educación inclusiva*

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### ABSTRACT

Based on the Social Model of Disability, this article seeks to highlight the processes of stigmatisation, discrimination and suffering that take place in schools, while also examining the processes of socialisation and education that students, families, professionals and activists encounter within the school setting. Furthermore, it addresses the absence of educational responses to diversity and the social and professional demands required from an inclusive perspective. To this end, narrative research is used to analyse the social and educational experiences of six individuals' life histories and thirteen life stories of students, families, professionals, and activists, categorised into three groups: the labelling process and its consequences; the response of students, families and professionals; and the effects

of discrimination on the person and his or her environment. The results show the challenges they face in finding the support necessary to engage in activism and empowerment processes with the goal of creating an inclusive educational environment that does not segregate students with disabilities in special education settings, but rather takes them into account in all pedagogical decision-making processes. The paper shows the need to place the voice of students and families at the very heart of the inclusive discourse; to recognise them as activists with the capacity to show, from their narrated experiences, the need to challenge the labelling process; and to play a leading role in research committed to educational and social change, thereby enabling new life maps while promoting a social movement for the right to education.

**Keywords:** inclusive education, special education, right to education, educational discrimination, disability discrimination, access to education

## RESUMEN

Partiendo del Modelo Social de la Discapacidad, este artículo pretende visibilizar los procesos de estigmatización, discriminación y sufrimiento que se producen en la escuela, así como revisar los procesos de socialización y educación que experimentan en la institución escolar estudiantes, familiares, profesionales y activistas. Al mismo tiempo, aborda la ausencia de respuestas educativas a la diversidad y a las demandas sociales y profesionales que requiere la misma desde una perspectiva inclusiva. Para ello presentamos seis historias de vida en profundidad y trece relatos autobiográficos de estudiantes, familias, profesionales y activistas desarrollados a través de una investigación narrativa en la que se analizan sus experiencias sociales y educativas, a partir de tres categorías: el proceso de etiquetaje y sus repercusiones, la respuesta de los estudiantes, sus familias y los profesionales, y las repercusiones de la discriminación sobre la persona y su entorno. Los resultados muestran sus luchas para encontrar apoyos que les permitan emprender procesos de activismo y empoderamiento dirigidos a conseguir una escuela que no segregue en centros o aulas específicas al alumnado nombrado por la discapacidad, y que les tenga en cuenta para la toma de decisiones pedagógicas. A modo de conclusión, se muestra la necesidad de poner en el epicentro del discurso de la inclusión la voz del alumnado y las familias; de reconocerlos como activistas con capacidad para mostrar, desde sus experiencias narradas, la necesidad de desafiar el proceso de etiquetado; y de protagonizar investigaciones comprometidas con el cambio educativo y social, que habilitan nuevas cartografías vitales e impulsan un movimiento social por el derecho a la educación.

**Palabras clave:** educación inclusiva, educación especial, derecho a la educación, discriminación educacional, discriminación por discapacidad, acceso a la educación

## INTRODUCTION

This article is based on the Social Model of Disability, which emphasises the need to challenge oppressive, dehumanising theories (Abberley, 1987). This *de facto* denial of the humanity of disabled people constrains their lives and those of their families, often leading to them normalising inequalities under the guise of structural functionalism and the biologist interpretations associated with it, as is persistently evident in the school setting. We therefore consider, in line with the ideas put forward by Barton (1998), that examining disability solely within the context of inclusion processes is inadequate; rather, it must also be examined in relation to other forms of oppression that intersect in schools.

Multiple studies on the effects of confinement have shown the importance of presence in the challenge of reducing inequalities (Bonal & González, 2021; Calderón & Rascón, 2022). The right to education is contingent not only on being physically present with others, but also on being treated as simply another member of the class. Moreover, the participation of families is crucial for the development of the right to education, meaning any barriers to family involvement also hinder the exercise of this right. It is therefore necessary to recognise the right of all people to learn, participate and progress, always involving their immediate environment in this process. This implies understanding that we learn thanks to *the other*, as different from me, and that differences (rather than homogeneity) are in fact what define us. Here too, the scientific evidence is conclusive: it is not only positive for students who have been diagnosed and labelled as different, but also for everyone else who benefits equally (Hehir et al., 2016; Justice, Logan, Lin and Kaderavek, 2014).

However, today the right to inclusive education is being violated in Spain despite the ratification of the Convention on the Rights of Persons with Disabilities in 2006 (Calderón, 2018; Calderón, Moreno & Vila, 2022; Echeita, 2017; Echeita et al., 2009; CERMI, 2010; ONU, 2017; UNESCO, 2020; et al.). These are serious systematic violations: “A pattern of structural exclusion and segregation based on disability has been perpetuated through the medical model” (UN, 2017, p. 16). This pattern often involves the subject being unfairly categorised and stigmatised based on psycho-pedagogical reporting and labelling, which wrongly assigns personal and family blame for the segregation.

This situation clashes with international research, which shows the inconvenience of a special needs segregated pedagogy (Ainscow, Dyson & Weiner, 2013; Hehir et al., 2016) that focuses on the characteristics of learners from a normocentric view, something contrary to the construction of an inclusive school. In contrast, the Social

Model of Disability emphasises the humanity of people with disabilities, an aspect that this perspective overlooks, thereby exacerbating such separation, particularly within schools. We therefore believe that disability studies must necessarily be based on more generic sociological and pedagogical theories and practices, embedded in philosophies and pedagogies of differences (Skliar, 2007).

Part of the unresolved problem with inclusive education may have to do with the fact that research tends to focus on teachers' perspectives on inclusion. Indeed, such research may not be sufficiently inclusive if it leaves out the voices and perspectives of other groups in the educational community or if it is not committed to the transformation of reality, as set out by Parrilla (2009). Examples of inclusive research in this context include the study by Echeita et al. (2009), which draws on professionals from the associative network; López and Carmona (2018) and Calderón and Habegger (2017), which focuses on families and their views of their socioeducational inclusion; and studies by Moriña (2010), Calderón et al. (2021) and Messiou et al. (2022), which delve further into student perspectives. In line with this research, we understand inclusion as being a societal process involving shared responsibility among citizens, while families and students play crucial roles in terms of evaluating the educational and social system, precisely thanks to the value of their (occasionally distressing) experiences in promoting social and educational progress.

## METHOD

This study focuses on narrative research that aims to understand different experiences (Clandinin & Connelly, 2000) by generating life stories and life histories. The work is part of a research project in which one of the goals is to find and document narratives on disability and educational inclusion (some of them from individuals involved in promoting human rights), with a view to disseminating and recognising their value. It also aims to review the processes of socialisation and education experienced in schools by students, family members, professionals and activists. The study was carried out in Spain between 2018 and 2022, and is based on two hypotheses:

1. The activism of people with disabilities and their close environment together contribute to the formation of identities that promote educational inclusion and social change.
2. The narratives and knowledge that emanate from the Social Model of Disability allow us to question and improve the current school model.

In an attempt to challenge the power relations that dominate research practices, biographical research allows us to generate new narratives that we have divided into three large blocks:

1. *Narratives through participation* for the transformation of collective ideologies. These are the foundations that underpin all the work, and were developed collectively in two large participatory events based on the dialogue of three hundred and two hundred individuals, respectively.<sup>1</sup> The demands for the construction of biographical narratives and proposals for action, including political advocacy, have been generated on the basis of these commonalities.
2. *Narratives through biographical research* in order to collect stories of exclusion and the struggle for inclusive education. Six in-depth life stories and thirteen autobiographical accounts of students with disabilities, families, professionals and activists committed to inclusive education from different parts of Spain have been developed in this regard, forming the basis of this study.
3. *Action-orientated narratives*. These have led to proposals that take shape in new ways of addressing reality by taking part in and producing tutorials, guides and materials to foster inclusivity. In other words, the research does not merely describe reality, but rather encourages its transformation through the action of the participants.

According to Atkinson and Coffey (2003), biographical-narrative research is a methodology of dialogue in which narratives reflect life histories, and information is constructed between protagonists and researchers in a given social context. This makes narrative analysis a highly valuable tool for thinking beyond the data, providing “a critical way of examining not only key actors and events, but also social and cultural conventions and norms” (Atkinson & Coffey, 2003, p. 97).

The inclusion of plural stories makes it possible to connect the present, past and future of the protagonists’ life histories (White & Epston, 1993). In this regard, the use of stories as a research technique aims for individuals to personally narrate their experiences to others, building a narrative identity (following Ricoeur’s approach, as elaborated in Moreno & Vila, 2022) that is rooted in everyday life.

We have followed the proposals of Bolívar (2014) and Pujadas (2002) in referring to life story as the autobiographical narrative constructed by the individual, and life history as the researcher’s narrative that enriches the story with additional sources, interpretation, triangulation and contextualisation.

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<sup>1</sup> They are available at <https://bit.ly/3z6opfl> and <https://bit.ly/41jfC4t>.

The research process involved a range of different phases:

1. Phase one: A series of social media posts ask people to submit stories that meet a set of specified minimum requirements, namely:
  - Recount a personal school experience, whether as a student, family or professional.
  - Take part in training and research activities (interviews, reviews, focus groups, etc.).
  - Inclusive education activism experiences are particularly welcome.
  - Participants are advised that those experiences with most narrative potential will be selected in order to highlight diverse realities and profiles.

The request itself was already a form of negotiation, which would later be reworked and adapted to each participant. Finally, a total of twenty life stories were collected from students with disabilities, families, professionals and activists committed to inclusive education.

At the same time, a group of people with outstanding activist backgrounds were invited to the first large participatory event to build their in-depth life stories alongside the research team, based on a series of biographical interviews, documentary evidence, drafting of documents, interviews with other actors, etc.

2. Phase two: The stories are selected and distributed among the members of the research team for formal review. After carefully reading them, a total of thirteen stories were selected, considering both the variety of profiles (seven mothers of children labelled with disabilities, three students, a school counsellor and two women activists) and also the narrative value of the text in terms of depth and descriptive and analytical capacity. The texts were reworked through a collaborative process with the original authors, allowing them to delve into specific elements of interest and make any necessary modifications or additions until they felt a strong connection with their stories. At the same time, the six life stories were constructed and negotiated in depth with their protagonists. These stories were told by three mothers, two students and an educational counsellor.
3. Phase three: The narratives are revised and edited, and then subjected to a negotiation process to finalise them and determine their scientific and academic use.
4. Phase four: The life stories are delivered to the research group, to start the analysis process based on identifying emerging categories.

5. Phase five: The “historified” narrative report is drawn up, based on the confluences and arguments of the texts from the categories developed. This interpretive report was generated through an evolving categorisation of the narratives using NVivo 11 qualitative data processing software, consistently following the three primary categories outlined in this article, encompassing more than a hundred topics. These categories have been negotiated both with the protagonists of the life stories, and in the “Narratives through participation” and “Action-orientated narratives” processes.

The research has been extensive and thorough, both in terms of scope and transferability. The participation narratives have served as the pre-text, a “river of communities of meaning” (Cortina, 2021, p. 177) that allows these life stories and life histories to be interpreted. Action-orientated narratives, as per Bertaux (1981), are a suitable means of addressing the oppressions experienced by the protagonists, offering a hopeful projection based on biographical research.

## RESULTS

The main results of the analysis of the stories will be presented based on the aforementioned fundamental categories, following a systematic categorisation process from which the narrative report was generated, and the evidence extracted.

### The labelling process and its repercussions

We are all subject to social scrutiny from the moment we are born. Even then, families must deal with affirmations and value judgements, especially when their members fall outside of heteronormative canons. These judgements gradually become labels that serve to categorise people according to their differences, affecting the social expectations projected onto them.

Physicians, families, and protagonists consider diagnosis a highly valuable tool in this context, as it provides information after entering often unknown terrain. In the educational arena, diagnosis offers certainty in the face of uncertainty, i.e., a solution to fear of the unknown: How should I act from now on? What should I expect? How will this new situation impact me? These and other questions put the overall context in a position to respond to new challenges. Ignorance therefore brings the potential for informal research and reconstruction of ideologies surrounding human nature, differences, social relations, etc., often resulting in families going

through a stage of mourning. Such mourning implies the death of uncertainty and, with it, of personal freedom. This point marks the start of a process of acceptance or resistance, not of the person (as is often stated in psycho-pedagogical analysis), but rather of the social mandate to be assumed by the families (Calderón & Ruiz, 2015): accept whether it is possible or not to decide, achieve, test, fail, solve, create... This is the dispute that develops in these initial moments. It is therefore essential that disability be understood as a social construction (Abberley, 1987; Barton, 1998), rather than as a solely biological reality to be uncritically accepted or not, and the diagnostic process as an exercise of power that imposes a whole narrative that frames a life (Calderón, Moreno & Vila, 2022).

My son Alejandro is born in November 2007, and he “fails” the very first exam of his life. At that moment, we realised the social significance of the situation, although we were unaware of the challenges that lay ahead... (Life story of Isabel, mother).

Shame and guilt then emerge in this process, as it implies the acceptance of normality as the organiser of reality. Social imperative, supported by the medical model, transforms social aspects into biological ones, thereby inhibiting the ability to question what is normal.

The experience had a profound impact on me, as I witnessed the journey of a girl who had spent ten years at school, four of which were marred by the label of “mental retard” on her report card, while teachers’ expectations for her were zero. In fact, the teacher said to me: “This child (...) can’t move on because she’s not very bright”. The phrase was: “She’s not very bright”. The experience had a profound effect on me (Life history of María José, school counsellor).

Similar processes also occur in other contexts, which respond to the insecurity of uncertainty with attitudes that embrace rather than shy away from questioning the categorisation criterion. Categorising somebody as a person with a disability therefore becomes a distinction compared to the correct norm, which is unquestioned. In this context, the discriminatory attitude is essentially conforming to the socially accepted norm when dealing with someone who has been excluded from what is considered normal. These (sometimes unconscious) attitudes strongly affect the processes of identity construction. Prejudice, indifference, rejection or condescension affect the image that children touched by disability forge of themselves, conditioning their relationships with others and vice versa.

I went into the store... I wanted to see how much some boxes cost (...). We went to the checkout (...) to ask how much they were, but they refused to let us buy them (...). I was there saying, “Excuse me, I’m talking to you”... but nothing, they

completely ignored me. It was as if I wasn't there. They took no notice of me... I was burning up with anger inside (Life history of Corina, graduate student).

Most of the stories agree that starting school is one of the hardest and most exhausting moments. A stage of life full of emotions, experiences and new learning that should be lived with happiness, and which ends up being in an ordeal for those involved. Their schooling becomes an oppressive, discriminatory process lived with deep pain and a great sense of loneliness.

At primary school, some girls noticed the way I spoke and asked me if I was retarded. And I didn't know what to say... I didn't know what that word meant, nor was I aware that my way of speaking was any different. I felt uncomfortable and confused, unable to react (Life story of La Yonka, student).

Ignorance also leads to a lack of empathy and humanity. In other words, every time a person is dehumanised through objectification, humanity is lost. In this regard, the stories highlight how labelling processes (understood as forms of oppression) shape the formation of individuals' and their families' identities, subjecting them to stigmatisation and tragedy while leaving them susceptible to social and institutional subordination, such as in the school setting. Continued pressure leads them to conform to the societal expectations imposed by labelling (Calderón & Ruiz, 2015), although this conformity is not passive, but rather generates resistance. People always have agency.

Until one day I said: "Enough is enough". I didn't say it, but that's what I thought. I just sat there, staring at the sheet. I was angry, very angry. They would say: "Come on Indira, cut the paper... Indira, come on!" And I was sat there with my arms crossed, looking at my paper and thinking: "No! I'm not going to keep cutting and pasting pieces of paper! Because I don't want to, I don't like it at all! OK? I want to learn alongside the others, I have a right to learn" (Life history of Indira, student).

### **Response from students, families, professionals and activists: from resignation to resistance**

The way we perceive others and the way they perceive themselves is influenced by the expectations we have of them. These expectations are built, firstly, on previous experiences and insight from parenthood, and, secondly, on normative and culturally assumed mandates concerning the roles of individuals with disabilities and their families, as well as the boundaries within which they operate. Prejudices and difficulties in managing emotions can also have a significant impact on families.

Some of them stress how lack of knowledge leads to helplessness, whereas knowledge leads to frustration.

This led to a school placement report being issued, and when they called me in to sign it, I saw that there were things I didn't agree with. But, when I voiced my concerns, their response was: "The placement report is obligatory if we are to attend to your son. You must sign the 'I agree' part", otherwise we cannot do anything'. And so, despite not fully agreeing with everything, I signed it, believing it to be in his best interests (Life story of Isabel, mother).

These are everyday situations of discrimination, in which diagnostic categories are used to legitimise exclusion in the social and school environment, even using the double emotional and social coercion of going through the labelling process as the only way to access certain resources and care, without explicitly acknowledging the violation of the right to education that this implies. There is a discriminatory regulatory framework which provides the basis for opaque practices, as noted by international organisations (UN, 2017).

The response of parents is shaped by the wider family unit, which can be seen as either a burden or a catalyst, often against a backdrop of prejudice.

For many people, we were a disgrace, a misfortune. My father's family was engulfed in grief, unsure of how to interact with us; however, my mother's family embraced us warmly, treating us just like any other two girls (Life story of Mentxu Arrieta, activist).

Particularly noteworthy is the juncture at which families often find themselves: parents seek answers to the various situations their children experience, but encounter social rejection in nearly every domain, particularly in education, where one would expect to find appropriate responses to their diverse needs. As a result, many end up (at least initially) in an attitude of resignation, either allowing the days to pass by without knowing how to address their problems or succumbing to an unresponsive bureaucracy.

Without receiving any explanation regarding curricular adaptations or other options, we are advised that this is the best course of action for Lucía, and I foolishly sign everything without questioning it: curricular adaptations and [schooling in] the ASD classroom. (...) Lucia spends the whole day in the ASD classroom. Everything they had said about only being there for short periods was a lie (Life history of Belén, mother).

Many professionals often face a dilemma, having to choose between adhering to the demands of the education system or embracing what they believe to be a genuinely inclusive approach to education.

Changing your way of working requires a *passage through hell* of your own inertia and of not meeting the expectations and desires of others, which may result in a belief that your professional competence will diminish in the eyes of others (Life story of Raul, school counsellor).

Resignation to the social mandate is a conformist attitude towards what others perceive a person to be, discouraging action in favour of passivity. In contrast, accepting who a person really is relates closely to having goals, striving to build them and to transform reality to align it with both our own and others' needs. This concept of acceptance is intrinsic to the notion of resistance, as it aims to establish power niches within the prevailing social framework in order to bring about change. It is a response to adversity that is intrinsically related to the capacity to fight for the rights of children and their families wherever they are not recognised or fulfilled, and to the need to transform their own realities into spaces for empowerment, awareness and the search for solutions.

This led to a new fight with the school, setting me against the other parents, but I don't care, David has the right to receive the education he is entitled to. They can call me crazy if they want. Yes, I am crazy Joanna (Life story of Johana, mother).

Once disability is recognised as a social construct, the push for resistance becomes challenging for the educational administration and hinders corporatism within many school institutions, which sometimes overlook the fact that a school is a community made up of families, students, and educational professionals, and that the actions of the latter must consider the needs of the former. In the stories, we constantly find discriminatory attitudes and abuses of power that strip the person and his or her environment of value, rights and dignity. As a result, the most activist families are often labelled as crazy and hysterical in the school context.

They always said I couldn't do it, that I wasn't capable. That attitude was the biggest burden throughout this time, and their assessment was far from accurate. They even told my mother that I was hysterical, crazy, for trying to exercise my rights as a person, as a student, as a human being. They told her to leave it, that there was nothing else she could do. But both she and I have continued our struggle (Life story of Quim, student).

All these issues lead back to shame or guilt. This is another dimension linked to social consequences and the pressure on individuals and their families. In some cases, the need for social acceptance leads to changes in routines and has consequences on self-esteem.

Meanwhile, I was doing everything I could to integrate, but nothing was working. I changed the way I dressed and started to wear makeup, but it didn't work. Every

time I came across a new group of people, I just knew that I wouldn't fit in, and, regrettably, all my fears proved founded (...). I tried to talk as little as possible. I hated it when a teacher asked me a question in class, and I even wished I could avoid speaking altogether (Life story of La Yonka, student).

Shame is a feeling that arises from fear of social disapproval. Comparisons with others in society often evoke a negative emotion that undermines our self-esteem, leaving us feeling inferior and insecure. Shame serves as a mechanism to adapt to our environment, originating from circumstances that particularly impact us and deviate from the conventional, challenging the apparent normality that is hidden behind a socially constructed system founded on an oppressive relationship. In families touched by disability, the impossibility to adapt to an unequal reality, shame, fear of differences and a lack of empathy become aspects that turn relationships upside down.

Last year she said to me: Mum, it's like I'm a ghost. I go in and out without anyone or anything noticing. That's the way it is (Life story of Isabel, mother).

Unfortunately, Daniel got worse (...). As a mother, it is unimaginably frustrating to witness one son in a severe condition and another child crying and feeling hopeless due to the absence of their mother, while I am left to handle everything alone because their father, who is a good person, was unable to handle Daniel's situation and ultimately withdrew (Life story of María Jesús, mother).

In this regard, particularly worthy of note is how the assumption of responsibilities by paternal and maternal figures is unbalanced, with instances where the mother, surpassing societal expectations, takes on the leading role and the fight. As we will see below, there is an intersection between gender and disability, evincing the importance of drawing lessons from past struggles and the role of women in caregiving (another form of oppression, often causing them to leave their jobs) and the unquestioned acceptance of patriarchy by many parents.

### **Impact of discrimination on the individual and their environment**

Discrimination not only has detrimental consequences for the individual, but also affects their environment. Many families report the pain they have suffered in situations of injustice during their children's schooling due to the inability of some education professionals to adapt the teaching-learning process to their children's needs.

On the eve of the exam, Indira was worried and wanted to know if she could use her pens and if she was going to have graph paper. I don't fall apart easily, especially

not in front of Indira. But it brought tears to my eyes. Then she hugged me and said: "We are a team, and we are going to make it to the top". Literally that. Always giving lessons (Life story of Noemí, mother).

These families suffer a significant physical, emotional and economic toll. Many say they are forced to make great efforts to cover the educational support required for the cognitive, social and affective development of their children while receiving no assistance from the administration.

Caregiving is a major challenge for the families of people with disabilities. However, there appears to be evidence that women feel an obligation to assume greater responsibility for these tasks as part of their gender role. This is a function that is rarely made visible, yet places great physical and emotional strain on the primary caregiver.

As always, responsibility for making changes and teaching Indira has fallen on me. This is something that has remained constant across all the subjects (Life story of Noemí, mother).

Many of these mothers have had to give up their professional careers temporarily or permanently in order to take care of their children. They set aside their personal and work commitments to fully dedicate themselves to the responsibilities of caring for and supporting these children, while also advocating for their inclusion. These women and their families carry out tasks that should be undertaken by schools and education authorities, but which often remain unfulfilled due to a lack of motivation, resources or training among educational personnel, exacerbated by the pandemic.

They made me go to my daughter's class and accompany her because her teacher had to go to the doctor and was going to be off work. I recall another instance when my daughter's class visited a farm school, and I had to drive behind their bus, wait for an hour after their lunch break, and then go in to administer her insulin (Life story of Esmeralda, mother).

Caregiver mothers are a resource that many schools manage at will. When it comes to taking responsibility away from the school, family participation is welcomed. However, when their actions are aimed at bringing about transformations that affect the organisation, operation and culture of the school, they are considered an intrusion. It seems that anything that might upset the school routine is considered an affront. That is why many families of children with disabilities often complain about them being stigmatised and labelled as mentally ill, troublesome, or disruptive.

In my case I quit work (I am a psychologist and I had a steady job)... that was the decision my husband and I made, we thought it was the best way to take care of David's needs. For the school, I am the crazy mother, the troublemaker, the rab-

blerouser... because I defend my child's right to education (Life story of Johana, mother).

Despite the challenges women caregivers face in fulfilling responsibilities that should be taken on by the education system and shared by the rest of the family unit, many of these mothers demonstrate a highly resilient activist mindset. Driven by their desire to protect the rights, needs and interests of their children, they persist in their fight against the challenges they face, generating collective responses, given the difficulty of doing so on an individual level.

This guide aims to promote the act of dissenting and the need for dissent within schools. Everybody involved in drafting it has experience of dissent in this context. We are a group made up of families and professionals, and our dissent has come from the violation of the rights of our family members or of our students within the educational system. We intend this text to serve as a guide to dissent among the three sectors that make up schools: teachers, families and students ("How to Dissent" Guide, in press).

This dissent arises from a commitment to justice and to safeguarding children's happiness. Unlike what happens in many schools, they are willing to adapt their routines, relationships and environment in order to reach a specific goal: to offer an inclusive education that brings them learning and happiness.

Three moves (three!) to be next to my son's new school. A school where they listen to families, do not label them, and go the extra mile for students' well-being. A school where the active involvement of families plays a crucial role. Where inclusion is real (Life story of Belén, mother).

Discrimination generates physical, social and psychological consequences that affect and exclude, causing a situation of great vulnerability that can seriously impact a person's self-concept and self-esteem. Some of the stories illustrate how, for these children, feeling undervalued compared to their peers can evoke feelings of boredom and indifference, and in some cases, even lead to depression.

The voices of the individuals and their families reveal the existence of systemic suffering, which can be prevented (or, at the very least, mitigated) through empathy, solidarity and a willingness to change; indeed, our obligation to uphold human rights and international law means we are compelled to take action.

## DISCUSSION OF RESULTS

Social justice should always be at the very heart of educational theories and practices. Inclusive education is education from and for social justice. The lack

of justice in social and educational procedures is highlighted by the demands for inclusion made by the individuals studied and their families, starting from the birth of their children and continuing throughout their integration and presence in the educational system. The different stories always show how the process of labelling and segregation go together and feedback on each other. This conjugates perfectly with that shown in other research (Bonal & González, 2021; Calderón & Habegger, 2017; Calderón et al., 2021; Echeita, 2017; to mention just a few), but, in this case, the narratives bring meaning and depth to the processes as they are based on individuals and families who have experienced them –and continue to experience them– in their daily lives while also fighting against injustice. In this context, the ideas of Calderón and Ruiz (2015) take on full meaning when they assert that people need to find trusted figures in order for social coercion to lose its power and allow individuals and contexts to free themselves. The testimonies collected vindicate this (which we believe to be of great value), reinforcing how disability allows us to rethink ourselves, our relationships and our politics (Saur & Sidorkin, 2018).

Furthermore, it is also important to recognise the value of activism in this area (as in all areas related to the violation of basic rights), which is where processes of resistance and change regarding discriminatory practices are generated. Families move from resignation to resistance when they become empowered, when they “become conscious” (as Freire would say) and decide to confront the situations their children are experiencing. Meanwhile, the system delegates responsibilities to parents, including basic care during school hours, but fails to consider their input in pedagogical decisions regarding their children. This leads to feelings of helplessness and displacement in crucial aspects for students’ development, and even to institutional mistreatment, mainly in curricular and relational matters, as the results have shown.

In line with the findings of López and Carmona (2018), it can be concluded that the most pressing measure is to promote awareness and training within the whole educational community and society at large, emphasising the need to develop solutions that enhance existing inclusive processes. It is imperative that we do not view the educational experiences of individuals with disabilities as disposable, nor should we force their families to adopt a narrative of tragedy as their only recourse.

Furthermore, there is a recurring demand in the stories around the need to provide support for students within the general classroom setting, rather than in separate classrooms. This is presented here as something essential in order for families to exercise their right to education in a real sense, and also aligns with research findings (e.g. Ainscow, Dyson & Weiner, 2013; Hehir et al., 2016; Stainback & Stainback, 2007), without forgetting the benefits it brings to the whole group,

not only impacting their education in terms of values, but also enabling the use of different strategies and methods for all students thanks to the presence of another professional in the classroom. This would also allow pedagogy to play its role in creating educational spaces of resistance, focused on developing student engagement, the joy of learning, and the sense of solidarity and shared experiences (Meirieu, 2022).

The study presented here involved some ethical as well as logistical difficulties, partly due to working with people's hopes and desires, starting from a position of suffering. This has generated dilemmas, concerns and a significant workload that at times has been emotionally demanding and challenging to manage. The participants have taken ownership of the research, turning it little by little into an example of citizen science and an untapped social movement. The collaborative networks generated within the framework of the research have served to generate new shared narratives in significant national and international political forums: social and life maps that not only fuel indignation at the violation of the right to education but also generate transformation, along with freely accessible resources that have been made available to citizens in order to make schools more inclusive.<sup>2</sup>

This work vindicates their concerns and desires, placing the voice of students and families at the very heart of inclusive discourse, highlighting their sufferings, processes and struggles while also recognising not only their research work, but also their role as producers of knowledge and as activists with capacity to demonstrate, through their narrated experiences, the need to challenge the labelling process and show that another education and another society are necessary.

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<sup>2</sup> An overview of this research projection can be found at <https://creemoseducacioninclusiva.com/>

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