

Students' Voice and Disability: Ethical and methodological reflections for Special Education research

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Abstract

Consideration of the Students' Voice takes us into a varied international and today also national pedagogical movement. The issue relating to the promotion of Students' Voice research paths with young people with disabilities is delicate. The authors, after a presentation of the movement, address the important issues of ethics and methodological critical issues in the research paths within the Special Education. It is important to highlight that also in Special Education research the focus must be not just to 'listening the students voice', but also to help students to become 'change agents', because they are the potential of transformation.

Keywords: Disability; Student's Voice; Special Education; Ethics; Change Agents.

Introduction

The term Students' Voice describes an international pedagogical movement¹ aimed at enhancing the active and committed role of students, in the conviction

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¹ The Students' Voice pedagogical movement spreads between the 90s and 2000s in the international context (Fielding, 2015, 2004) thanks to some pioneering studies conducted by the

that an adequate understanding of educational contexts passes through the involvement and co-responsibility of the former in the management of the latter (Grion, Cook-Sather, 2013; Cook-Sather, 2002). This pedagogical perspective does not assume a univocal definition, as it is characterized as a constant dialogue between the different members of the educational community (Cook-Sather, 2013) aimed at increasing well-being in school life (Zuccoli, 2013; Rudduck, Flutter 2004) through the creation of spaces in which the ‘voices’ of students are listened to, recognized and legitimized as transformative elements of the educational context². This objective is achieved by the movement through the concrete “sharing and distribution of power” (Cook-Sather, 2018, 2006; Fielding, Bragg, 2003) and the creation of a co-leadership between students and educators/teachers/researchers.

In the idea that there is «something fundamentally wrong in building and reconstructing an entire system without ever requiring the opinion of those for whom the system is likely designed» (Cook-Sather, 2002, p. 3), students are considered, from the Students’ Voice movement, between «[...] those who enjoy authority to participate in both critical analysis and educational reforms [...]» (*Ibidem*), as the main informants of training practices, as well as relevant critics, and therefore legitimately identifiable as expert partners with competence.

In an attempt to offer an overview of how the term Students’ Voice entered into the pedagogical plots, Cook-Sather underlines how this recognizes «[...] not only as an advocate of efforts to reposition students in educational research and reform but also as a participant in such efforts who at the same time recognizes the potential dangers of both these efforts and the term currently used to describe them» (Cook-Sather, 2006, p. 361). In fact, «however committed student voice efforts may be, will not of themselves achieve their aspirations unless a series of conditions are met that provide the organizational structures and cultures to make their desired intentions a living reality» (Fielding, 2004, p. 202).

In this perspective, over the years, there have been plural approaches that have given students an increasingly central and active role in the field of school management and reform (Grion, Cook-Sather, 2013), in addition to educational research (Cook-Sather, 2018), characterizing the movement for its complexity³.

researchers Jean Rudduck and Julia Flutter (2004) on the scholastic experiences of children in the UK.

² The terms “Pupil Voice” (in the United Kingdom and in Australia) and “Students’ Voice” (in the United States and Canada) have spread to identify a new perspective on the role of the main stakeholders in the school and University context.

³The multiplicity of directions undertaken by educational research of analysis underlines various readings and practices emerged on the basis of the reference literature. Among those, a

In the last decade in Italy, there have been numerous educational researches in a Students' Voice perspective that have affected the various school levels and orders: the primary school (Dettori, 2017; De Vecchi, 2015; Gemma, Agrati, 2015; Zucoli, 2013), the secondary school (Dettori, 2015; Grion, De Vecchi, Colinet, 2014; Dettori, 2009), the upper secondary school (Grion, Maretto, 2018; Grion, Manca, 2015; Dettori, 2013) up to the University field (Bellacicco, 2018; Di Vita, 2016; Zanon, 2015; Ghislandi, Raffaghelli, 2013).

Specifically, it is in this last context that research has proliferated. This is both because of the maturation process of students able to participate with greater awareness and relevance to decision-making processes in didactic and educational contexts (Di Vita, 2017), and because of the «momentous change that has irreversibly transformed the nature, the goals, and the scientific, educational and organisational practices» (Melacarne, 2017, p. 1) thanks to «new working scenarios and new knowledge needs [that] have emphasised the critical factors and contradictions of curricula and strategies of University governance that are all too often fixed on theoretical-disciplinary logic» (*Ibidem*).

1. Students' Voice and Special Education

Entering into the Special Education sphere and considered the importance to the Voice of people with disabilities (Del Bianco, 2019; Giacconi *et al.*, 2018, 2019), one of the central questions of the special educational research should

first distinction concerns the existence or not of ministerial indications from governments in support of the Students' Voice movement or that share its vision. For example, in the United Kingdom, in Canada and in New Zealand are the same governments that, with different policies, actively involve students both in the analysis of their educational experiences and in actions aimed at educational reforms (Cook-Sather, 2018). On the contrary, in the United States, where there are no National guidelines, «individuals or organization take it upon themselves to honour student voices and partner with students to develop and revise educational practices» (Cook-Sather, 2018, p. 19). A second distinction that emerges within this analytical guideline, collects the evolution of the movement within the different orders and school grades (youth participatory action research - YPAR). Historically, as the first research work conducted in this area also demonstrates (Flutter, Rudduk, 2004; Flutter *et al.*, 1996), it is in the first grade and second grade primary schools that the pedagogical movement has found space to start. Thanks to a greater attitude towards respect for the authentic listening of the 'voices' of children, strategies, that are able to include their perspectives in the school routine, have been developed (Cook-Sather, 2002). On the contrary, higher education, especially University education, is lagging behind the formal integration of the Students' Voice perspective in educational research, although in recent years there have been many steps taken in this direction, both internationally (Matthews *et al.*, 2018; Cook-Sather *et al.*, 2014; Dunne, Zandstra 2011; Healy, Jenkins, 2009) and national (Di Vita, 2017; Gemma, Agrati, 2015; Grion, 2014; Dettori, 2013, 2009).

be the following one: are University trainings and services offered by the University capable of realizing the autonomy and personal aspirations of those who attend it? (Bellacicco, 2018). The question enters into the merit of the educational offer, going beyond the frequency statistics of people with disabilities in higher education. Specifically, we are wondering if the presence of «educational and emancipatory experiences in which students enhance metacognitive, training and methodological skills» (Bellacicco, 2018, p. 13) are able to develop their attitudes and practices, that can be used in productive contexts and in society (Pavone, 2018).

Despite the extensive literature «only recently have higher education institutions started listening to people with disabilities, and this must be investigated further» (Pavone, Bellacicco, 2016, p. 112), furthermore «some field surveys show that the contribution of students with disabilities to the development of University policies is still not relevant» (Bellacicco, 2018, p. 73) and that «researchers in the field of disability and PSE [Post-Secondary Education] need to become academic activists and take on more of a political voice in their examination of exclusion and inclusion» (Seale, 2017, p. 14).

Several studies have been carried out with the aim of identifying the elements that facilitate or hinder learning and belonging to the academic context (de Anna, 2016); among these is the Students' Voice movement (Bellacicco, 2018; Bandiera *et al.*, 2017)⁴.

Various institutional reforms and services provided (CNUUD, 2014), which strive to guarantee greater access to higher education for all people, do not correspond to an effective accessibility in the academic contexts and a real participation of people with disabilities in the academic life (Del Bianco, 2019; Bellacicco, 2018; Giaconi *et al.*, 2018a; Giaconi *et al.*, 2018b; D'Alessio, 2015). For this reason, there are several studies that, starting in the 1990s (Brandt, 2011; Hurst, 1996), and with different methods of qualitative research (Seale, 2017), want to involve students with disabilities enrolled in the University field. Although not all of these investigations are explicitly framed in the Students' Voice movement, the trend of such research was to use the voices of students with disabilities «to illuminate the barriers facing [...] and the impact they have» (*Ivi*, p. 3) and to identify appropriate strategies for

⁴ The movement for Independent Living, born in the 1970s in the United States from the University of Berkley and thanks to a more general sensitivity to the issue that in those years was also being structured in actions legislative, there was a historically decisive impulse to the right of study for people with disabilities and their full participation in academic life. It is in this climate of social democratization that disability voice has taken more and more space in legislation and institutional policies, mobilizing «financial, human, professional and technical resources» (Pavone, 2017, p. 241), which led to a significant increase in the number of people with disabilities who choose to invest in higher education, in order to carry out their life project (Giaconi, 2015).

overcoming them (*Ibidem*; Kubiak 2015), as well as redeveloping the educational curriculum (Barber, 2012), the organization of teaching (Moriña *et al.*, 2014), spaces, times, practices and academic supports.

The literature of reference, in this direction, underlines the importance of student well-being to materialize personal and formative aspirations (Del Bianco, 2019; Bellacicco, 2018; Santi, Di Masi, 2017; Giacconi, 2015). Other research is aimed at listening to the difficulties in the transition phases from high school to University (Giacconi *et al.*, 2020; Giacconi *et al.*, 2018a; Hong, 2015; Pernia *et al.*, 2016; Wessel *et al.*, 2015) or from the University context to the world of work (Bocuzzo *et al.*, 2011). Also in this direction, several scholars analyze architectural barriers (Giacconi *et al.* 2020; de Anna, 2016; Gilson, Dymond, 2012; Hong, 2011) and teaching and evaluation (López-Gavira *et al.*, 2015; Kubiak 2015; Mutini, Marchisio, 2005). In the end, there are others studies that are focused on the experiences of students with Down Syndrome (Ianes *et al.*, 2018) or with Asperger's Syndrome (Giacconi *et al.*, 2020; Vincent *et al.*, 2016; Townend, Pendegast, 2015; Hastwell *et al.*, 2012) in different training contexts.

Going into the field of Special Education research, the urgency is to conduct important methodological and ethical reflections (Perry, Sias, 2018; Graham *et al.*, 2013; Groundwater-Smith, Docket, Bottrell, 2015; Dettori, Grion, 2015). One concern, on one hand, is the need for researchers in Special Education to acquire a position of “ethical symmetry”⁵ (Grion, Dettori, 2015, p. 855) that should lead to research agendas able to contribute to the improvement of all people (Groundwater-Smith, Docket, Bottrell, 2015); and, on the other hand, to balance the interests of the researchers and the values of the institution in which the research takes place (Graham *et al.*, 2013). Finally, some authors (Groundwater-Smith, Docket, Bottrell, 2015; Grion, Dettori, 2015) emphasize, as an ethical question, the critical situation that can arise within the research conducted with students such as, for example, the presence of differing or opposed student’s positions from the adults that are conducting the research or the institutions in which the research takes place. Another critical question, that those who are used to conduct these studies could face, concerns the non-acceptance of the presence of young students, even with disabilities, within discussions that concern research in education and teaching by some researchers.

⁵ Ethical questions relating to an asymmetry between researcher and young person with disabilities in terms of role, self-recognition or maturity could be accentuated in Students' Voice research with disabilities. To encourage ethical symmetry also in these cases it is possible to recognize the potential of people with disabilities in terms of evaluating life contexts and agents of change.

Moving from these reflections, different authors have developed plural research methodologies within research in education (Somekh, Noffke, 2009), to encourage the co-participation of students, also with disabilities, allowing them to become co-researchers (Fielding, Bragg, 2003) or agents of change of practices within their Universities (Dunne, Zandstra, 2011). Considering the methodological aspects of the involvement of students with disabilities within Student Voice pathways, a series of potential critical issues may occur which must be underlined (Del Bianco, 2019; D'Angelo, Del Bianco, 2019; Giacconi, 2015). For example, necessary considerations must be made regarding the creation of an environment that can make students with disabilities feel at ease, establishing immediately with their collaborative and trusting relationship which starts with a clear explanation of the motivations and objectives of collaboration procedures for participation and the transformation of life or school contexts of belonging. Attention must also be paid to the communication methods that must be chosen with reference to the functioning profile and communication peculiarities of each student with disabilities (Giacconi, 2015; Lloyd *et al.*, 2006; Paterson, Scott-Findlay, 2002; Stancliffe *et al.*, 2002).

In the growing awareness of the importance of an active involvement of students with disabilities in forms of shared governance, the research has been articulated abandoning more and more the use of the students' voice as a simple advice (Caldin, 2016), that turns out to be decisive also in terms of increasing agency (Giacconi *et al.*, 2020), personal and social empowerment (Giacconi *et al.*, 2020; Del Bianco, 2019; Yair, 2008) of the students involved. It is important to highlight that also in Special Education research paths the focus must be not just to 'listening to the student voice' – implicitly if not deliberately – supports the perspective of student as 'consumer', but also to help students become 'change agents' explicitly supporting a view of the student as «'active collaborator' and 'co-producer', with the potential for transformation» (Dunne, Zandstra, 2011, p. 4)⁶.

2. Conclusions

This reflection on the Voice of Students with disabilities allowed us to legitimate the reorganization, the improvement and the construction of new practices and environments that are increasingly universally inclusive.

The alignment between the students' point of view and the University field can be important in terms of awareness and life-orientations programs, with the

⁶ It is in the acceptance of these critical issues that the University of Macerata and the University of Arizona are oriented to launch, in the academic year 2020-2021, a pilot study aimed to identify the proposals of students with disabilities as 'change agents'.

aim to help students achieve and acquire attitudes that can make «people resilient in their personal, professional and social life» (Bellacicco, 2018, p. 19). In this direction, it is possible to allow students to make metacognitive reflections on their studies and on their perception of inclusion in the University context, establishing spaces for the exercise of one's self-advocacy. The co-creation of inclusive environments can allow the implementation of opportunity to accept the critical points in a proactive framework aimed at encouraging the exercise of self-determination and active participation, as well as increasing personal agency for an independent life (Del Bianco, 2019; Caldin, 2016).

The literature (Frison, 2017; Summers *et al.*, 2014; Stein, 2013) indicates that a non-adherence often conceals an incapacity or reluctance to express oneself and one's needs or support one's own rights. This motivates us to agree with Seale, concerning the need for «more research into how academics and support staff can develop and encourage self-advocacy skills in disabled students» (Seale, 2017, p. 6). Further reflections will have to be conducted on the difficulties in disclosure (*Ibidem*) as the first barrier to a life project is one that does not want to be established by others (Pace *et al.*, 2018, p. 22), and therefore needs conscious actions of self-advocacy.

Therefore, the need emerges to structure daily listening spaces and planned surveys so as to organize the services and the supports of the study according to the actual and changing needs of the person. In this direction, we hope to increase moments of co-planning, in which also students with disabilities can help and organize proposals that respond effectively to their needs, proceeding from the perspective of a collaborative design for all (Giaconi *et al.*, 2020; Borgato *et al.*, 2017).

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