Education, Disability and Inclusion

A Family Struggle against an Excluding School

Ignacio Calderón-Almendros and Sabina Habegger-Lardoeyt



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and

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To Rafael's mother and father, for proving that, without love, pedagogical efforts lose their purpose.

To Rafael's brothers and sisters, brothers-in-law and sisters-in-law, nephews and friends, for being living arguments for inclusion.

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FOREWORD

Ignacio Calderón and Sabina Habegger have given us all a gift with this muchneeded book on education, disability and inclusion from the vital and powerful counter-hegemonic discourses of insiders and participants. As we accompany Rafael, his family and allies through their experiences in school, we learn first hand the ways in which schools as social institutions reconstruct culture and identity all too often to the detriment of students like Rafael. The layered discourses throughout the book, coupled with an analytical framework and empirical evidence, leave us with no doubt that our approaches to teaching and learning need to change.

This book begins with the premise that Rafael, and all children and youth have the ability to learn and grow, and are born with the potential to be educated. Part one of the book devotes considerable attention to issues that have long plagued our classrooms and society: issues of equality, fairness, opportunities to learn, attitudinal barriers, and the ways in which our current policies and practices compromise and impede progress. This section provides ample evidence that disability and intellectual aptitude are not characteristics of the student as much as they are a characteristic of the situation. Schools seem to be more about categorization, sorting, labeling, and testing students rather than they are about preparing students for a life of active citizenship and community and family involvement—in short, life after school. After all, students are ultimately tested in the experiences of life, not on math or reading scores. Rafael's experience in particular puts a spotlight on the effect schooling has on a sense of cultural belonging and positive self-identity—the essential tools for community living.

Throughout the book, the depth and breadth of this portrait of action research is impressive in and of itself. Covering over a decade of experiences, the internal and external researchers use multiple sources of data: standardized tests, student and family narrations, observations, informal interviews, and extensive written documentation of reports and letters. The authors exhort the reader to engage with the text actively and critically, to undertake a self-examination of his/her own attitudes and practices. They ask us to consider: what responsibility is assumed by the school as an institution? What is the purpose of assessment and diagnosis? What should be taught? When should it be taught? How should it be taught? Is it ever considered that the cause of a problem could be found outside of the student being evaluated?

Answering these questions with a critical reading and response requires a different frame of reference and analysis than the scientific positivism of biology and psychology that has permeated and driven special education thinking and practice. The authors challenge this thinking and practice with an alternative analytical framework that draws from discourses, theories and interpretation systems which take into account issues of social justice, culture and resistance. Specifically, the

FOREWORD

authors begin by noting that the starting point for a biological framework focuses on individual biological limitations and personal characteristics. This framework ignores the broader socio-cultural cultural forces and contexts under which schools operate. A socio-cultural framework takes into account the powerful influence of culture and society on individual ability, growth and potential in the context of the environment. It also recognizes the inequality and complex power relations inherent in school practices-particularly those of diagnosis and exclusion. Notably, Rafael's experiences in school and his responses to it, reflect Paulo Freire's theory of resistance as well as his concept of banking education (students as empty vessels to be filled with factual knowledge by teachers), and critical pedagogy (students and teachers as co-constructors of knowledge writ large through critical thinking and experiential learning). This paradigm shift-from scientific positivism to socio-cultural and resistance theories-is perhaps the most important contribution this book makes to provoke needed change in the current school system. This shift pertains especially to teachers who are the frontline of school practices. It forces a change in the teachers' role as mere technical practitioners to critical intellectuals who can resist school practices of banking education. It means that students like Rafael as well as his allies and family members-those at the grassroots levelhave the tools to take on the role of resisting and denouncing institutional vices that perpetuate inequality and prevent social justice.

The book concludes with a description of Rafael's experiences post mandatory schooling. A counterpoint experience in a musical ensemble and the music conservatory reveals a very different approach to learning that is motivational, student-centered, and experiential. One has to ask why the formative years in schooling could not emulate these practices. In the conclusion, Rafael's successes in post-secondary education, and as an accomplished musician inspire us with hope for the future—not just for Rafael, but for all people who have been labeled with disabilities and subjected to exclusion and low expectations. When we value every student's talents and abilities and look beyond labels to the student underneath who is waiting to be discovered, then our world opens to infinite possibilities. The book makes a significant contribution to advancing inclusive education and challenges all of us to actively engage in the work of social-justice in our daily practice as teachers, education professionals, administrators, family members, and individuals with disabilities. We are all part of an interconnected world and need to play our part, if we are to be truly inclusive.

Susan Peters

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CHAPTER 1

INTRODUCTION

In place of hope, there'd be the employment of trickery designed to hide truths that could propel the oppressed into fighting, should they only guess or intuit those truths.

Paulo Freire (2015:101)

In this book we seek to understand how cognitive difference is addressed in Spanish schools. In order to do this, we have analysed the specific experience of a person with Down's syndrome, Rafael Calderón-Almendros. The analysis includes his family's dealings and conflicts with the school he used to attend. This is part of an action research process that they were involved in for several years. It does not arise from the discourse of teachers or other intellectuals, but from the life experiences of one of the groups most oppressed, not only by society in general, but also by schools as institutions, and in particular by teachers as their agents. These three agents have an unequal share of the power to construct the meanings that should be legitimately taught and learnt, and how they should be implemented.

This book focuses on the third stage of the action research project,¹ which studied the struggle of Rafael's family against the discriminatory practices that, in their view, were being used by the school. Through the use of various methods, but mainly by analysing documents from the case and others subsequently prepared, we aim to shed light on the process from a perspective of education that is inclusive, radical and committed. This serves to reflect upon the role that both schools and professionals play in the education of their students, bearing in mind that instruction is not the same as education.

The study is structured into two major areas: a theoretical one and an empirical one. The former, entitled 'Analytical Framework', provides the theoretical grounding to understand the conceptions developed by the student's family over the years which were fundamentally based on an affectionate home life. However, these concepts and representations were in stark contrast to a school culture excessively based on the academicism, qualifications and competitiveness demanded by the labour market. This is why basic, simple, family discourses must be re-written and adapted to scientific/pedagogical language, in order to resist the administrative and scientism-based arguments prevailing in schools, which serve various underlying interests. Three levels of discourse production can be identified here. The first one is the family's everyday discourse in their relationship with Rafael, with the school and with the internal researcher—Rafael's brother and co-author of this book. The second one is an attempt to organise, systematically arrange and give coherence