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What I think of school: perceptions of school by people with intellectual disabilities

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ABSTRACT

For people with intellectual disabilities who do not enter the labour market, school is usually the main chapter of their socialization with the wider society. Nevertheless, little is known about their long-term perceptions of this period. We conducted interviews and focus groups on the school experiences of 16 Portuguese adults with intellectual disabilities. Results show differences between older and younger participants in their accounts of social relations and educational methods, which result from changes in special educational policies in Portugal. Overall, members of both groups evaluate their school experience positively. Our results indicate that although there is a move towards more inclusive schools, discrimination is still prevalent. These results are discussed in terms of their psychosocial consequences, as well as their implications for educational policies, and inclusion. This study contributes to a better understanding of the school experiences of people with intellectual disabilities and how policies impact them.

Points of interest

- We study how adults with intellectual disability who are not included in paid employment see their school experiences. We conducted interviews and focus groups with 16 Portuguese people with intellectual disability.
- Our results show differences between a group of older and one of younger participants, resulting from changes in Portuguese educational policies.
- Teachers were central to the school experiences of the older group, while auxiliary staff members take this role among younger

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participants. Younger participants report more prevalent and outspoken discrimination than the older group.

- Concerning teachers' practices, older participants report being given the same tasks as students without disabilities, and being equally punished for misbehaving. Younger participants report having adapted tasks, whilst receiving certain benefits as a consequence of their disability.
- Both groups evaluate their school experience as positive overall, and seem to understand discrimination as a natural part of it.

For people with intellectual disabilities who are not included in the labour market, school is often the main chapter of socialization with their communities and wider society. Arguments for the participation of pupils with intellectual disabilities in mainstream schooling stress that it provides them with skills and knowledge that are important for their social inclusion and citizenship. Moreover, their participation is also aimed at providing pupils with psychosocial inclusion – namely through interactions with peers with no disabilities, prejudice reduction, and self-concept improvement – which are of major importance for their psychological well-being.

Nevertheless, research on the school experience of people with intellectual disabilities has shown that it is often far from a positive one (Pivik, McComas, and LaFlame 2002). However, and despite these difficulties, pupils with intellectual disabilities are optimistic about their own future (cf. Cooney et al. 2006). Although several studies focus on the school experiences while they are still in school (Cooney et al. 2006; Kelly and Norwich 2004; Martlew and Hodson 1991; Pivik, McComas, and LaFlame 2002), the long-term impacts of this period for those with intellectual disabilities who were not included in the labour market have been left unexplored. We believe it is important to understand how these people view their school experience in different dimensions, at a later stage of their lives, when their optimistic aspirations were proved wrong and they have not been included in the labour market, and to understand the psychosocial consequences of this. This is the main focus of this study.

Overall, this study thus contributes to a better understanding of how school and different approaches to inclusion are experienced by pupils with intellectual disabilities, by focusing on their long-term perceptions and in the specific context of Portugal.

Social discrimination and school

The experience of people with intellectual disabilities in society is often characterised by strong discrimination and stigma, as this is one of the most

stigmatised groups (Gordon et al. 2004; Miller et al. 2009; Siperstein et al. 2007), which is generally more socially excluded than other groups in society (Myers et al. 1998). When compared to other types of disability, the peers of those with intellectual disabilities have characterised them as the most undesirable for building friendships with (Gordon et al. 2004), the most unfavourably described (Omote 1986), and those regarded with the least positive attitudes (Nowicki and Sandieson 2002).

Previous research has shown that the experience of those with intellectual disabilities in school, as in other spheres of society, is strongly influenced by discrimination. Pupils with intellectual disabilities and other disabilities are more socially isolated than those without disabilities (de Monchy, Pijl, and Zandberg 2004; Pivik, McComas, and LaFlame 2002; Swearer et al. 2012) and experience bigger social distance from their peers (Ditchman et al. 2013; Kersh 2011; Werner and Roth 2014).

As expected, people with intellectual disabilities are not indifferent to this discrimination. Different studies have shown that people with intellectual disabilities are aware of the stigma and the discrimination that comes with the label of intellectual disability (e.g. Chen and Shu 2012; Jahoda and Marková 2004; Jahoda, Marková, and Cattermole 1988). The awareness of this stigmatised label has been shown to be related to an array of negative consequences for those with intellectual disabilities, such as self-stigma (Ali et al. 2012), lower self-esteem (Petrovski and Gleeson 1997; Szivos-Bach 1993) and more negative self-evaluations and social comparisons (Dagnan and Waring 2004; Paterson, McKenzie, and Lindsay 2012). Notwithstanding, it is important to notice that people with intellectual disabilities do not passively internalise these negative features about themselves (see Jahoda, Marková, and Cattermole 1988; Jahoda et al. 2010). In line with the findings of Edgerton's (1967) classic study, several studies have shown how people with intellectual disabilities use strategies of "social creativity" (Tajfel and Turner 1979) in order to deal with stigma at an individual level, namely through downward comparisons with others with more severe intellectual disabilities (Finlay and Lyons 2000; Jahoda and Marková 2004; Valentim and Dinis 2014).

On top of that, recent years have seen an increase in collective responses to society's expectations concerning those with intellectual disabilities. Most significantly, through social and self-advocacy movements by those with disabilities (e.g. Fontes 2014), and intellectual disabilities in particular (e.g. Anderson and Bigby 2017), which have had important consequences in bringing about change and awareness in regards to disability. Nevertheless, stigma still has a very strong impact at a personal and social level for those with intellectual disabilities, as it inhibits them from interacting with peers with no disabilities and of participating actively in their communities and leisure activities (Beart, Hardy, and Buchan 2005).

As mentioned above, the school environment is often characterised by discrimination for pupils with intellectual disabilities, and this brings about important consequences. Namely, people with intellectual disabilities have been shown to worry more about being a victim of bullying when compared to those without intellectual disabilities (Forte, Jahoda, and Dagnan 2011; Young, Dagnan, and Jahoda 2016). This is not without reason, as students who receive special education services are more at risk of being victims of bullying (Swearer et al. 2012).

In this regard, the institutional context is particularly important, as the schools' policies have been shown to impact prejudice and discrimination towards pupils with intellectual disabilities. Previous research in this field mostly compares the impact of different types of inclusion. Some research has shown that those with intellectual disabilities attending mainstream schools reported being more stigmatised at school than those attending segregated schools (Cooney et al. 2006). Nevertheless, the opposite pattern has also been shown (Martlew and Hodson 1991). In particular, pupils from special education schools described being a victim of more bullying by pupils from mainstream schools, by peers outside school, and by people in their neighbourhoods, when compared to mainstream pupils (Kelly and Norwich 2004). Likewise, attending segregated schools may lead those with intellectual disabilities to be less aware of the stigma which they are victim of in society (Todd 2000), and of their own difficulties (Davies and Jenkins 1997; Todd 2000). So overall, inclusion policies clearly impact the experience of those with intellectual disabilities at school, but the way in which they do so is neither consensual nor clear.

In this regard, it is important to note that, as most research on the topic of intellectual disabilities and of discrimination more broadly, the role of the specific context in which studies are conducted is of central importance when interpreting their results. Thus, how people with intellectual disabilities are included and perceived in a specific society, its policy traditions and how these vary across different educational contexts should be taken into consideration. Likewise, it is particularly relevant to understand the impacts of policies at a micro level, through in-depth research in particular contexts. Following this, we aim to contribute to this debate by providing an in-depth study on the longer-term effects of the school experience for people with intellectual disabilities in the Portuguese context. Our results should not be interpreted as generalizable, but instead as an in-depth case study of how people with intellectual disabilities see their school experience. Since the country's democratization in 1974, special educational policies in Portugal have progressively moved towards an inclusion-based approach (see e.g. Costa and Rodrigues 1999), whereby the educational system strives to attend at every students' specific characteristics, differences and difficulties (see e.g.

Sapon-Shevin 2007). In this regard, the Portuguese context is a particularly interesting context for studying these topics.

This study aims to contribute to research on the inclusion of people with intellectual disabilities in three ways. Firstly, it explores the school experiences of those with intellectual disabilities – as perceived by themselves – in Portugal, where there are no studies which have done so, and where policies concerning this issue have gone through important transformations in recent decades. Secondly, it aims to provide further insights into the relationship between types of school inclusion of those with intellectual disabilities and discrimination. Finally, it takes into account the views of people with intellectual disabilities concerning their school experience after finishing their school trajectory, a perspective which has not – as far as we know – been explored in previous research.

This study explores such issues by adopting the following research question: *How do people with intellectual disabilities in Portugal see their school experience after finishing school?*

Departing from debates with professionals working with people with intellectual disabilities, this study aims to further contribute to applied work on this topic. By giving a voice to people with intellectual disabilities on topics that are structural to their lives, it provides important information for policymakers and those working with people with intellectual disabilities at schools or occupational centres. In doing so, it allows for a better understanding of what can be done to enhance the experience and learning outcomes of those with intellectual disabilities at school.

Research process

Ethics and empirical approach

Ethical concerns are central to research with people with intellectual disabilities and are becoming more important for researchers in this field (e.g. McDonald, Keys, and Henry 2008). In this regard, it is particularly fruitful for researchers to establish personal relationships with participants with intellectual disabilities (Becker et al. 2004). In line with these recommendations, as well as the challenges researchers face with collecting data from people with intellectual disabilities (e.g. McDonald and Kidney 2012), we focused on a single institution and its users, with which both the authors were previously familiar with. This is a small daily occupational centre for young people and adults with intellectual disabilities who have finished their formal education and are not included into the labour market. It serves around 20 users, from both rural and urban areas of the central region of Portugal.

There has been a growing movement for the inclusion of people with intellectual disabilities in all phases and aspects of research. While inclusive

research is often argued for, its challenges have frequently been outlined as well (e.g. Bigby and Frawley 2010; Tuffrey-Wijne and Butler 2010; Walmsley 2001; Walmsley and Johnson 2003; Zarb 1992; Oliver 1992; see Woelders et al. 2015 for an overview). Particularly, research with people with intellectual disabilities raises specific challenges which have been "marginalised" in disabilities studies (Walmsley 2001, 189) and have only recently been addressed. Namely, while in disabilities studies more generally there has been a push for the inclusion of participants as members of the research team (e.g. Pinto 2018), we believe that the diversity of people with intellectual disabilities must be taken into consideration, particularly when dealing with data analysis and theorising by people with more severe impairments (Stalker 1998).

Our approach in this study was to seek a balance between including participants and securing their well-being, while aiming to provide an insightful account of their voice for advocates, academics, policy-makers and practitioners in the educational and occupational fields. We addressed this by involving participants in the discussion of the topic and what their involvement in the research would entail. Given the characteristics of our participants and our general approach to this research, we believe this was the most suitable to ensure both the well-being of our participants and to follow a rigorous methodological approach in order to have the expression of their voice, while being transparent in terms of our design and issues of reflexivity (Chamberlain 2004).

Concerning participants' involvement and adequate consentment, we met with the institution's staff before data collection started, and explained and debriefed the research procedure. In a first phase, and in order to provide as much as a familiar process as possible, members of the institution's staff and the research team explained and discussed the ideas of the project, what would be involved, and expected from both sides to participants. Following this, participants – as well as their families or legal guardians – were debriefed and consented to participate in both phases of the study, as well as audio-visual recording of the sessions.

Concerning the well-being of participants, we conducted all data collection in the facilities of the daily centre the participants are, as to ensure a familiar context for them. Similarly, we make use of the role of the institution's staff by combining their involvement with participants with the contributions of the research team. Thus, we opted to have the psychologist of the institution conducting the interviews and to have one of the institution's staff member as a moderator in the focus groups.

Participants

16 (nine women and seven men) participants from the same day centre participated in this study. All of them did their schooling in Portugal and had

concluded it by the time of the interview. They were aged 19 to 52 years old and, according to standardised labels, had "moderate" to "severe" intellectual disability. Individuals' names and the institution's identification were not included in the transcriptions so that their identity remains confidential.

Procedure

This study combined semi-structured interviews with focus groups. Qualitative approaches are a promising and growing methodological approach for research with this population, by providing them a voice and an avenue for describing their experiences through their own lenses (Beart, Hardy, and Buchan 2005; Beail and Williams 2014). Specifically, semi-structured interviews entail a flexibility that provides a good insight into the interviewee's experiences (Kvale 2007), and that allows the interviewer to develop specific topics of interest as they emerge in the interview (Gibson and Brown 2009). As mentioned above, and as to conduct research in an environment that is familiar to participants can make participants with intellectual disabilities more comfortable during the research process (Gates and Waight 2007), the interviews and focus groups were conducted in the institution facilities and lasted between seven and 27 min (with a mean of 15 min).

Focus groups were conducted with the same group of participants, in order for findings from the interviews to be triangulated (Denzin 1978). Focus groups allow participants to interact and for questions raised by them to be developed (Willig 2001), making it easier for participants to speak about sensitive topics (Farquhar 1999) and to make personal revelations (Frith 2000), and can therefore provide a good atmosphere to discuss the issues being studied here. Group discussions are frequently used in the activities of the institution, so this procedure was not unusual for the participants.

Two focus groups were conducted, one with a group of six older participants and the other one with eight younger participants. This division was guided by the preliminary results of the interviews, in which the difference between the experiences of these two groups of participants was already very clear. Two participants from the younger group were interviewed but did not participate in the focus groups, one due to illness, and one because his family moved abroad after the interview phase. The focus groups were conducted in the institution's facilities and one session lasted 80 min, whilst the other lasted for 89 min.

The topic guides for both interviews and focus groups focused on issues arising from previous research and from discussions between researchers and staff working with the participants. Thus, they included topics deriving from comments which participants had made in their day-to-day conversations concerning their school experience. Further, the topic guides were drawn up in order to avoid questions that could lead to acquiescence, *nay-*

saying or *yea-saying*, biases that are common when working with people with intellectual disabilities (Heal and Sigelman 1995). Likewise, the use of pre-determined categories and more abstract concepts were also avoided, as to do so can be expected to enhance the understanding of these interactions (Finlay and Lyons 2000).

Both interviews and focus groups were focused on the last school which participants attended. All data was collected in an environment that is familiar to the participants and they all expressed their enjoyment in participating in this study.

Audio and video recordings from both the interviews and focus groups were transcribed and a thematic analysis was conducted on this data, following Braun and Clarke (2006) guidelines.

The construction of the codebook was inductive (Boyatzis 1998) and based on the prevalence of codes and themes across the data (Braun and Clarke 2006). This study adopted fragments as the coding unit, which correspond to the full development of an argument or idea (Zeromskyte and Wagner 2017).

Once the codebook was constructed, three independent judges coded the data separately, and manually. Following this, they evaluated the coding and analysis together, discussing discrepancies on coding and theme rankings. Once the judges agreed on a final codebook, it was used to recode the dataset, using NVivo 11.

Results

Results from both interviews and focus groups are presented together. In the analysis, a major difference emerged between different age groups. As such, participants can be clearly divided into two groups, an "older group" (above 38 years old at the time of data collection) of six participants, and a "younger group" (below 38 years old) of ten participants in the interviews, and eight in the focus groups. The codebook for both groups is the same, and the comparison between them followed Lindsay's (2019) guidelines.

This division was based on the participants' school experience, corresponding to different moments in terms of the development of special educational policies in Portugal (see Costa and Rodrigues 1999 for an overview), which deeply impacted how participants relate to their school life. Those belonging to the older group did not have special education programmes, shared their school curriculum with their peers without intellectual disabilities and were kept in primary school (1st to 4th grade) throughout their entire school curriculum, until they were 13 or 14 years old (at the time, Portuguese students would usually leave primary school when they were 9 or 10 years old). Participants in the younger group were in mainstream schools with an adapted curriculum – developed by special education teachers – , with withdrawal (special education) classes, and moved on from the first cycle (1st to 4th grade) to the second and

third cycle (5th to 9th grade) of basic school and, in the case of two participants, to secondary school (10th to 12th grade).

As a consequence of attending different levels of schooling, there is also a difference in the schools which participants attended. Thus, older participants remained in primary schools, which in Portugal – at the time in which they attended school – were usually small-scale schools for children of one or several villages in more rural areas, or of a particular part of a city in urban settings. In contrast, younger participants moved into schools for the second and third basic cycles, which in Portugal usually host students from different parts of a city and surrounding areas, and cluster different school levels. As such, these schools are usually much bigger and host a much larger and more diverse pool of students than primary schools.

The thematic analysis resulted in three main themes: social relations, educational methods, and school as a positive experience, which are presented below.

Social relations

Godlike teacher vs ever-present auxiliary staff

Among the older group, school was understood as being inherently connected to the role of the teacher. Most participants from the older group had one or a small number of teachers throughout their entire schooling period. In accordance with the small dimension of Portuguese primary schools at the time, the teachers were seen as the central figure in the school life of older participants. Participants from this group described their teachers as the school's main figure of authority, setting rules, guarantying that these were followed and to whom the participants would have recourse if something happened.

> I liked her, yeah […] they [teachers] would treat me well. Sometimes, when I… I would run away from them, because I was scared of them.
>
> Older group, woman, focus group

As a consequence of the prominent role of their teachers, older participants seem to have a mixture of feelings towards them. In the quote above, a participant stresses that she liked her teachers, and that they would treat her well, only to then mention that she afraid of them as well. This mixture of feelings towards their teachers was quite common across older participants and can be seen as a consequence of the prominence of the teachers in their school experience, as well as of the authoritarian teachers methods used at that time.

> – Did you have someone with you or not [during class breaks]? Were you alone?

– I had someone.

– Was it the teacher? That one you …

– No, no. It was a staff member.

Younger group, man, interview

Contrastingly, among younger participants, the figures of reference within school were clearly auxiliary staff members. According to this quote, and to other participants from this group, these staff members were always present, possibly closely supervising participants when there were no classes for them to attend. Thus, it seems as if these auxiliary staff were the main mediators between pupils with intellectual disabilities and the school community. Although it cannot be understood from the interviews, it would be important to explore the intentions behind such close supervision, as well as the extent to which it is effective in providing students with intellectual disabilities better and healthier relationships with the school community and an overall more inclusive experience.

Discrimination

Members of both the older and younger group of participants reported being a victim of discrimination by their peers. However, there were important differences between the discrimination experiences of participants from the two groups.

> *No one would play with me, they would never play with me and the school had a pavement, and I would sit on the pavement looking at others, I would sit in the sun on the pavement because they wouldn't play with me. So … Looking at others, sitting there, looking at others.*
>
> Older group, woman, focus group

In this quote, an older participant describes how her peers at school would refuse to play or even to interact with her. Although only a few participants from the older group referred being a victim of discrimination, the ones who did, describe covert forms, such as their peers refusing to play with them. This finding is in accordance to previous research pointing to people with intellectual disabilities being more stigmatized, and seen as less desirable friends by their peers at school (Gordon et al. 2004).

> *They would call me … "Look at the retard! Look, look the Mongo!" Look at this, look at that, and I couldn't take that anymore.*
>
> Younger group, woman, interview

As can be seen in the above quote, and contrastingly with what is the case among the older group of participants, the discrimination which younger participants report being a victim of played a central role in their

representation of their school experience. Not only was discrimination more constant, overt and even aggressive – when compared to the older group of participants – but a larger portion of this group mentioned episodes of discrimination. Furthermore, this discrimination took various forms, with the most commonly mentioned acts being name-calling and physical violence, as in the quote here presented.

> I would play alone … By myself … and I would play basketball.
>
> Younger group, woman, focus group

Moreover, among younger participants, the discrimination they reported came in more diverse ways. Thus, as in the quote above, a great number of younger participants mentioned spending a large part of their free time in school isolated from others, alone, and without any specific activity. Additionally, such discrimination is clearly expressed by the friendships younger participants established in school. Participants from the younger group also reported that during breaks and free time they interacted mostly with other pupils from special education, and under the close supervision of an auxiliary staff member. As such, it seems as participants from this group, in addition to being victims of more blatant discrimination, were also – as older participants were – isolated from their non-intellectual disabilities peers.

Educational methods

Non-adapted curricula vs adapted curricula

All participants from the older group stated their classroom tasks were the same as peers without intellectual disabilities.

> Yeah, the classwork was the same […] Sometimes the teacher would come to me "What's wrong, son?" and then sometimes she would help me. It wouldn't be telling me how to do stuff. It would be helping me doing it.
>
> Older group, man, focus group
>
> Yeah, once the teacher didn't … She got mad at me for not finishing that [a school task] and while all the others went for lunch, I stayed there, alone in the classroom, doing it.
>
> Older group, man, interview

The quotes above present instances in which participants from the older group stressed that teachers gave them the same tasks as any other pupil. However, even though there were no adapted curricula, what is particularly interesting in these quotes is that they show how teachers attempted to compensate for participants' difficulties in a variety of ways, ranging from forcing them to stay longer in class, to being more benevolent with them

when they made mistakes. As such, from the participants' accounts it seems as if even though there was no official or broader strategy concerning the education of those with intellectual disabilities, teachers would personally seek for strategies to help participants overcoming their difficulties. More importantly, these strategies seem to depend mainly on the teacher's personal approach to the issue.

> And then when they told my classmates they would go to [name of] *secondary school… I was… I was a bit like "Hey! Come on…"* […] *I would have liked to go, but I never did.* […] *In those days, there was no special education.*

> Older group, woman, interview

As can be seen in this quote, the lack of an adapted curriculum had consequences for participants, not only for their educational outcome, but also for their social-psychological well-being. As the participant does in this quote, several participants from the older group talked of feeling frustrated at not being able to perform as well as their peers with no intellectual disabilities, for not being able to proceed beyond primary school, and for being kept at a primary school with other pupils who were increasingly younger that they were.

In the face of this frustration, participants reasoned their failures in different ways. In the previous extract, the interviewee seems to explain the fact that she did not progress beyond primary school on the basis of an external cause: that there was no special education available at the time she was in school. This explanation is particularly interesting and resonates with Edgerton's (1967) classic study, and on people with intellectual disabilities's strategies to preserve a positive self-esteem (e.g. Valentim and Dinis 2014).

Alternatively, there are also some participants who, in the face of their inability to perform at the level of their peers without intellectual disabilities, blamed it on their disability, or fully acknowledge their special needs.

> At home we would bring, we had some tasks in the books, for us to do: either maths or questions. Questions I was kind of able to do them, now maths… My sister was the one helping me with that. At home, my sister was the one helping me doing those tasks and exercises. We had a lot of them… But the writing part, I would do that!

> Older group, man, focus group

For some participants from the older group, not only did teachers tried different strategies to overcome participants' difficulties but their families and friends did so as well. As such, some participants from the older group reported that their own family or friends of their family helped them with school tasks, such as their homework, but also during school vacations. These people would voluntarily help participants with school-related tasks during summer holidays or weekends, giving them extra-school support in an attempt to overcome their educational needs. Thus, it seems that among

older participants, and in lack of a broader special education policy, the opportunity for pupils with intellectual disabilities to get some support was dependent on their teacher's personal approach and on the availability of their families and social networks to do so.

> – *Did you prefer to have classes with special education or with the other* [larger] *class?*
>
> – *With special education.*
>
> – *Why?*
>
> – *Because they would teach more stuff.*
>
> Younger group, man, interview

In contrast to the older group of participants, younger participants had special education classes only with students with intellectual disabilities, as well as with some classes with peers without intellectual disabilities. As it is the case in the previous quote, all participants from the younger group preferred the special education classes. Among the reasons participants mentioned for this preference is the argument that they understood these classes to have a more appropriate and individually-based style of teaching, to provide a discrimination-free environment and, for some participants, they felt like they learned more in these classes.

Physical punishments vs benefits

The narratives from the older and younger groups of participants differed significantly when addressing what happened when they misbehaved at school.

> – *It would be like… We would have to turn to the wall in a corner. There… In the corner. And we would stay there for as long as the teachers wanted.*
>
> [Several people speaking at the same time]
>
> – *The next day, she went to get the ruler and BAM!*
>
> – *Who hit you with the ruler?*
>
> – *The teacher. … [She hit] my classmate… She pulled her ears. […] Later, I also got it: she pulled my ears!*
>
> Several participants, older group, focus group

As in the quote presented above, among the older group, references to physical punishments from their teachers were very common. Participants recalled incidents in which teachers would slap or hit students, or pull their ears – both with and without intellectual disabilities – who misbehaved or simply failed in school tasks. These episodes are often related and explained as a reason for why the older participants were scared of their teachers.

However, it is worth noting that such practices were somewhat widespread in Portuguese schools at the time, and should not be interpreted as a specific treatment of pupils with intellectual disabilities.

> – *They broke their school card, so the man* [auxiliary staff member] *yelled at them.* […] *And I had mine here, I also broke it at some point.*
>
> – *You broke yours as well? Did someone yelled at you?*
>
> – *No, not me.*
>
> Younger Group, man, interview
>
> – *Yeah, there was a queue, a huge one. In queues, I would just pass in front of them. Well, I would go to the queue but then I…*
>
> – *So would you stay in the queue or would you just jump it?*
>
> – *I just went in front of the others.*
>
> Younger group, woman, interview

Among younger participants, there were no accounts of physical punishments from their teachers. Alternatively, as in this quote, this group of participants reported instances of not being punished for behaviours for which their colleagues with no intellectual disabilities were, such as being able to skip classes, bully colleagues and other misbehaviours. These are clear examples of special dispensation, a concept which describes instances in which behaviours which would be considered wrong or socially punishable are accepted when enacted by those with intellectual disabilities (cf. Gibbons 1981).

In the second quote, a participant describes how she would jump queues at school. Similarly, several younger participants reported instances in which they, together with other students from special education, seemed to gain privileges from their condition. Of these, the most prevalent ones were being allowed to personally choose what sports to do in physical education classes and to skip the pupils' queue in the cafeteria, following instructions from auxiliary staff.

These findings go in line with previous research pointing to parents and teachers understanding disability as different from what is perceived as normative, and those with intellectual disabilities to need help or protection (O'Byrne and Muldoon 2019). Moreover, according to our results, not only did the adults surrounding participants seem to perceive them as different, but also to need differential treatment, through enhanced protection, or a special dispensation. More importantly, these findings point to how those with intellectual disabilities are not only acutely aware of the more explicitly negative consequences of their stigma (Jahoda and Marková 2004) but also of the more subtle – and often seen as well-intentioned – ones, such as the special dispensation and privileges presented above.

School as a positive experience

When evaluating their overall experience of school, the majority of participants from both groups stressed they generally enjoyed it and value skills they developed there.

> *I went to school, all normal. What matters is that I liked school, what matters is that it went all right … Just those things* [being discriminated]. *But nothing serious happened.*

Younger group, man, focus group

In this quote, a participant from the younger group stresses that – although he was discriminated – no greater evil has resulted from his attendance of school. Quite surprisingly, it seems as if this participant, as others did, sees discrimination as something inevitable about attending school, and as nothing extraordinarily bad happened, he evaluates his school experience as normal, or good.

> *I knew math, my name … If I hadn't been to school I wouldn't know* [how to sign] *my name, I wouldn't know how to write my name* […] *If I didn't know how to write my name, my mum would have to sign cheques for me.*

Older group, woman, focus group

The most common reason for why participants evaluated their education as a positive – but also useful – experience is the range of skills they developed there, which they perceive as useful in their daily lives today. As an example, in this quote, a participant stresses that school was instrumental for her to learn how to sign or learn basic mathematics, skills she values because they allow her to be more autonomous in her live. This instrumental view of school is well agreed upon among participants from the two groups, and so they often stress having learned how to write, read, and sign their name as the most positive outcomes of school. Further, they mentioned other skills, such as learning how to recycle or improving their speech, and the friendships they developed in school.

Overall, although participants were victims of strong discrimination, they value the skills and social relations they developed at school, and are aware of how those skills were important for their social life afterwards.

Discussion

This study provided an insight into the experiences of 16 people with intellectual disabilities in Portuguese schools and their long-term impacts. Results show that two small groups of participants – an older group and a younger group – have very different experiences and perceptions of their school experience. This division results from transformations in Portuguese special education policies. The participants from the older group did their school experience before the

implementation of special education in mainstream Portuguese schools, while members of the younger group attended school after it was adopted.

Our analysis resulted in three main themes, two of which these two groups of people clearly differed in: their social relations and the educational methodologies used at the time of their schooling. A final theme concerned participants' general view of their school experience as a positive one, which prevailed across participants from both groups.

Regarding participants' social relations at school, among older participants the teacher is seen as the central figure in the school community, with participants liking but also being afraid of their teachers. In the younger group, participants reported being almost permanently supervised by adults. Nevertheless, this increased supervision does not seem to have the desired outcomes, as participants from the younger group feel strongly isolated from peers outside of special education and described being a victim of discrimination from non-intellectual disabilities pupils more constantly and in more blatant forms, when compared to the older group. Thus, modern 2nd and 3rd cycle and secondary schools seem like an educational environment that is more prone to discrimination than the old primary schools with no formal special education. This was a surprising result for which we do not have a definitive explanation. It could be linked with the differences between the small and more familiar environment of those older primary schools, and the more recent large schools where pupils with intellectual disabilities interact with a greater number of pupils. Alternatively, this could be due to an almost complete lack of contact with other pupils and their indifference regarding pupils from the older group, resulting in near social invisibility, but nevertheless mitigating overt forms of discrimination. This points to the need of understanding policies and their – at times undesired – effects better. In this regard, qualitative and in-depth studies such as this can provide a promising avenue to understand these mechanisms in detail, and to find better ways to act upon them.

The preponderant role of auxiliary staff among the younger group is in line with the results of Norwich and Kelly (2004). In the case of Portuguese schools, these auxiliary staff are unprepared to work with people with intellectual disabilities and have not received any pedagogical training. This raises concerns regarding their impacts on the education and independence of those with intellectual disabilities, especially taking into consideration how the supervision by these staff seems to be a constant feature of their school experience outside classes.

The educational methods reported by the participants differed significantly between groups as well. Participants from the older group were given the same tasks as any other student, while teachers adopted specific compensatory strategies, hoping they would overcome their difficulties. Moreover, participants were retained in primary schools until they were older

than all the other pupils, a fact that could have psychological and emotional consequences for some participants, such as learned helplessness (Abramson, Seligman, and Teasdale 1978). In fact, several participants did stress the negative consequences that had on them.

Accordingly, there seems to be a move from treating people with intellectual disabilities like any other student and hoping they could move beyond their disability (among the older group), to adapting their education to their disability, and the overall way in which they are treated within the school environment (among the younger group). This is significant not only for their schooling but also for the consequences of misbehaving and the discrimination which participants were a victim of. Therefore, and likely as a consequence of the increased awareness of issues concerning intellectual disabilities, the school authorities usually responded with special dispensation and privileges (see Gibbons 1981) in the face of misbehaviour from the younger participants, which sharply contrasts with punishments given to the older participants. Of particular interest is how participants were aware of their differential status, and of the special dispensation and privileges that came with it, being able to take advantage of them. Thus, as in previous research on identity and their knowledge about disability (Valentim and Dinis 2014), stigma and self-perceptions (Finlay and Lyons 2000; Jahoda and Marková 2004), these results point to how people with intellectual disabilities are aware of their particular status, as well as the consequences of how (intellectual) disability is understood by society. Such a result stresses the need of understanding intellectual disabilities not as a medical condition, but how it is socially represented, and how this affects the lives of those with disability.

Participants from both groups see their education as an overall positive experience. According to participants, the skills they learnt at school have been shown to be valuable for their lives afterwards, giving them the ability to participate better in society, by being able to sign, to understand prices or just be better understood by others. Thus, and even though these are people who have not been included in the labour market, school was still an experience that has given them important skills to live in society, and participants valued that. Besides, the ability to read and write also has important consequences for self-concept and identity processes for people with intellectual disabilities. As Valentim and Dinis (2014) showed, for these people, objectifying disability in an inability to read and write allows them important gains in terms of self-concept.

The contrast between the overall positive evaluation of school experience and the discrimination experienced points to the tension between positive and negative aspects of school for people with intellectual disabilities, already found by Norwich and Kelly (2004). The positive aspects are related to learning and skills acquisitions; the negative aspects are related to discrimination and devaluation. Overall, most participants evaluated school as a

positive experience, and seem to understand that discrimination is – to a certain degree – a part of it. This finding points to how, despite a move towards inclusive schools in Portuguese special education policies (Costa and Rodrigues 1999), our younger participants' experience of school was still strongly shaped by others' views of their disability.

The implications of these results are multifaceted. Firstly, the stark differences between older and younger participants are clear evidence that changes in educational policies can have lasting effects on the lives of people with intellectual disabilities. Secondly, this research provides further input on the impact of mainstream schooling. Although younger participants were able to continue their formal education beyond the first cycle of basic school and to have their classes and curriculum adapted – with obvious social-psychological and pedagogical gains from this – they reported being victims of stronger discrimination than those of the older group of participants.

Furthermore, participants from the younger group clearly and overwhelmingly preferred support classes in mainstream schools. This is in accordance with the findings of Norwich and Kelly (2004) where an important part of mainstream primary school pupils preferred learning support in withdrawal settings. It can be argued that, despite our participants' clear preference, contact between people with intellectual disabilities and those without intellectual disabilities is desirable, as it can lead to less support for principles of eugenics and overall more positive attitudes towards those with intellectual disabilities (Yazbeck, McVilly, and Parmenter 2004). However, as reviewed earlier, some studies have shown how those with intellectual disabilities can be more stigmatised in mainstream schools (e.g. Cooney et al. 2006). Thus, in a topic whose research is often framed as opposing one way of inclusion versus the other, we provide a more nuanced view of different types of inclusion, through the voice of those with intellectual disabilities and by studying the specific case of Portugal.

As in Cooney and collaborators' (Cooney et al. 2006) study, we found reports of negative treatments in mainstream schools that raise concerns about their efficiency in promoting the psychosocial inclusion of people with intellectual disabilities. Likewise, younger participants' clear preference for separate special education classes in current mainstream schools goes in the same direction. Overall, although our participants see school as positive, it still seems far from an ideal experience for those with intellectual disabilities.

The small size of our group of participants is a limitation of this study. However, our methodological design aims to deal with this problem by trying to provide a more reliable account. As such, we collected data through interviews and focus groups, and had three judges coding the data through independent analysis and, after that, solved discrepancies through extensive and in-depth discussions. Nevertheless, we also need to take into account that

narrative reconstruction of school experiences could be different between the two groups of participants, given the time gap of these experiences between them. Considering the limitations of our study, it is still important to know what adults with intellectual disabilities think of their school experience after completing it, and after realising that they will not be included in professional paid work. Taking the perspective of these people into account, giving them a "voice" is important when addressing the issues of this study, as well as in other domains of the lives of those with intellectual disabilities (e.g. Foundation for People with Learning Disabilities 2005).

Conclusion

Our results show that there is a need to understand both policies and social-psychological processes better in order to tackle discrimination towards people with intellectual disabilities in schools. The results of this study provide a detailed account on the specific Portuguese context, which can nevertheless be used to inform policies and research in other areas of the globe. Particularly relevant are the findings that participants in this study evaluate their schooling as an overall positive experience, due to the value and utility it provides to their life afterwards. But there are not only positive takeaways from our results. The prevalence of descriptions of blatant discrimination in modern inclusive schools and the perception of this discrimination as a natural part of the school experience should be take seriously into account for policy-making and practice. Another important point that this study highlights is the clear preference of our participants for support classes in mainstream schools.

Our results point to several avenues for future research. Namely, further research on the effects of separated classes, their long-term effects on learning outcomes, development, and resilience, particularly through the perspective of those with intellectual disabilities is needed. Such research would allow for a better understanding of what might be better strategies to accommodate the needs of those with intellectual disabilities, as well as their opinions about school and how that could be translated into effective educational policies, educational practices, and used in fighting discrimination.

Disclosure statement

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