Challenging education. Towards a more inclusive horizon for ASD students throughout compulsory schooling… and beyond!

Learning with families and their children about the role of social participation in this turbulent process

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Foreword

As main co-investigators of the National I+D+I Plan project corresponding to the 2017 call of the State Program for research, development and innovation oriented to the challenges of society, within the framework of the State plan for scientific and technical research and of innovation and entitled “Analysis and assessment of the inclusive education process of students with ASD, from early childhood education to university. Participation as the axis of analysis” (Ref. EDU2017-86739-R. EDITEA), it is an honour to be able to present to all of you this text which, as one of the products derived from this project, includes some of its main results. Before briefly presenting its meaning and explaining its structure, we consider it necessary to make some preliminary considerations. The first one is that it is, in effect, one of the products of mentioned project. On the website of the research group that has led this project, EQUIDEI, you will find complete information on other academic works or dissemination articles, lectures or communications at congresses.

The second important consideration is that all of the people in this group have the firm conviction that it is our ethical and professional obligation to carry out actions that allow the results of the research to be transferred and be as accessible as possible, -funded with public funds-, to the widest possible audience and, very particularly, to those who are less able, certainly for different reasons, to access academic channels (specialized journals and conferences) where this type of results are usually disseminated. We refer, for example, to
families or university students themselves, to the teachers or to the technical or support staff of the educational administrations, be they national, regional or local. This does not mean that these academic channels are not important and necessary for the validation, by peers, of the findings and analyzes carried out. However, it is also true that these same channels seem clearly insufficient to support the transformation and improvement of some areas as the cultures, policies or practice systems of schools in order to make them more inclusive.

The third and final consideration is that we wanted to have this version ready to offer it to all the participants in the International Congress on Social Participation and Inclusive Education that, as a group, we have organized to contribute, from another complementary area, to the dissemination and public discussion of our research work, as well as to know other works of proven quality. We precisely hope to be able to improve this first version, with the reflections and analyzes that are generated in said Congress, because we understand that the most important thing is that the knowledge derived from our work, or from others, can be useful to continue advancing in the purpose shared by many people, an education with greater equity, building a more inclusive and fairer society.

To reach the widest possible audience, we have considered that the best way to do this is through a narrative analysis and presentation, of a qualitative nature, inasmuch as it is well known that narration, whether oral or written, is a privileged and direct way to reach the thoughts and emotions of those who read or listen to such narrations. For this reason, the text is structured in three different parts. The first is to present, in a brief and concise way, the main reference frameworks that have guided our research, be it the most general and related to how we understand the meaning and the process towards the full fulfillment of the right to an inclusive education, that is, regarding what role it has and how we understand social participation, in this framework, since this construct of social participation has been one of the main axes of the project. The second part, the more properly narrative, is organized by thematic blocks that, in our opinion, they group with meaning in the main results / analysis that we have carried out. They are not all that have emerged after the different methodologies used, but all of
them that are, in our opinion, worthy of consideration. Finally, the third part is a small compilation of documentary or audiovisual resources related to the objectives of this project and that we think may be useful for those who need them most: families, teachers and support and counseling personnel, in a broad sense and comprehensive of the term.

It is necessary to make explicit that the results / analyzes presented are derived from a project that has been carried out with a group of people with ASD, their families and professionals in the educational field rather modest in terms of number and within the same diverse, how could it be otherwise, since diversity is the mark of humans in all its identity and cultural manifestations. Therefore, nothing is further from our intention that making the readers of this document understand that our analyzes and results are generalizable to other groups of students vulnerable to exclusion processes, to other school or local contexts, or in relation to what is said of the teachers or professionals who have been part of said participants. They may be “extrapolated”, to a certain extent, to the extent that the reader identifies in their own context, family or school.

Throughout the text, we have tried to avoid, as much as possible, an academic language and the typical formalities of other types of documents, such as the use (and sometimes abuse) of references to other works or sources. We are driven by the desire to reach the minds and hearts of those who must be the main part of the solution (the teaching teams and those who accompany and support them) and not part of the problems of segregation, marginalization or school failure / dropout that many students continue to live daily with the consequences derived from all this for their own quality of life and of their families. We have been very aware that it is important to use an inclusive language with respect to gender and, for this, we have opted for a hybrid position,

One last reflection on this long Prologue. Recently some good colleagues from the Early Care Teams in Madrid reminded us of the words of Ryūnosuke Akutagawa: “Individually we are a drop. Together we are an ocean”. The project from which this document is derived, like the document itself, has been possible
because many people, together and mobilized by shared values (starting with the participating families), have worked for it, being united in the firm conviction that a more inclusive school is possible and, for that, we must denounce everything that prevents it and celebrate and share each and every one of the steps that lead us towards that goal.

Gerardo Echeita & Cecilia Simón
Representing the EDITEA project team

Manuel
Preface

This Preface contains, as an extended summary, the contributions of the three invited conferences to the Congress: Professor Anke de Boer, Professor Robin McWilliam and Professor Gordon Porter. It also includes a brief text by Fernando Mudarra, general director of Ayuda en Acción Education, because thanks to the generous sponsorship and support of said NGO, it has been possible to count on the participation of the speakers and with the publication and dissemination of this document.

These words serve to express our most sincere and profound gratitude to all of them.
Inclusion as an embracement

Helen Keller said, "The best result of education is tolerance," but we want more than tolerance. We want more than just acceptance. We want embracement, which, translated into Spanish, is that proverbial and very welcome greeting: we want a hug.

In this short text and at greater length during my speech at the Congress, I will summarize a section of a book of which I am a co-author on inclusive education (Gajdzica et al., 2020) in which we considered how to approach inclusive education in practice, emphasizing its future. The story begins, however, with the organization of inclusive education. In the United States of America, where I live, inclusion is organized through a cascade of services whose data is communicated to Congress, given the federal nature of our country. The main options in this cascade for students who are usually considered to have special educational needs have been the following: normal classroom (s) all day, some resource classroom (integrated or itinerant), many resource classrooms, symbolic inclusion,

In the United States, funding for opportunities for educational inclusion comes through the Individuals with Disabilities Education Act (IDEA), which is possibly the most progressive legislation in the world to support inclusive education for such students. However, this law comes from a country that has not signed the 2006 United Nations Convention on the Rights of Persons with Disabilities. IDEA provides some funding for services directed at infants and toddlers (Part C), for special education for children and youth ages 3 to 22 (Part B), and for research and technical assistance to the States (Part D).

Even if funding is available, the skills and qualifications of teachers largely explain the success or failure of inclusion and education of these students, something that obviously also requires investment by States. Special educators and therapists have to be trained to be good collaborators, advising teachers,
and ordinary educators have to be willing to participate in this collaboration, adjusting their teaching to individualize or "differentiate" their teaching.

What happens in an inclusive classroom? Suppose we have overcome the barrier of placing a child in a general education classroom, now we need to ensure that the child participates in a meaningful way in classroom routines. But let's not blame the victim: it is about the fit between (a) the child's abilities and interests and (b) the demands of the routine (ie, the activity or "the lesson"). For engagement to occur - and that is, in my opinion, the goal - we have to align these three aspects: teaching the child, changing the routine, and changing expectations. The criterion is to try to achieve goodness of fit, not simply whether the child can meet the demands of the routine or the classroom.

Researchers have revealed a host of barriers to inclusive education. There is a central theme: the use of two models, the so-called "rescue" and the "recommendation". In the rescue model, the "special education" team take the child out of the classroom. In the recommendation model, the “special education” team bombards the faculty with suggestions. Neither of these models has been effective. Instead, the collaborative consultation of the “special education” team with teachers has been, and promises to be, even more effective when done with fidelity to best practices.

The future of inclusive education in the United States could hinge on developing the competencies of teachers in “special education” teams, rigorous training of general educators, and a focus on engaging all of them. Teachers on “special education” teams, as mentioned above, must be experts in collaborative consultation, incidental teaching, and helping strategies. Incidental teaching is like scaffolding or expansion. It consists in ensuring that the child is participating, in following his initiative, in provoking a more sophisticated form of participation in the child, and in ensuring that the interaction is reinforcing (Casey & McWilliam, 2008; Casey et al., 2012). General education teachers also need rigorous training.

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1 It refers to what is understood in the Spanish context by “support teachers, PTs” or in other contexts, such as Chile, to "special education teachers" or in Mexico to those who work in the Support Services Units to the Regular Education (USAER).
in ecobehavioral teaching strategies (Lee and Niileksela, 2014). This would ensure that they see the learning path through changing the environment in which the child learns, rather than thinking that the problem is with the child. This vision of learning leads to a particular focus on participation (“engagement”). If all the professionals involved in the child's education understood that the child's participation in daily routines, at home, in the classroom and in the community, are the keys to learning and their successful functioning, their approach to the students would be individualized and therefore relevant (Almqvist, 2006; McWilliam and Casey, 2008).

How do families view inclusive education? This conference will include data to answer this question. From my perspective as a researcher, model developer, and parent, I recognize competing values for inclusion, such as wanting specialized help for our children and wanting our children to participate in regular society (Bailey & McWilliam, 1990; Bailey et al., 1998). After more than 30 years of studying these issues, I think we need to address three areas (Gajdzica et al., 2020)

1. The special education system should stop relying on diagnostics for placement and services and instead rely more on behavioral descriptors of learning and behavior needs.

2. Collaborative relationships should be established with families, so that professionals help the inclusion (that is, participation / engagement) of the child in the routines of the home and community.

3. Schools should focus on standardization (Bailey and McWilliam, 1990; Bailey et al., 1998; Wolfensberger, 1970), so that children and their families have the same opportunities as others. Full or part-time segregation is a largely outdated idea that generally does not provide supports to the child's caregivers when the child is not in that educational setting (i.e., at home or other care settings). It is time for professionals to collaborate with all the child's caregivers, so that the child can learn in all their environments, which would be a standardized approach to education.
References


Anke de Boer - University of Groningen (The Netherlands)

A model to promote social participation in the framework of inclusive education

The inclusion of students with special educational needs in mainstream education is a current trend, visible throughout the world. Many countries in the world have signed and ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006). Article 24 of the UNCRPD focuses on education rights, with special attention to attendance at regular education. The important outcomes for students to consider are academic and social development, which are also highlighted in Article 24. Therefore, it is not enough to focus solely on academic outcomes. We must also seek positive social development.

The social development of students with special educational needs can be hampered when their social participation is low. Social participation includes four themes, namely: acceptance by peers, friendships with peers, interaction and contact with peers, and a positive social self-concept. Research has shown that the social participation of students with special educational needs is worrisome: for different types of SEN it has been found that students with SEN are not accepted by others and / or have no friends, interactions with peers are scarce, and their social self-concept is less positive (see: Mamas et al., 2020; Nunes et al., 2001; Rotheram-Fuller et al., 2010). It is important to mention that these results are mainly found when comparing social participation with typical development peers. However, these results show that students with SEN do not fully participate in social life. Across the world, it has been recognized that poor acceptance or rejection and bad friendships can have negative consequences in the short and long term (Bukowski and Raufelder, 2018; Ladd and Kochenderfer-Ladd, 2016). In short, it means that we should try to promote the social participation of students with SEN in mainstream education. It has been recognized that bad acceptance or rejection and bad friendships can have negative consequences in the short and long term (Bukowski and Raufelder,
In short, it means that we should try to promote the social participation of students with SEN in mainstream education. It has been recognized that bad acceptance or rejection and bad friendships can have negative consequences in the short and long term (Bukowski and Raufelder, 2018; Ladd and Kochenderfer-Ladd, 2016). In short, it means that we should try to promote the social participation of students with SEN in mainstream education.

The question arises, then, of how social participation can be promoted. We found that the attitudes of classmates are related to their acceptance of students with SEN, which leads us to think about improving attitudes and, therefore, in the end, social participation. Using Contact Theory (Allport, 1954), we found that peer attitudes can be improved through information and contact with peers with special educational needs. Interventions that include both components were shown to have the strongest effects on attitude change. However, the empirical evidence on the link with (one of the themes of social participation) is still scarce.

In recent years, we have (further) developed an intervention that includes an information and contact component. The intervention is based on the Making Friends program, developed by Favazza et al. (2016). The intervention uses picture books that guide discussions about special educational needs (information component), cooperative learning activities (contact component), and parental involvement (students' primary social group).

In the framework of the Congress to which I have been invited, I will summarize this intervention model in more detail. In addition, some of the first results of the study will be presented.
References


In my intervention at this Congress, I will focus on pointing out some of the necessary critical steps to make schools inclusive, with specific reference to classroom teachers. Moving towards inclusion is part of a global commitment to equality and human rights reflected in the United Nations Convention on the Rights of Persons with Disabilities - Article 24.

I have personally participated in this endeavor in various functions for over 40 years, primarily in the province of New Brunswick in Canada. My work has emphasized the need to develop and use policy to provide schools and teachers with the support they need to successfully implement inclusion. It is essential to maintain leadership and the defense of inclusion and the values on which it is based (Porter and Towell, 2017).

To a large extent and as a result of this accumulated experience, I consider that the general principles on which the practice of inclusion in the classroom is based are the following:

- Ensuring that students learn in a "common learning environment" in enriching schools and classrooms.
- Lack of success in teacher-led learning tasks is seen as a challenge for the improvement of the school and the teaching staff, and NOT a result of student shortcomings.
- Schools organize staff and practices to SUPPORT teachers in their work.
- Limited resources are used in the most productive way to improve school capacity and school instruction for all students.

I have also been able to reaffirm myself in which are the main practices that help teachers to provide inclusive instruction in typical classrooms. Among them are:

- The climate and environment of the classroom.
- Personalized Learning Plan - when necessary.

- Peer commitment and support.

- Establishment of instructional plans that accommodate all students, following the principles of Universal Design for Learning (UDL) - often implemented using strategies that are derived from important psychopedagogical principles and frameworks such as:
  
  ● The Theory of Partial Participation.
  ● The Zone of Proximate Development – Vygotsky.
  ● Levels of Cognitive Development - Bloom.
  ● The Multiple Intelligences Model - Gardener.
  ● Cooperative Learning - Johnson and Johnson; Slavin; Kagan.

I hope and trust that after my intervention we will be able to initiate a debate on the different roles that are involved in the creation and maintenance of these inclusive classrooms and schools and on the consideration of what is the most important role for this process. A debate and a conversation that, in any case, should have continuity in each school committed to a more inclusive education.

References

Ayuda en Acción

Fundación Ayuda en Acción has been working since 1981 to make a reality the access to quality, inclusive and equitable education. In Spain, our main challenge for the next three years is to promote an inclusive educational system that considers the diversity of needs and capacities of all students, and that eliminates all forms of discrimination, as well as obstacles to participation.

For this reason, Ayuda en Acción joins and supports the development of this international Congress organized by the EQUIDEI research group, to reflect on the most effective practices in inclusive education, with special emphasis on students with autism spectrum disorders (ASD) and in the important dimension of their social participation, with the purpose that the final conclusions become inputs to improve teaching cultures, policies and practices at all levels and schools and ensure that no girl or boy is left behind.

*The foundation Ayuda en Acción for a more inclusive education*

*Fernando Mudarra*

*General Director of Ayuda en Acción*
PART I

Frameworks

ME SIENTO BIEN

Me siento bien
Si pasa alguien
En la calle pasando un perro
Me siento como un hierro
Me gusta estar con amigos
No con enemigos
Yo estoy en casa tranquilo
Yo tengo un guante de vinilo
A la voz de un padre
Y tienes una madre
No me gusta estar solo
y no estoy loco

Héctor Muela
13 años
1. Inclusive education and social participation

As the final purpose of the project we have undertaken is to improve school education so that it is more inclusive than it is now, we think it is necessary to make, even briefly, a characterization or definition of what we are pursuing; that is, what is its meaning and scope (why, what and who are we talking about when we talk about inclusive education); through which great tasks it takes shape to try to become real and what is its intrinsic nature. All these considerations are important because if what is sought is not shared, it is likely that those who, in one way or another, have to intervene in this process are wanting different things and this is a very important obstacle to continue moving forward.

This task of making explicit the meaning, tasks and nature of inclusive education is widely covered in many texts, some of them promoted by the large international organizations in the field of education, such as UNESCO, and others carried out by academics, researchers and experts from all over the world. On the website of our research group, EQUIDEI, We have collected enough works and references, both our own and others, to delve into this subject as much as desired.

That is why we do not want to repeat what the members of this team have also said and written about previously and, for the sake of the stated purpose of this document, we only want to make a few brief notes of the reference framework that we have adopted in this project, so that, among other considerations, our analyzes are contextualized as best as possible and, for example, the central role that the dimension of social participation has for us is understood. It should be said, on the other hand, that, although it is true that, honestly, we believe that what we affirm has broad support in the specialized literature published on the matter, we do not have the vanity to think that it is the only possible interpretation.

What is said below will be written in similar terms in other of our publications, but, to avoid, as has been indicated, the reiteration of references in favor of a reading as agile as possible, we will avoid both these citations to
previous works of the equipment such as those referring to the sources that we once had into consideration, and that we thus leave reflected in the different original works from which we have abstracted the summary that is now presented.

1.1. Why do we talk about inclusive education? What are we talking about when we talk about inclusive education?

About a year ago (September 2020) the initiative of a group of good people was announced who launched a campaign with the eloquent title of “Inclusive education; wanting it is creating it”. We are not going to go into the analysis of its opportunity and scope here, but we are going to use its slogan as a trigger to organize the presentation of the frame of reference that has guided this project and, around which, its results must be evaluated. What helps us now, from the outset, is to ask ourselves questions regarding the premise from which this campaign starts: What do you want when you want a more inclusive education? Who wants it? For whom? And what actions are necessary, not only to desire it, but to create it? Once again, we have to remember that we will do it very briefly because otherwise it would take many pages. It should also be noted that everything that is simplified or summarized is deformed and that someone might rightly think that many elements are left out without analyzing. Sorry for it.

What do you want when you want an inclusive education? You want to contribute from school education (with the modest but significant specific weight that corresponds to the school) to the construction of an equally inclusive society, that is, a society that recognizes the equal dignity and rights of all people, regardless of their gender or social condition, their particular ways of being, feeling, loving, believing or thinking of their origin or state of health. But not only is it pursued a society that nominally recognizes the intrinsic equality of all

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2 In this text, the expression school is used as a common term to refer to all educational centers of formal education, from early childhood education to university, that fulfill the educational functions attributed in the current laws, each one within the stage that corresponds.
people but is also active in removing the multiple obstacles that maintain existing situations of inequity and inequality.

One of these obstacles is that of a school that, from its origins to the present, has been selective and exclusive, leaving out or expelling those who questioned or did not fit into the current model for various reasons. In short, the defense of societies with greater equity would not be coherent or credible if the school was not inclusive itself and did not prepare future generations to live together with equal rights and opportunities for all children, adolescents and young people that are in our nursery schools, colleges or institutes.

**Who wants this society?** Some might think that this aspiration is only of some people, dreamers and utopians. The truth is that it is the aspiration that, since the middle of the last century, is reflected and endorsed by the international community at the highest level that we know today, as is the framework of the United Nations. Indeed, since the Universal Declaration of Human Rights (1948), until the recent Declaration of the Rights of Persons with Disabilities (2006), an International Code of Human Rights has been formed, with pieces as important as the Convention for the elimination of all forms of Racial Discrimination (1965), the Convention for the elimination of all forms of Discrimination against Women (1982) or the Convention on the Rights of the Child (1989). Definitely, the answer to the question is simple; This more inclusive and more equitable society is loved by all good people and countries and, by the way, we want it for everyone as well, even for those who do not share these moral and ethical principles in a minority.

For other part, and, incidentally, as can be appreciated, this desire is not a whim but a human right in capital letters, with all the legal recognition and legal protection due to fundamental human rights, such as the right to education that from now on, it should be interpreted as the right to an inclusive education.

**What school, then, do we want?** We want an educational system that is capable of creating and maintaining schools for all (melting pot of democratic citizenship), where it is possible for all girls and boys, adolescents and young people of school age, without exclusions or euphemisms regarding that “ALL
AND ALL , participate in quality educational experiences that, supported by their uniqueness as people with equal dignity and rights, provide them, in the first place, valuable opportunities to be together - not separated or distant in schools, classrooms, or different groups, differentiated or special--; secondly, actions and a school climate where they can be recognized and valued in and for their diversity of personal, social and cultural characteristics and their voice taken into consideration in matters that concern them and, at the same time, thirdly and, in good measure, for all the above, to be able to learn without the limits imposed by poor educational expectations, prejudices or social, family or school conditions of inequity. In summary, we aspire to a school with the capacity to articulate with equity the school practices that allow everyone to be together, to play and learn; to feel part of a group of equals with whom to establish positive social relationships and be able to participate socially in school life and, to learn and perform, from the outset, "to infinity and beyond." In short, make universal what any mother or father wishes for their own children of school age: quality education.

And how far are we from that school? Although our systems and schools have made great progress in this direction in the last fifty years, it is still quite true that there is still a long way to go (to transform, improve and innovate our education system and its schools), in particular to include the groups of students who continue to challenge the educational status quo existing, that is, the organization and operation of educational centers, and what and how to teach and evaluate that has been practiced for a long time. Among these challenging students, many of whom are still out of the regular school, are students who have atypical developments due to functional disorders or limitations and who, therefore, require more and more complex and generalized supports to function in his personal, social and school life. It is important to make it very clear that the problem it is not in the personal characteristics of these students, but in the

3 Girls no longer go to segregated schools against their will; nor are there schools for "whites" and for "blacks" or only for gypsy or migrant children, to recall some examples of progress towards more inclusive schools that have occurred in the last fifty years or so.
enormous resistance to change that school systems display when power relations and the status quo maintained by resistance are questioned. Therefore, his non-inclusion in the common school, what he is informing us is how much remains to be improved so that his right to an inclusive quality education is real. These considerations are important because our work aimed precisely to recognize some of the barriers that persist in school cultures, policies and practices, and that have become evident through the experiences of students with ASD. Also, to recognize and celebrate everything that has made possible the existence of truly inclusive experiences, when they have happened.

What tasks do we have before us so that the inclusive education that we want is recognizable in schools? Undoubtedly many, complex and very difficult. A good part of them revolve around the great collective and collaborative enterprise for the educational communities of the schools (from early childhood education to high school and beyond), to critically review if their current school cultures, their plans and programs and, Finally, the teaching, learning and assessment practices that take place in the classrooms respond in a fair way to that ambition of articulating with equity the presence, participation and learning of the students who are and who could be at their center. For this, it is necessary to mobilize knowledge, attitudes and determination in all those who constitute such educational communities (management, teachers, families, students, administration and services personnel), which speaks to us of the importance of having a clear shared vision and leadership appropriate to the scope of the task, together with an outstanding ability to mobilize all the necessary support and resources as well as the collective wisdom to make a constant process of improvement sustainable. There are the main factors that explain the challenge and the problem of inclusion, and not in the personal conditions and specific needs of educational support of some students who, being important, are not the problem. This attribution of inclusion problems to students to be included is what we have been thinking and believing in the past. But this is not, in effect, but a belief ingrained in our minds; that is to say, it is not an unshakable truth, but a constructed one and that, therefore, can be
And meanwhile these changes are generated, what can we do? This is probably the most difficult and delicate question to answer. This is because we all know well that change (in all spheres of life and in education as well) takes time; that it does not occur overnight, as well as that it is not linear, uniform or irreversible. And while schools get to work (if they decide to do it!), Prepare, plan and implement some of the many improvements that will undoubtedly be necessary, the truth is that many children (particularly those with more extensive and generalized support needs), what do they need now! For today, not tomorrow, the changes indicated will be living situations of partial or total segregation, marginalization, contempt or who knows if mistreatment by their peers and, therefore, they will have less learning opportunities.

The multiple dilemmas that this causes (to the administration, managers, teachers and, last and foremost, to families as guarantors of the rights of their sons or daughters), will be the cause of many losses and doubts. The options are in plain sight. For some the best thing will be to leave everything as it is, because they think that so conservative that "the remedy is worse than the disease." They may settle for some minor changes, with a sort of part-time and restricted inclusion (in some schools only), for some students (for example, for those with less complex support needs), or only during the initial stages of school (early childhood education and maybe elementary school). For others, the decision will be to get going,

We do not come to morally judge the decisions that families make. What moves us is to provide different forms of support to all of them, starting with understanding the inherent and unsolvable difficulty that all dilemmas have. The second, listening to their experiences, desires and concerns and, thirdly, sharing one and the other with whoever wants to listen to them, being open to empathize with them and mobilize their agency so that they try to change what is within their power to change. This is precisely what we intend to achieve with this document and with the project from which it is derived.
1.2. The multifaceted dimension of social participation

In the project that we have developed, it was made explicit that we believed not only opportune, but also very necessary, to analyze in detail what was happening in the inclusion processes of students with ASD with respect to the dimension of social participation and that, jointly, with the presence and learning, form the heart of these processes. We have already pointed out above what we understand is behind this important concept and, a good part of the analyzes that will be shared in the third part of this document, deal directly or indirectly with it. Therefore, we do not want to expand now in its analysis or go beyond sharing some ideas about a concept or construct (as there are many others in psychology, such as happiness, for example), of a multifaceted nature, that is, it has many faces and can be studied from very different points of view.

In the context of the project, we have agreed to understand and study the social participation of a student as the perception of their degree of acceptance and positive relationships with their peers in their reference groups, as well as being considered in the decisions they make. They affect you. This happens not in a vacuum, but in function of the opportunities (or restrictions) offered by the school context. For this, it is essential, previously, to be and significantly share common spaces, times and actions with their peers.

To share this meaning, we have played with three expressions that seek to capture the essence of this dimension. In this sense, we have suggested that participation results from the articulation of situations and affects related to being part, feeling part of a group, and taking part in the decisions that affect it. We believe that feeling part of a group of equals is the fundamental nucleus of this dimension because, as we well know, we are social beings who strongly need each other.

For the families in our study, participating in early childhood is, above all, being together in the same spaces, making it easier for them to interact and share

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4 Construct: theoretical construction to understand a specific problem. RAE dictionary.
activities with peers. In the primary education stage, families make great efforts
to provide opportunities for interaction with peers so that their sons and daughters
are part of a group of peers in age. And as development progresses, in
adolescence and early youth, when self-identity is being built and is aware of it,
families give more prominence by taking part.

As in other dimensional constructs, this one is also better understood and
visualized, when viewed from its less positive side. In this sense *there is no social
participation* when situations of segregation or isolation prevail; when
relationships with peers lead to humiliation, belittling or mistreatment or when the
voice of the students is not heard or considered and, on the contrary, their agency
and decisions are manipulated or impersonated.

We know well that students who are located within the autism spectrum has,
from the outset, in general, significant difficulties for social interaction and
communication and, therefore, for social participation. It is a situation in which, if
there is no specific support and mediation processes, it can lead to a space of
social exclusion that is very risky for them and their families.

Once again it seems appropriate to highlight that our intention in
developing this project has been guided by the purpose of understanding the
school dynamics that facilitate or, where appropriate, hinder the development of
social participation of these students (and other aspects in their process of
educational inclusion), with the firm conviction that policies and practices can be
implemented support, in a broad sense of the term, that minimize said risk.

So far it seems appropriate to arrive with a summary of the main frames of
reference, criteria and purposes that have guided our project. It is time to fully
enter the task of sharing some of the results that derive from it, especially those
who tell us how the families and the students who have participated have lived,
perceived and felt their schooling.
PART II

Listening to families with sons or daughters with ASD about the school experience of their sons and daughters: experiences, troubles and hopes.
2. Previous considerations. How have these results been reached? From particular to general. Warnings and cautions

Next, we are going to present five thematic blocks around which we have grouped the main analyzes that we have carried out in this project corresponding to some of its objectives. These analyzes are consistent with a qualitative, interpretive approach to these objectives and that have had as a core element trying to capture and understand how the schooling process of students within the autism spectrum has been (or is being), from education from childhood to university (in some cases), seen from the perspective of the families of these students, themselves and on some occasions, other key informants.

As we pointed out in the Foreword, this is not a synthesis or summary document of the entire project, but only of one of the four studies that have configured it. In other texts derived from the same project, other results can be consulted, in our opinion, equally valuable and relevant. In several of these texts, as well as in the project's report, the different methods used have been fully accounted for, as well as the procedural and ethical criteria so that the results obtained can be considered reliable and valid, within the limitations that they impose their own methods and the number of participants.

It should be noted in this regard that we have had the invaluable help of 22 families and their sons or daughters, belonging to two Autonomous Communities (Madrid and Valencia) initially distributed into five groups, around five important moments in the school life of any student, such as they are the moments of educational transitions; from home to nursery school, from there to primary education; from this to compulsory secondary education; from this to post-compulsory education -which in some cases has been high school, in others vocational training- and, finally, some cases of students who have arrived at the university after completing high school studies.

As these transitions are not similar when you are enrolled in a subsidized center (which usually have several or all stages in the same school), than in a public one (where nursery and primary education are taught in centers other than
those of education secondary), we have tried that our sample had a balanced representation of both types (concerted and public), although it is true that so far we have not made any analysis under this consideration, as well as in relation to the Autonomous Communities of reference.

For the selection of the participating students, we wanted to put ourselves in the most challenging situations possible and, for that reason, we sought with the help of the entities that collaborated with us, students with autism who were considered students with special educational needs. Finally, a set of diverse participants was configured, which cannot be categorized as the same or comparable in terms of their intensity and type of support required.

In view of the above considerations, it is evident that the results to be shared come from a small sample, for convenience, and therefore not representative. Therefore, we strongly invite the readers of this text not to generalize or extrapolate without any caution the conclusions that may be derived from our analyzes to all students with ASD, in any type of school or school at the same times or school stages.

Although it sounds contradictory, this does not mean that these results have no value beyond themselves. Qualitative research like this one has proven to be useful within the framework of a naturalistic generalization, where the reader has the ability to interpret whether what is being told has meaning and value for him or her and whether the description of the context from which it comes and the conditions schools in which it happens are very similar to their own. In short, and pretending to put ourselves in the shoes of our readers, the reasoning would be as follows: “if what these families and their children say is very similar to what we are experiencing, then surely it will be so because there are common processes that explain what is happening, be it for the better or for the better.”

Finally, we believe it is very necessary to highlight that the interpretations we make in this document are not the truth. They can also be biased, imprecise,

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5 To all of them, whether their collaboration was direct or indirect, we thank them intensely for their generosity and help in the development of the project.
and undoubtedly incomplete. But the only way to gain certainty is precisely by sharing and discussing them openly and calmly with those who have been the sources of the information analyzed; with those who are the main actors in this turbulent and dilemmatic process towards more inclusive school cultures, policies and practices, but also with those who want to engage with us in a frank, honest and rigorous dialogue about all of this. That is, on the other hand, the original purpose of the Congress that we have promoted. Facilitate a space for meeting, knowledge and reflection on how and where to move forward to make effective, something more than yesterday, but less than tomorrow.

3. Thematic blocks: stories and stories

The ordering of the thematic blocks that we are going to follow, and the integration in them of certain contents or sub-themes, does not respond to a single criterion, but to the expectation that their articulation will contribute to generating an understandable story, with meaning and, where possible, easy to read.

The citations that accompany the topics and subtopics are introduced with an initial whose meaning refers to the role of the person in the context of conducting the interview: M (mother), P (father), E (student) or D (teacher). All of them are also specified followed by a name, for example, M. Gil. This name (for example, Gil –pseudonym-) refers to the student with whom they are linked. Thus, M. Gil would be Gil’s Mother. It is also indicated in which of the educational transitions analyzed it is located; TS1, TS2, TS3.

Stories and process

School education is, among many other possible considerations, a process, something that happens in a time that does not stop and where many

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6 TS1; From “the cradle” to primary education; TS2; From primary education to secondary education; TS3, from ESO to other post-compulsory studies, including, where appropriate, the transition to university students.
things happen simultaneously. It is a path that sometimes intersects with others, forks or becomes entangled, and that can lead those who travel through them to expected or unexpected destinations. By its very nature it fits well, it feels comfortable, with the stories and stories that try to capture, among other aspects, its temporality, because they bring us closer and tell where that process has taken place, who have appeared at some point in this and what kind of imprint they have left or what effect different events, events or circumstances have had.

As has already been pointed out several times, in this research project the team involved has tried to get a complete, credible idea of what this formal educational process can be like - from birth to compulsory secondary education and ... beyond-, of a particular group of students: those who consider themselves within the so-called “spectrum of autism”. It is very difficult for us to speak in collective terms, that is, as if it were a homogeneous group, when we are the first to defend the uniqueness of all human beings beyond sharing with some certain common and similar traits in terms of cognitive functioning, social, emotional and behavioral.

Although the timing of the educational transitions between stages has been the criterion chosen to select the participants, we have chosen not to follow that organizational criterion in the presentation of all the results that we will now show, except for the first of said transitions. We are talking about the first great educational transition, although currently there are usually two or three micro transitions: the one that occurs, first, from birth to schooling in early childhood education centers that teach the first cycle of education. stage (0-3), wrongly called “nurseries”; the second is that which occurs either between these and other centers (both public and subsidized) that teach the second cycle of early childhood education (3-6 years) or that which occurs within the center itself, between the first and second cycle, in the few cases in which the entire stage of early childhood education is taught in such schools. Lastly, the one that occurs between the end of pre-primary education and the beginning of primary education, which, in some cases, may entail the change of school or its continuity
when it comes to infant and primary schools. In subsidized schools, which also usually provide, at least, compulsory secondary education.

During this vital time, before and after these transitions, it is usual for students with autism in particular and other atypical developments to see their schooling itself reinforced and compatible with interventions of the so-called Early Attention (AT), attention that, according to the dominant model, it tends to be carried out both in centers, public or private / concerted, with variable intensity and duration depending on the public policies intended for this purpose and the families’ own resources.

It is a stage dominated by the initial emotions of a frustrated expectation and where, among many other events, important schooling decisions have to be made that can determine the life and school history of children. They are also the years of the first relationships with educators, educational guidance and early care professionals, encounters and relationships that, at times, are not what one wants and expects.

3.1. Before and after your arrival. From the cradle to the nursery school.

**Emotions, expectations and expectations.**

When it is identified that a son or daughter has some type of alteration in their development, it is, for their parents and extended family, a stressful life event, with an enormous emotional impact, as it disrupts the culturally shared parental expectations regarding the birth of a child.

“\[You set up expectations for yourself when your child is born and suddenly, they tell you; "Well, look, no, this is what awaits you from now on." More than anything, fear, right? Fear... You ask yourself what is going to happen in the future when you are not there and your child is... That is, thousands and thousands of things, fears of all kinds. M.Gil.TS1\]"
Families must cope with what for most is an emotionally complex process that can vary from family to family.

The signs of a development that is intuitively perceived as atypical, raise the alarms that "something is not right" and the beginning of a diagnostic process, itself loaded with fears, anguish and frights.

In those moments, a process loaded with emotions, expectations and expectations begins that could be described as a diagnostic pilgrimage that runs, in parallel, with a certain educational movement in the search for early care and, where appropriate, for a school center or appropriate nursery. Indeed, assuming the concern that something is happening in development, a double pilgrimage appears. On the one hand, the search for a diagnosis that, on many occasions, takes a long time to arrive, when there has already been a lot of time for speculation, doubts, observations and consultations with professionals. In these circumstances, the diagnosis is received with relief.

But, on the other hand, those same parents do not hesitate for a minute to mobilize to achieve all the rehabilitative and therapeutic interventions that, in most cases, are grouped around a model that could be called classic or traditional Early Care, although this causes them, as we say, a continuous transfer from one service to another, which in addition to schooling in a nursery, has a non-negligible economic cost.

"The monitor (of Gil) in the nursery, at that time it was X, well... She also had suspicions. He did not clearly say the word autism, but he began to refer to me as

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7 For most families, “nursery” is the name they use to refer to what from an expert point of view we denominate infant education centers 0-3 years.
8 We refer to the model based on attention based on the work of specialists (stimulation, psychomotor skills, speech therapy, etc.), at the headquarters of these professionals, during relatively short intervention periods (45/60 minutes), distributed throughout the week in one, two or three sessions, as considered and also according to the cost that the families can attend. However, it is good to highlight here that there are other models of intervention, focused on families and their training to take advantage, for example, of daily routines to stimulate children’s capacities.
taking the child somewhere, a neurologist or something because he saw strange things in him and of course, then between that and ... That me, instead of putting the bandage on the eyes, because I preferred to say yes, it’s true, I think my child has something, so from then on, we had an appointment at the private hospital where we went to a pediatric neurologist and there they told us that... On that first appointment... Of a possible ASD. They told us "possible ASD maturation delay"... So, from that moment on we started already... They started all kinds of tests in the hospital... They did electros for him there, they did (tried) ... Sleeping tests they could not do because he did not let himself; They did the audiometry... Everything was going normal, they also did the fragile X, a karyotype, that is, they did a lot of tests. At the same time, we were doing it privately, I already went here to the pediatrician at the health center and I communicated everything they had told me and so on and there at the same time I began to manage it through the public hospital. Then i started also seeing the neurologist... Neuropediatrician from the public hospital, and how she saw that all the tests that had been done previously were the same as what she was going to do, so obviously that was work that we already had in advance. There we also had to start asking for everything from CRECOVI⁹.

As we have been pointing out, the first three years of life of children with autism and that of their families are immersed in a kind of emotional and educational ups and downs, waiting, on the one hand, in many cases, for a

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⁹CRECOVI is, in the Community of Madrid, the Regional Coordination Center for child assessment. Its main functions are; the determination of the need for early care of minors between 0 and 6 years old; recognition of the degree of disability of minors up to 6 years of age and recognition of the dependency situation of minors between 0 and 3 years of age. Families and / or legal representatives of children under 6 years of age can contact CRECOVI by referring professionals from the health, educational or social services field when there is evidence of delay in development or suspicions of the appearance of possible biological or psychological disorders that may affect it, always providing the corresponding medical or psychological reports. To obtain an appointment, it is necessary to complete one or more applications with the documentation indicated in the forms to use, which are separate and independent for each procedure. Once the request is registered, the CRECOVI staff will coordinate the appointment to, where appropriate, match the different evaluations that have been requested. 
diagnosis that most of the professionals involved are suspicious, but almost none of them want or can confidently recognize. In any case, whether the diagnosis is late or not, most families agree that the “first news” is a defining moment in their lives.

On the other hand, the first school experiences generally occur in nurseries where -depending on the offer and the models that each Autonomous Community has promoted-, the educational experiences of children can be very varied in their quality, referring to both to the educational action itself of those who work in them, as well as to the ratios, spaces or additional services that they can, or not, count on.

In any case, everything points to educators\textsuperscript{10} that, as such, they care, care for and love “their children”; who establish good relationships with families and who try to do their job as well as possible, although not always with the best means and conditions, nor guided by the best models of early educational intervention, with there still being a long way to go.

Also, the relationship with families is greatly facilitated since they are very willing to support the school education of their children in everything that is in their power and want their school experience to be as positive as possible.

At the same time, families tend to have a positive perception of the educational work carried out, which, however, seems mediated by the desire that their children be well cared for in an ordinary school setting and by the affection with which the people who treat their children treat their children. they work in those centers. But all this is not synonymous with tranquility or permanent happiness, as there are also many hard moments and dissatisfaction due to the disconnection between the different educational interventions that are being carried out.

\textsuperscript{10} The majority presence of women in the early educational stages is well known.
The relative school tranquility that the families in our study have felt during the first three years is coming to an end as the moment of what will be the second educational micro transition approaches: the transition from kindergarten to a school to attend the second early childhood education cycle (from 3 to 6 years). Concerns arise because they are moments of significant tension and anxiety in families due to all that this entails. In the first place, it is the moment in which families are going to face the quasi-final decision on the modality of schooling for their children; integration/inclusion in ordinary nursery and primary schools (in one of the options provided for this; ordinary with support, or specific classroom) or schooling in special education schools.

On the other hand, it is also the moment to choose, generally, between concerted or public education, a decision in which legitimate reasons for the educational model that they themselves have lived or linked to the moral formation they want intersect for families. their sons or daughters (for example, that they are centers with a religious ideology), with reasons of opportunity, available resources or the available offer near their home, among other factors.

It is obvious, on the other hand, that families face these decisions from the baggage of their own social capital and their knowledge and experience, a very

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11 Very few centers in Spain have maintained what was proposed in the LOGSE (1990) as a great educational commitment for early childhood: that this would run in educational centers 0-6, with two different cycles (0-3, 3-6) but coordinated and taught in the same “nursery school”. For reasons long to explain, the exception, such as the Centro de la Alquería, in Valencia, are those that have maintained this innovative 0-6 scheme.

12 Social capital is spoken of as “capital” that is built from trust and relationships between people. People who, due to their work and/or character, have extensive networks of friends or acquaintances, have “more social capital” to face, for example, difficult times, crises or support needs.
relevant factor when, quickly, they have to become experts in all these issues (type of centers, modalities, services, etc.) and in the bureaucratic and technical procedures that will mediate their decisions (psycho-pedagogical evaluation, opinions, schooling resolutions, etc.).

Most of the participants in our study correspond to those of mothers and fathers with higher education and sufficient skills to face these learnings. But it is also easy to imagine that other more vulnerable families will be at risk of increasing the tensions of these moments due to their lack of knowledge or roots in the current social and school culture. Let us think, for a moment, for example, of migrant families, with low economic resources and with little command of the host language.

We have just referred to the technical-bureaucratic procedures that families will have to live after this first transition. At this point, it should be pointed out that families face, first of all, a situation that, in general, puzzles them. It is about the fact that from the moment your son or daughter has the presumption (or certainty) that they have, as are our participants, autism and, therefore, enter the group of students considered with educational needs. They are no longer the ones who will freely decide where they want their child to go to school. Control of the process passes, to a large extent, to the competent administration, something that families, in general, tend to consider a clear violation of how they understand the right they have to choose the education of their children.

“...And it seemed a bit unfair to me because at the end we have to go a little against the system, against the people who guide where my son has to be and, in the end, it will be a person who will judge whether we are right or not. With which, the situation seemed to me a bit violent and unfair because if we consider that we want to take our son to an ordinary school with supports or even the option of the ADS classroom, they had not even given us that option. Well, it seemed that the doors were closing on you, you had no alternatives.” P.Nic.TS1.
It is true that families always have the recourse to formally show their disagreement with the decision adopted (by signing in that sense the proposal for an opinion made by the guidance teams responsible for this matter). Disagreement that not always, far from it, entails a change of criteria on the part of the administration. When this point is reached, families face another dilemma: appeal through the judicial means of administrative litigation the resolution of the administration (with the cost of time, effort and money that this entails) or resign themselves to what it touches.

“We were even informing ourselves with a lawyer what right we as a family had to defend another alternative (to the one proposed; Special Education Center). They told us that yes, we could be against the report that they (the counselors of the orientation team) issued and continue to defend that the best thing for our son was not Special Education but Ordinary with support. M.Nic.TS1.

On the schooling process of students with nee and the underlying model.

According to the existing model in the majority of the autonomous communities of Spain, the schooling of these students is subject and conditioned to the results of a psychopedagogical evaluation carried out by Educational and Psychopedagogical Guidance Teams¹³, which is reflected, in the case of students considered as nee, in a schooling opinion that has a very important weight in the final administrative resolution of the competent educational authority¹⁴ regarding the proposal or modality of schooling that is finally offered to the family / student.

On the other hand, the general or ordinary schooling processes and procedures, which the educational administrations implement every year between the months of April and May, are not applicable, sensu stricto, for the

¹³ With this or other related names
¹⁴ In the case of the CM, the director or general director of the Directorate of Territorial Area corresponding to the schooling area.
students considered with need, since they and they. They are subject to their own or adapted rules, regulations and deadlines, facts that, once again, fill families with uncertainty and concern, which is why they feel like a difficult process to understand and with many information gaps.

“(You have to) find out about all the different orientation teams that are in the process, (about) all the possibilities that exists if you are a child with SEN or not, about how the points go, who do you have to complain to, if it’s not on the charts or whatever. And now, to top it all off, what I’m telling you, we didn’t get the place, no one could explain to us why we did not get the place when we had points above the cut-off. You don’t even know who you have to complain to, or where you have to go or who you have to talk to...M.Nic.TS1.

“Later, when the enrollment period came out, we thought that the EIT was going to give us directly the school in which our son was going to enter, because they are supposed to have the information about the places that are available and so on, that was what I thought. But no, they told us that we had to go looking for schools, the one we liked and others to fill in the registration with the order of preference. M.Gil.TS1.

For this reason, it is not surprising that one of their first demands in this regard has to do with the need to urgently review and improve this procedure so complex to understand, from the outset, for the majority of families and which is seen as a administrative barrier of the first order.

“One of the complaints that I have about the system is that there is no information or an easy way to get it. We had to go center to center meeting with teachers, with the director... P.Nic.TS1.
This complex, uncertain and, in any case, very bureaucratic process of specific schooling for students with SEN, is more complicated in the case of students within the autism spectrum, thus adding a last drop of concern that, in some cases fill, at times, the glass of the families’ resilience capacity.

“\nWell, the schooling process has been always a martyrdom, it has been horrible. From the first moment they gave us the Special Education opinion and we learned that this already conditioned you, that in all public schools they were going to have that opinion and that we would no longer have the option of entering an ordinary public school. From that moment the point was to inform us as much as possible of everything ... So, that was in July, because you are leaving in July because schools are finished and you do not know anything. We left with the uncertainty of saying we do not know next year what it will be, if they will have assigned us the ASD classroom or not, and you are already a little worried all the summer in that aspect, but... M.Nic.TS1.

It is about the fact that the proposal or method of schooling that usually seems more successful for many (schooling in preferential ordinary centers that therefore have specific classrooms to support the schooling of students with ASD), is subject to its availability, being frequent that there is a mismatch between the demand for places in these preferred centers -with their support classrooms-, and the annual supply of them\textsuperscript{15}.

\textit{The role of educational and psychopedagogical guidance in this process. Albur between professionalism and luck}

In all this process of schooling of students with nee, the professionals of the educational guidance services have a very important role and their

\textsuperscript{15} https://twitter.com/teaincluye?lang=es
professionalism, or lack of it, can greatly condition the educational trajectory of the students and impact on the quality of family life.

In any case, families are greatly affected by a model and practices of psychopedagogical evaluation that are poorly understood but which, above all, have a tremendous impact on the image that parents have of their children and their expectations.

"(in the psychopedagogical evaluation) the future of your child is defined in a photo, which is what that woman (the counselor) sees in a moment [...] You get caught by the first inexperienced evaluation, you believe it all, you... You don't have critical capacity because what they are telling you is so hard that you don't even have time to think, everything falls on you and you go home without power... Then days go by, we talk to other people and you start to remove the darkness that has thrown you and start understanding things ... P.Nic.TS1.

As we have been reporting, the role of these services or guidance teams is, therefore, critical at a time when families are faced with the need to face the first of the educational transitions that will mark the school development of their children. but that entails, as we have already anticipated, two parallel decisions of great importance. On the one hand, it is about facing the decision between an ordinary schooling (in some of its possible modalities that we have just indicated) or a possible schooling in a special education center.

On the other hand, there is also the decision, already mentioned above, in which center parents want to school their children with ASD, a decision in which the weight that the public or concerted character has for the families may be prevailing. but also, as Nic's family shows, the inclusive educational project of some centers that, therefore, are perceived as suitable for their aspirations and expectations.
What we did was try to talk to all the schools that had a ASD classroom, sign up for the open house days, which were at 4 in the afternoon or at 12... special education schools, YX, JK, and another... And then, well, the one that was right next to my work because a colleague told me that a child with Down Syndrome was going there. So, the director’s speech began by saying that education today has nothing to do with the times we are in. In the past if you were a nerd in language and mathematics then you were a nerd, but if you were good at gymnastics, you were a disaster because that kind of a child is a failure... And it is true, and he was talking about multiple intelligences, that a child can be good at technology and not be a disaster.... So, we liked that, that they had tried to evolve, that education is not only based on that, on learning language and math, it is based on many more things... That they have collaborative learning methods, that children from the age of 3 have a partner with whom they feel accompanied and share. So, we saw all those things from normal education ...M.Nic.TS1.

Yes, we saw that they were receptive to the fact that there are different children and they accepted that diversity. Well, we said it was a good place and what we wanted for Nic. A place where from the beginning they accept that the child has different capacities. And that, if a child fails, it is not the child, but perhaps it is the method that fails for that child, not the child that fails.P.Nic.TS1.

On the other hand, we must remember that the fact that early childhood education in its second cycle 3-6 is associated, for the most part, with primary education (6-12)\(^6\), makes it the key to entry to the desired schools (whatever they were). If it is possible to enter the desired school, in the first year of nursery education, children can already stay in it, if they want, until the age of twelve, that

\(^{16}\) In fact, public schools are called Infant and Primary Education Colleges (CEIP).
is, until the end of primary school. Or even do all the secondary school also if it is a subsidized center, since these usually have all the educational stages, which does not happen (with some exceptions\(^\text{17}\)) in public education, where at the end of primary education boys and girls must go to Secondary Education Institutes (12-16 / 18).

For all these reasons, families live these two decisions (type of schooling and specific center), with great concern, anxiety and not a little stress, and hence also the importance of the existence of a good system of orientation and public psycho-pedagogical counseling of quality that accompanies them and guides them in this regard, something that rarely happens. But this, unfortunately, is not well guaranteed, and what is observed is that, on the one hand, it is a process that may be interfered with by the complementary reports of the private TA centers and, to a large extent, at the mercy of professionalism of the counselor or counselor of the public counseling team that has been the lot of the families. All of this is also conditioned by a peculiar schooling policy for students with ASD,

If a family is lucky enough to get the school and the desired schooling modality, a certain calm comes after the emotional storm of the preceding weeks, a calm that usually lasts until the next year begins at the chosen school.

“\textit{In that regard, I have always had very good luck, I do not know if it is because of the therapists who have been assigned to me or because they liked us more than others. But we have been very lucky, really, both when choosing a school and with the therapists. M.Gil.TS1.}"

But if a family is unlucky enough to not get a place in the desired school, an abyss of greater anguish opens up, if possible, because from that moment on they remain at what the educational administration determines, through the Schooling Commissions of each district or zone. This leads families who can, to deploy all their ability to find a center that they consider appropriate, generally in

\(^{17}\text{https://www.educacionyfp.gob.es/dam/jcr:0c07af81-8d1e-4d2f-a6ff-3c988a6f0a49/tabla-1.pdf}
the private sphere, because they fear that the proposal made by the administration may not be to their liking and consistent with their convictions.

The common thing in one situation or another is that the families of the students with ASD, like the rest of the students with SEN, have to “do it themselves” when looking for a center, because the system does not provide them with any (or little) specific help beyond informing them - usually through the orientation teams -, of the preferred schools or prepared and willing to... as the case may be.

In this sea of uncertainties, we believe that few will be surprised if we affirm that the transition processes for the purposes of coordination and transfer of information between kindergartens and schools are, in general, non-existent. Neither the times nor the terms nor the circumstances described help to ensure that this first great transition could be made under quality conditions from the point of view of facilitating the knowledge of the new center for families and children and for them to have information on previous schooling. of the child.

As there is very little legislation in this regard (and even less control over what is ordered), what is done or can be done is, once again, left to the chance of running into professionals, in both centers that, voluntarily and voluntarily want to try to ease this transition for families and students. Do not forget that students with ASD in particular are especially sensitive to changes in routine, spaces and people and that, even if they are small, it would be very valuable to support them in this process.

Therefore, the quality of the transition is reduced to the quality of the welcome that the new school is willing to offer its new student and the enormous and surprising capacity of the children to adapt to the new center.

“Anyway, what I do have to tell you is that as soon as I handed in the registration, when I turned around, I met the director and she was asking me, (and telling me) that she was very happy that the child was there and that they would contact me and the PT would call us to do another interview. And in that meeting
In summary, the situations described seem to point to the fact that, unfortunately, we do not have an educational system that ensures that the first steps in the schooling process are given with guarantees that all children can have comparable educational opportunities and be accompanied by the school measures, support and psycho-pedagogical counseling they need so that their right to inclusive education is effective, starting with the right to a transition between cycles in conditions. Maybe yes and maybe not!

3.2. The following educational transitions. It would cost so little to make them better!

The quality of the educational system is also measured in its details, and the detail of the school transitions cared for and accompanied does not seem to be on the real agenda of educational policies. The trend that we have reflected on the occasion of the first transition is the one that, in general, is observed in all educational trajectories and stages and, not only for students considered with special educational needs (nee), but for the majority in general. Everything indicates that it is a task that is not given due importance and whose value tends to be minimized, under the premise that the majority of children will quickly learn and get used to new circumstances, because they will be doing it! greater!

Of the transitions to come, that from primary education to compulsory secondary education, the dreaded ESO, is especially delicate, in particular, in the public system, since it involves a change in a school - usually small in terms of facilities. and space, very tailored to boys and girls-, to a senior high school and...
usually also (in big cities), to large places, with several buildings frequently, with much more teachers and subjects and living with children and girls (16 to 18 or 19 years old), who are seen by boys as "big boys."

But it is not only a matter of spaces, but in secondary education, the tutorial action (in whose plans, PAT, the preparation and reception of new students should be inserted) is experienced, by many teachers, as a burden and, It is not uncommon for many of the tutorials in the first two years of ESO to be assigned to temporary teachers who have just joined the center, so that, even if they wanted to, it would have been impossible for them to coordinate effectively with the tutors of the schools primary school where its students come from.

"Then the transitions do not work well. From kindergarten to primary school, if it is the same center, it is okay, but from primary to secondary, which are different centers, they do not work well, it would be necessary to do a specific transition work when a boy with some diversity passes because it is important to give him the opportunities and support that need, but if not ... TS2 family."

On the other hand, and given that the institutes receive students from several primary schools attached or naturally linked to them, this coordination between primary and secondary tutors is especially complex given the always busy schedules and the overload of tasks and schedules of each other.

In this process, the mediation of the educational and psycho-pedagogical guidance teams can be a very valuable support to facilitate said transition to the students considered with nee, and this is the case, in some cases. But once again on account of an individual overexertion for a task that is in addition to the usual ones and for teams that, with few exceptions, have fewer professionals than necessary to do this and other tasks with quality conditions.

Again, in the absence of good planning and execution of this transition, it is families with children with ASD or other special educational needs, who
assume, to the extent of their possibilities and disposition, this task of facilitating knowledge on the part of the new ESO tutors -or at least, the management team of the Institutes or the person responsible for the orientation department of these-, of the specific support needs of their sons or daughters. Along with this they offer, as always, their willingness to be in permanent contact for whatever is needed, but they also show their concern (encapsulated from the beginning of their schooling), so that, in this new and difficult stage for all students, that takes place during pure adolescence, your worst expectations and encapsulated fears are not met.

"The image I have of high school it is like a jungle. Is he really going to be okay? TS2 family.

It is obvious that when transitions occur within subsidized schools, the children's knowledge of their school is greater, in terms of spaces and routines, just as it tends to be more frequent (and is sometimes better protocolized) the transfer of academic and personal information from some tutors to the next, within the same stage and towards the following ones. Many of these centers have their own counseling department, which implies better conditions, from the outset, so that this process of change of stage is not so blind, as is often the case between public primary and secondary schools.

Now, in our opinion and having seen what we have seen, neither of the two types of centers (subsidized or public) is guaranteed a well-anticipated, articulated, comprehensive transition process (not only referring to the transfer of academic records and observations) that is participatory and careful. For all these reasons, from children's rights to quality transitions. Boys and girls who do not have to pay with almost always unsatisfactory experiences of these changes, the structural limitations and resources of our educational system. Once again these processes are at the mercy of the circumstances, of the schools and the teachers in luck. "Well, it went well for us." But if it does not go well for you !, the emotional
discomfort is double because it has not been something that has been regular or bad for everyone,

After secondary education the following transitions can only be classified, as worst, when, however, it is of fundamental importance to the personal future of students. And if they are bad for the majority, for the students with more support needs, they are disastrous, because this only increases their inequality, at the same time that they show the lack of equity of the system in an issue, which is not trivial.

“If a child who starts from the age of 3 and is diagnosed, has a curricular adaptation throughout primary school, reaches secondary education and since it is mandatory to graduate from secondary school, you cannot start with curricular adaptations, they have to be taken away from you. [...] If they don’t take them away, they told us “it is that he is not meeting the objectives, the objectives are to do that without curricular adaptation, without more time and he does not do it, so what do we do?” And I said “well. I refuse to let them take away the curricular adaptation “,” think about it “, all this from 1st year of ESO,” think about it because maybe it doesn’t qualify” and everything is focused on graduating ... [...] If you do not have a degree, you may have a certificate such as that you have been studying secondary school and then access one of these programs, Basic Vocational Training where you have enrolled now. But accessing one of these programs does not guarantee that they will enter, he can be left out [...] It seems super unfair to me, it was a contradiction for which I did not understand the educational system very well either. [...] If he stays out I covered a bit, let’s say, my backs in having the option that the counselor gave me of repeating that year, we did that story with the center... Thank goodness that in the end he entered. M.DD.TS3.

We are talking, for example, of the “transition to active / adult life”, since some students upon finishing their ESO studies may (or may only) think of trying to insert themselves into the complex and competitive world of work that is at
doors of the Institute or school. We are also talking about the transition to possible and different post-compulsory studies (baccalaureate, vocational training or others, regulated or unregulated), all of which requires powerful and well-designed academic and professional guidance plans (POAP) that should be designed to all students and implemented throughout the entire stage, and not just as something specific.

What we have observed and known is that if, in general, academic and professional guidance leaves much to be desired in most schools (subsidized and public) for students without need, what is unusual is that what is done is thought and carried out with an inclusive approach, that is, for all students. An approach of this nature implies thinking with universal design criteria, but without losing sight of specific measures and actions, when needed, for some students (such as students with ASD). Only then will you not deprive any student of their right to a good orientation which, by the way, is much more than a brief and hasty information on some “exits” or academic options.

In summary, what these analyzes reveal is, as has been pointed out, a weakness and neglect on the part of the authorities of the personal, academic and professional orientation, where plans and actions must have their natural space to ensure quality transition processes for all, that is, inclusive. These general plans of personal, academic and professional orientation, together with those related to tutorial action, despite being contemplated in the regulations that govern the organization and operation of secondary education centers (public and subsidized) and, in particular, being inserted in the functions of the guidance departments, they tend to be seen as a matter of relatively little importance. This is, as something that can be solved with a few actions and all this despite, for example, the data that show the high figures of early school leaving in our country, a reality whose improvement would need, among other factors,

Changing this situation would not cost much materially, although it is a complicated change in culture, because it would mean seeing school education, not only from the narrow point of view of the strictly academic, but as an
intentional and well-planned action to prepare all students for a quality personal and social life.

3.3. Social participation. From said to fact there is a long way. Also, from being there to being part there is a long way!

As we have indicated in the first part of this document, within the framework of this project we have understood and defined “social participation” as a complex construct in which several dimensions intersect that have elements in common but also aspects of their own, some of the which are more salient in some moments of development and, therefore, in the different educational stages.

The first thing to point out is that we are talking about a psychological or psychosocial dimension that affects the emotional well-being of all people at all times of their lives like no other. An emotional well-being that is linked to the sense of belonging and the need to share games, relationships or activities (real and increasingly virtual\textsuperscript{18}). Being together is the necessary basis, although not sufficient, for the next step, which is to feel part, that is, to feel good about oneself, with a positive self-esteem that, as we well know, depends a lot on the value of peers, on the perception of being part of a group where positive social relationships are established and cultivated, from the lightest to friendship. Finally, increasingly as adolescence progresses, the importance of taking part in decisions that may affect you socially (within and outside the social groups of reference) and in which, as in other spheres of your life, the students want to be heard and taken into consideration.

\textsuperscript{18} Virtual communications through the platforms to use have been, in this sense, fundamental to alleviate the perception of isolation, unease and personal discomfort that the COVID 19 pandemic has brought with it.
This complex characterization of the construct of social participation will gain great importance as schooling progresses, until it becomes, in our opinion, a core and critical dimension when assessing the quality of the inclusion process of students with ASD, but also anyone else’s. In other words, the important thing is not that students with ASD or other specific needs for educational support are in a greater or lesser proportion and time in ordinary schools, but how they are, how they feel in them (participation) and how much learn. It does not hurt, incidentally, to remind administrations and especially public opinion, that when talking about the level of inclusion in our country, evidence is shown not only of the number or percentage of students with nee

In the first years of life and in the first experiences of schooling and returning again to our analysis of the voices of families about social participation, this participation moves in the field of being together and being part of a group of equals in age.

“Let’s see, I think it was clear that I was lonely, so I don’t know if ... Let’s see, I would have liked to receive help, obviously, but more than that they put me with a group of people I did not know and with whom I had not met. The first thing, I would have looked at is my own interests and would have talked to me about basically that, that not everyone has to think exactly the same. And try to find a group that has common interests, but not identical, which is what I was looking for. E.TS3.

My son has been in his class since he was 6 months old, from kindergarten, since he was a child, he is used to being with children and what he likes is being with children, with his people. M.Gil.TS1.

On the other hand, it is known that at these ages (between one and three years), the game plays such an important role for development. Also, the fact that boys and girls have not built a negative perception of the difference. This creates
a space for coexistence in the classroom that is perceived as very inclusive, and families generally feel satisfied with the fact that their children with ASD are part of a group of equals with whom they share not only spaces, but also routines and games.

“...So, we are happy that he has advanced in many aspects. They have been much more open to children, they have shown us videos playing with the children in the happy playground, they are super happy.... What I want Nic to learn are the routines, to integrate, that if they are in an assembly they have to sit in the assembly, to listen to others... And those things he is doing and they transmit that to you... He participates in the assembly because he does not know how to speak, but he listens, he sees what others are saying, then at home he tries to convey it to you. M.Nic.TS1.

At the same time, when there is a good teaching performance, the peers of boys and girls with ASD learn well to recognize their specific needs, to help them and to accept them naturally.

“In general, children treat him super well. So, I don’t really know what the school has done, but when I’ve been with them in line and so on, the children are aware that Nic has certain difficulties, he doesn’t do certain things, but hey... In the end they understand. At first, they may ask you what is wrong with him, that it is different, but if you normalize it, they see it as normal. M.Nic.TS1.

At these early ages, families experience an enormous positive emotion when they are informed that, for example, the day has gone well, "without incidents", that they have been well or when, for example, when entering or leaving the nursery school, they see some gesture of approach towards them on the part of a particular boy or girl. In this sense, everything points to the fact that, if properly intervened, boys and girls develop a kind of empathy towards their peers with nee and display behaviors and attitudes of care, play and recognition.
Hunting and capturing social relationships for our children.

If somewhere we have said that the first years of schooling -until the beginning of primary education as a symbolic frontier- are a moment of tranquility with regard to concern for social relations given their characterization at those ages, it has soon starting the journey of a long stage that will make families, once again, have to deploy varied strategies to support their children when it comes to facilitating, not just being together with their peers, but also starting to be part of a group, that is, to have positive social interactions and relationships geared toward that precious and often difficult goal of building friendships.

It is not easy for students on the autism spectrum to initiate and sustain meaningful interactions and communications with their peers, just as it is not easy for them to learn to understand and be patient with their peculiar way of being, their restricted and highly recurrent interests. If there are no structures and supports to mediate this process, in many cases it will become very difficult and then situations of isolation will gain ground. For this reason, it is essential to define the supports that each student needs and provide them throughout the entire schooling.

Within school time, this isolation can be perceived as less than what happens outside of school, since school time is full of individual work and when not of group actions directed by the teachers. Which does not imply, that this is the best in the attention to the dimension of social participation. It is understood that the school is responsible for generating these valuable opportunities for interaction in the different spaces, inside and outside the classroom. On the other hand, the great knot in the stomach for families regarding the concern about the isolation of their children occurs in non-school times, on weekends in spontaneous activities outside school, in "staying" to play or do something shared and in the (no or few) birthday invitations.

From what families tell us, it is rare that they do not try and mobilize all the strategies and good arts within their reach to achieve outside of school, that such relationships and encounters take place.
This concern and difficulty will increase as children get older and is critical, for the first time, in adolescence. This is the group stage, of creating a self through group identification through shared tastes, fashion or games (as is the whole world of video games, for some boys or girls). And when you have narrow interests, as is often the case in childhood with autism, it is difficult to fit in, be accepted, and be part of some of those emerging groups. From which there are important implications for the educational context when working on aspects related, for example, to the recognition, acceptance and appreciation of differences by their peers.

The younger it is easier and the older they get it is more difficult, but above all because there comes a time when a gap opens up between the interests of some and others that is very difficult, in this case for a child with autism. So that gap is much bigger, it is complicated because there comes a time that if a child is having a conversation with another and if he turns around and leaves because he does not stay in the conversation, then, in the end, you say: well, it is a no. AT de Ja (TS3).

Hence, if these relationships with school companions are not achieved, families who can strive to look for them outside, first through the general community activities established by municipalities or ad hoc groups, for leisure, sports or culture. But it is rare that these groups are designed for everyone, that they are genuinely inclusive, so it is not uncommon for the trials to find in them options to be part of peer groups end, in a short time, with a significant dose of frustration. for children and their families.
“Let’s see, parents ask you to go because we think it can help him, because we have talked many times about activities that we think can help him socially to have a habit of being with people, whether we want to or not, in the end you have to promote it. We have tried and signed him up for many extracurricular activities [...] and he has made the effort to go there and that is where I no longer dare to speak. He has made the effort, up to there yes, now what he thought while there... He does not tell it when he returns. P.Ja.TS3.

“...My mother signed me up for soccer, although I hate it a bit. I suppose that because I had to do some sport. But I'm useless, in fact, instead of catching me and saying "you defense", they said "stay there and play a stick." So... [...] At first my father signed me up for tennis, but then I decided to stay because I liked it. Of course, it is playing alone with another ...E.Ja.TS3.

Hence, in the absence of other options, it is better than nothing to sign up for the offers that the associative movement of people with ASD usually develops within the framework of its members' leisure and free time plans and programs. In the end, the important thing is not to leave without enriching, as far as possible, the well-being of feeling part of a group, of having someone with whom you share interests and hobbies. We see, then, that the currency of a certain degree of segregation is the currency to pay for a certain degree of social participation.

In this area, as in others, one of the difficult paradoxes that accompany the process towards more inclusive realities emerges, be it at school, in free time or in sports (and also, later at work). As the common is not prepared to be inclusive and resists change - it is true that these changes are difficult - necessarily open the doors of the specific, but therefore separate from the common. They are spaces, groups or activities where, at least, there is relief to many needs felt by the most vulnerable groups, such as students with ASD and, with this, the existence of a certain well-being that cannot and should not be neglected. But
for these same reasons, these mechanisms operate against plans to improve that (school, sports, leisure,

"We took him to the workshop they recommended for him on weekends. In the workshop he met this boy, similar to him. He made a lot of friends with him. [...] In fact they are still friends, although they don't go out together on weekends. TS3 family.

The double-edged sword of ubiquitous digital technologies.

It is evident to all that digital technologies for communication and leisure have penetrated our lives, and that of our sons and daughters, to places that, until recently, would have seemed like fantasy to us. They are there with their double potential - for relationship and communication with others who do not have to be physically next to them, but also for accompanied isolation and self-absorption. Indeed, for all children and adolescents’ access to screens -as an expression to refer to the use of games, applications or access to videos or TV programs and, where appropriate, to information about their interests, through mobile phones, tablets or computers - it has become an inseparable companion in their lives and an inexhaustible source of entertainment. The difference,

In this as in other areas (for example, in the use of social networks) everything will depend on the ability of families to try to modulate its use, that is, to maximize its advantages and minimize its risks. This is not an easy task for the vast majority of families who, from the outset and generally, do not know or handle themselves as well as their children with them. Here emerges the need for an urgent task of training and advising families in this field, as well as the students themselves, because we well know that technologies, through social networks, can be an unbearable amplifier of the worst situations of Peer abuse due to abuse of power, the dreaded and worrisome “bullying”.
This reality has emerged strongly during the development of this project, which has partly developed in times of pandemic and restrictions on mobility for all. We were able to know, for example, that, in the case of some older students with ASD, that mastery of the screens has made it easier for them to take advantage of online classes and, with it, for their parents a peace of mind that they urgently needed, among other needs, to be able to telecommute. In addition, it was an ideal means of being part of a group (network play, for example), minimizing face-to-face social relationships that, as is well known, are costly for students with autism spectrum disorder.

_The slippery terrain between wanting and needing to be alone and being isolated._

This theme of the role of screens connects with another tension that emerges repeatedly when living with childhood, adolescents or young people with ASD. We refer to the narrow dividing line between the right that they have to be alone, in their world, disconnected from the outside, but calm and safe from noise, contacts and events that they do not control, and the risk of chronic isolation that curtails the need and the right to be part of social groups.

"I tell little, sometimes I don’t talk much because when I write a message, something worries me, if they tell me something bad and they mess with me, and that’s why... What is difficult for me is to understand. And so, that’s why I don’t speak much on WhatsApp and stuff. E.Ju.TS3."

"I have spent several recesses alone and that is quite difficult, that is, half an hour doing absolutely nothing, without having anyone to talk to, they are very difficult to endure... [...] Six months of social disintegration. E.Ja.TS3."
I wish we had a predesigned and useful answer to alleviate this tension and especially to recognize when you are on one side or the other of the dividing line. In this regard, the main support to be implemented is that of continuous supervision and continuous dialogue between educators and families, since they are specialists in knowing their children deeply and, the first who are willing to collaborate in the task of build participatory environments. We are thinking, for example, in the design and implementation of inclusive patios.

This is a subject that we have thought a lot about and about which we will have to continue thinking and working. But throughout the project we have also established our firm conviction of that, if the school context offers opportunities to take part and appropriate support mediates, the need to be alone will be less.

Indeed, as is well known, Autism Spectrum Disorder (ASD) has among its defining elements deficiencies in social interaction and communication, along with restricted patterns of behaviors and interests. Nobody is going to deny these difficulties, but it is important to bear in mind (although it is taking a lot to change the vision) that these deficits interact with the environmental barriers, determining the functional limitations at the social level that a person with ASD experiences. Therefore, if we intervene on the barriers to participation in the school environment, create opportunities and mediate with specific supports, the result will be adaptive social functioning and social inclusion.
If we are allowed to make a comparison, we would be talking about supports, for example, for interaction and social relationships (such as programs for accompanying students, the circle of friends or programs for social and communication skills) that, like crutches, walkers or wheelchairs for people with reduced mobility, allow or would allow children and young people on the autism spectrum to display communicative and social behaviors that would make possible a better school and social inclusion.

This leads us to affirm that children with ASD are not incapacitated for contact, relationship and social participation. They need an explicit, planned and supervised educational intervention so that the weeds of marginalization, contempt or mistreatment do not grow in their wake. We are not talking about miraculous interventions, but about systemic interventions aimed at making the school environments of the center more participatory, and developing plans, programs and strategies known and applied in many places, inside and outside our borders.

What are we talking about when we talk about friendship in the TEA universe?

It could well be said that the maximum exponent of the dimension of being part of a group would be given by the establishment of friendly relations with some of their peers within those groups. The concept of friendship and the behaviors
that characterize this relationship change at different stages of development. It is a constructed relationship that implies an affective bond characterized by its reciprocity (that is, mutual knowledge and appreciation, acceptance of the other and expectations that each person accepts and cares for the well-being of the other, while expecting to receive the same); intimacy (sincere and direct communication) and the development of prosocial behaviors that seek the benefit of the other.

The question is whether this is applicable as such to childhood that is located within the autism spectrum or if, on the contrary, we must handle some modulating elements in their case. This reflection seems important and necessary to us, because one could fall into the error or pursue and intervene to promote in these students a model of friendship that does not fit their development, or give up doing anything under the false belief of that this is an achievement out of reach.

What we have appreciated and learned from sharing their children's life stories with families and talking to them too is that when we talk about the friends they care about and need, their best (though usually few) friends are the ones who they know and understand their needs (communicative, sensory, social ...), they respect and can share their particular interests or tastes, and they provide them, at times, social support.

“The concept of friend? Well, a person you trust and that you can lean on, and who is capable of helping you and you too. A person with whom you maintain a stable relationship and whom you can trust. [...] But my definition of friend is not... I mean, those kinds of people I like to spend a lot of time with, I call them best friends. Spending a lot of time is, for example, that I like to be with them as much as possible, that is, that I have a good time. And that, in general, that if I pick up and they say "hey, do you want to come?", Well I say "okay, I'm going", I have a good time, I'm with them, I suppose we will be playing Nintendo, as always, but ... And that is, well, let’s all understand each other basically. EJa.TS3.
In this sense, we believe that it is important that, in schools, they find among their peers other children with autism and with different support needs that do not make them feel isolated and that help them to see that their situation is not unique because, among other things, it has no classmates or at its center with whom it can share its intense interests and tastes. This consideration has already been taken into account in the inclusion policies for Deaf students (particularly those who use sign language as the preferred means of communication). For this reason, it was seen the need to incorporate into the centers where they are educated a staff called (in the Community of Madrid, for example) "deaf advisers" one of whose main functions, in addition to facilitating the learning and use of sign language, it was to be a cultural reference, understood as a reference that oral language is not the only form of communication and that you can become an adult by being a user of their language. In this sense, it is a success that the inclusion policies of students with ASD follow a similar pattern and that in the centers there is at least a small group with which to identify and, where appropriate, build their friendship model, which Not being the same as the one that operates in the majority of students without ASD, it also fulfills the same psychological functionality that is very important and necessary for their well-being.

What the families in this study have also shared with us, especially those who already had older sons or daughters, is that in the evolution of social participation, as we have here we are analyzing, being part of and feeling part of a group, with the expectation of reaching situations of friendship, it will become LA (with capital letters) the main concern of families and, at those ages, also the main concern of the young people themselves, contradicting once again the false belief of that, being autistic, this is not an issue that affects them and therefore does not concern or worry them19.

19 As an example, you can see the series "Love on the autism spectrum." https://www.netflix.com/es/title/81265493
And in their case, we are also talking about their need, like everyone else, for love and positive sexual relationships, because it would be wrong if we allowed the belief that they, as well as other young people and adults with disabilities, continue to be installed. Being as they are, this makes them asexual beings, and without the need to receive and give affection and love.

We have no problems yet because sexuality has not appeared, but we are going to have a lot of problems because he wants to be a father. He was born to be a father, what happens to me, comes with the chip on being a father. You have it changing dolls' diapers, playing dads, everything. And he wants to be autonomous, he wants to get married, he wants to have a wife, he wants to have a large family. You say, there will be a moment when you have to face life and say, well, let's see, you are great and handsome, now, what if the girl you love
doesn’t want you? There are many things that, in sexuality, people learn from friends. But if his social ability is reduced, a friend will not explain it to him, I will have to explain it to him. Tasks as important as sexuality … I tell him many times, “Is that to flirt you have to be polite, you have to know how to dance, you have to be funny, you have to know how to tell jokes …”. I am already preparing him so that he can go out and meet a woman, because I am going to find that now. And there is going to be a moment that, if you’re lucky, maybe a girl from her class … I’m telling you, he’s good, he’s handsome, he’s careful … Maybe he’ll accept it, but if not … TS2 family.

3.4. The instrumentalization of inclusion in order to make other children “better” “more understanding.” The excruciating bitterness of commiseration for families.

On many occasions, when it has been tried to justify the value of educational inclusion policies, a well-intentioned argument has been used to which, however, the saying that “the road to hell is paved with good intentions” can be applied. We refer to the argument that these inclusion policies, what they allow to achieve is that the “poor” children with disabilities who were in special schools and have difficulties, come and be with “normal boys and girls”, something that would be very good for these, because it would make them see that there are “different boys and girls” (as if they weren’t) and in this way they will be better people in the future, more understanding of “diversity”. One can understand the reasons why these arguments are there and that, even,

“Of course, they think that it is very enriching (having a ASD Classroom at school), not only for the child, but for all the rest of the classmates, they are committed to inclusion, so everything is oriented so that the children in their class and others, they think it will be very enriching for all of them to be with children with SEN. That has been the first motivation: both for the children and for the whole school, teachers and everything. M.Gil.TS1.
So, I believe that in the end a “different” child is of whatever type, (it helps to create) the awareness that there are different people, that each one contributes in a way and in the end it is necessary to adapt and think about all of them, not only in yourself.... And another thing that we liked about that center is that here the children, apart from the fact that it deals with diversity, is that we see that if one child goes slower than another, what they make others understand is that nothing happens if today we don't learn this we are going to go at the same pace as the others ... Because they are teaching an ethical lesson, you are saying that in the world there are people different from you and you have to adapt to each need. And children learn from that. M.Nic.TS1.

But it is not an innocuous argument, but a slippery one, not infrequently annoying and in the long run dangerous under what circumstances. It is, because it gives inclusion policies a certain instrumental character for the benefit of some children, but not all. Figuratively, some families have come to us to say something like: "My child with ASD is not a resource for your child without ASD to learn that there are different children." That is, school should not be made (as it is still mostly) for normal children, but for everyone. "And my daughter or my son has the same right as yours, to be in that school, to participate and feel good about what happens there and, for all that, learn and perform to the best of their ability." That is, their rights and needs are not behind or below those of other children, nor are they subject to not disturbing, interfering with or harming those who euphemistically continue to call normal students. It will be a problem and a task for the school and the educational system to create the conditions for this that we could well call an extraordinary school, so that everyone has comparable, fair opportunities to be together, participate and learn. But it is not our children's problem!

It is not strange, therefore, that some families feel (in privacy) annoyed and hurt with these well-intentioned but hurtful arguments, because it is not the pain or the commiseration of those who have been lucky enough to be normal that
their children need, but rather the conviction that the history of segregation or contempt for this most vulnerable student body is a history, like others, of discrimination that must be left behind as soon as possible.

*The quality of family life (parents and siblings) on the tightrope all day.*

From the distant day when the information that their child had autism was confirmed, until today, no matter what today, the families (fathers, mothers, siblings, grandparents, etc.) of these children, adolescents or young people They have been there (and will continue to be), being their main support; its champion, its link for the generally weak inter-agency coordination (health, education, social welfare); your seeker and supporter of extracurricular and leisure activities, with an unwavering and unconditional love, all of which does not mean that without costs.

Rather, the opposite, that is, with a great impact on their quality of life, be it on a personal, couple, family or social level and, of course, also economically. Among other cutting edges for mothers and fathers is the pressure of being all day waiting for someone to call me from school: “it has bitten”, “it has not eaten”, “it has hit”, “it has escaped”, and so on. but, if they don't call, the concern is not mitigated, because then they spend the whole day waiting for “what will have happened” and what they will be doing with him / her “, “what decisions they will be making without us (the family) ”. But yes, “when they need you to help out (party, outing, excursion, etc.) very quickly they call you; And you are so happy! but to think about their curriculum, what and how to teach them, they are “the experts” and you have little to contribute ”.

The perverse effect of being able to think about the future also means that these concerns are present from birth and that they accompany them during the development of their children, although, paradoxically, it is very likely that some are mitigated over time, precisely as an effect of a well-managed parenting, a school education that, with all its limitations, has been able to fulfill its role and
with the accompaniment and support of what we call organized civil society, in
the form of associations and organizations in the sector.

It is not our intention to sugarcoat this narrative that now ends. There is no
guaranteed happy ending, but neither is it that it is an eternal homelessness! The
future is not written and, as we have been defending since the beginning of this
document, the quality of life of children, adolescents and young people on the
autism spectrum will depend a great deal on the determination of those who have
the capacity to establish policies. (educational, social or for employment) with the
capacity to optimally mediate between the capacities and characteristics of this
childhood, and the demands of the environments in which they have the right to
function with guarantees of equity and inclusion.

4. In conclusion. And what can we do?

The saying goes that "a good understanding needs few words." Throughout the text, some of the multiple barriers installed in its educational
system and in the cultures, policies and school practices have appeared (some common to all educational stages, others typical of some of them) that should be
removed to make the study credible. solemn declaration that inclusive education
is a right for all students and therefore also for students with ASD.

It would be somewhat repetitive and above all tiresome and detrimental to
the purpose of this text, to recount, order and explain such barriers again. If
someone needs this information, we will gladly put at your disposal all the
references you need to work where not only the existing barriers are analyzed,
explained and detailed, but more importantly, the actions and supports necessary
to transmute them into cultures, policies. and inclusive practices.

For this reason, our latest reflections are aimed, above all, at asking that
one last effort be made: that no more excuses be sought to try to justify what is
not justifiable today; the segregation (total or partial), the persistence of situations
of marginalization, contempt or mistreatment of many boys and girls with ASD or
the neglect of their learning and performance. Not everyone is on this dark side of reality, but it is enough for us that one was to demand the required changes with equal intensity.

No more excuses! Was the topic that was also raised on Facebook by a mother who knows what we are talking about, not many months ago and that in a short time generated hundreds of threads where many excuses were collected from which families with children in situations Vulnerable people receive daily, here and in other parts of the world, given before entering that common school that refuses to change and when, despite everything, they manage to integrate (badly in more cases than would be desirable) in them.

We are going to point out some of these excuses. Before school:

- We have vacancies for that group ... Ah, but if it is with a disability certificate, we have no vacancies.
- For you to get started, your diapers must have been removed.
- We do not have a pedagogical guidance team, and she needs it.
- Our building does not have ramps.
- We have many students per group; he needs classrooms with fewer students.
- Don't you think it can be an uncomfortable situation for your siblings?
- It cannot start until the companion joins.
- If the companion is absent, they cannot attend school.
- You have to go through intake interviews with the team.
- We have no experience in inclusion. We are not prepared.
- Our school is very demanding academically, you are going to feel bad.
- What diagnosis do you have?
- Didn't they tell you about a special school?
- We need the reports of the professionals, a psychopedagogical evaluation, with CI.

And when they are inside, they have other excuses prepared:

- Has a lot of difference with their peers
- She has a bad time, she has no friends
• We did everything possible, we got here.
• There are mothers and fathers who complain, we do not want to expose you as a family
• The act is going to make him very nervous, he better not come.
• You have to reduce the day to one hour, it is the best.
• Outside the classroom he is calmer, we are going to create a space for him.
• The teaching team is not prepared to accompany them.
• The special modality is the most beneficial for her, there she will have pairs.
• We have the problem with your group, they cannot be late.

The families that we have interviewed, and who have so generously shared with us snippets of the life stories of their sons or daughters, have come to tell us, to conclude something like the following: "I don't know what you will do or stop doing. do as a teacher, counselor or person in charge of the educational administration of these matters, but we cannot and do not want to ignore the well-being of our sons and daughters and, therefore, we will continue, in our own way, with our strength, trying to ensure that their school experience resembles that beautiful story that we have read and heard in many places. And if ... for a while you did the empathic exercise of tracing yourself to our motherhood and fatherhood: Where do you think it would take you?"

Thanks for listening!
Pablo

"Estudio de mano"
Pablo: 1º ESO 2013-2014
PART III

Resources and references to keep thinking and doing.
This last section contains some documentary and audiovisual resources in Spanish that may be useful for family members, teachers, counselors or people belonging to the TEA collective. It is a selective compilation and not a recommendation, since in some of these resources analyzes and proposals may be raised that we do not necessarily or 100% share. Therefore, as is often said in the editions of some texts, what is said in these resources does not necessarily compromise or reflect the opinion of our group.

For its organization we have used the following headings: action guides and information organized around various areas, as well as stories, films, TV series or short films. A series of resources and / or applications related to personal and family well-being are also made available to the reader.

It is also important to remember that all state Federations of associations of people with autism (such as Plena Inclusión, Autism Confederation Spain, and the Spanish Federation of Autism) as well as the vast majority of regional and local associations, and platforms such as TEAIncluye, have in their web spaces with information on resources and information of interest on the subject or provide contacts to learn about them. In this sense, this final section of the text does not intend to supply such sources of information, but rather to complement them and, above all, to remember precisely that what is lacking to significantly advance the task of promoting a better quality of school and social life in Children and adults with autism are not knowledge (theoretical or practical), but what is lacking, on many occasions and in people, is the will and determination to take them to action in congruence with the values that underlie the goal of a more inclusive education for a more inclusive society.
I. Guides

**Before the diagnosis**

Information for parents when they suspect a problem of social and communication development.


Good Practice Guide for Early Detection of Autism Spectrum Disorders


Good Practice Guide for the Diagnosis of Autism Spectrum Disorders

https://www.catedraautismeudg.com/data/articles_cientifics/8/ddedcc91420c4a00aec818a57ce05ed2-guiadiagnostitea.pdf

You're not alone.


100 Day Handbook for Families with Young Children Newly Diagnosed with Autism.


A child with autism in the family.

https://sid.usal.es/idocs/F8/FDO20581/familia_autismo.pdf


Information for parents after a diagnosis of Autism Spectrum Disorder (ASD).


Informative guide for families of people with Autism Spectrum Disorder.

Education

Students with ASD: guidelines for planning the educational response. Inclusive proposals to intervene in Infant, Primary and Secondary.

https://www.educastur.es/-/efemerides-02-04-dia-mundial-sobre-el-autismo-guia-alumnado-con-tea

Steps for an effective relationship. Communication with your son or daughter's educational center.


Changes in the LOMLOE for students with special educational needs.


An attempt to shed light in the middle of the storm (part 1). Real problems in the right to inclusive education

https://hayderecho.com/2020/12/02/un-intento-de-arrojar-luz-en-medio-de-la-tormenta-1a-parte-problemas- reales-en-el-derecho-a-inclusive-education/

An attempt to shed light in the midst of the storm (part 2). Clarifications about special education

https://hayderecho.com/2020/12/03/un-intento-de-arrojar-luz-en-medio-de-la-tormenta-2a-parte-aclaraciones-sobre-la-ley-celaa/

Asperger Syndrome: A Guide for Education Professionals


Supports 2030: a journey to advance towards personalized and community supports


https://www.observatoriodelainfancia.es/ficherosoia/documentos/5484_d_GUIA-BULLYING-TAE.pdf

Responsible and safe use of ICT in students with Autism Spectrum Disorder.


http://www.autismo.org.es/sites/default/files/comprendo_mi_entorno_manual_de_accesibilidad_cognitiva_para_personas_con_tea.pdf

Guide of assessment of the cognitive accessibility of environments

https://www.plenainclusion.org/sites/default/files/guia_de_evaluacion_de_la_accesibilidad_cognitiva_de_entornos.pdf

Strategies to maintain routines and support sensory integration. Practical ideas to do at home.


Technical-pedagogical support guide: special educational needs at the preschool level.


Guide for students with Autism Spectrum Disorders. Transition from primary to secondary education.


What should we know about Secondary Education?

http://riberdis.cedd.net/bitstream/handle/11181/6443/Qu%C3%A9_debemos_saber_sobre_la_Educaci%C3%B3n_Secundaria.pdf?sequence=1

Friend circle

http://aetapi.org/download/circulo-de-amigos/

Inclusive patios

https://www.elhuertodeideas.org/sites/default/files/Documentos/PATIOS%20INCLUSIVOS.pdf

Guide for the care of university students with Asperger's Syndrome.

https://web.ua.es/accesibilidad/documentos/cursos/ice/quia-asperger.pdf

Towards a model of university support for students with Asperger's Syndrome: needs and proposals for action.

Education of adults with autism.

Quality of life
Quality of life and autism spectrum disorder. The higher the quality of the support, the better the lives behind it.
http://www.autismo.org.es/sites/default/files/calidad_de_vida_y_tea_coleccion_calidad_de_vida_web.pdf
I also decide. A practical guide for people with autism spectrum disorder and high support needs to make decisions about their lives.
http://www.autismo.org.es/sites/default/files/saludmental_digitplan_2.pdf

Job
http://www.autismo.org.es/sites/default/files/un_potencial_por_descubrir_digital_baja_cuerpo_junio_0.pdf

Rights
Easy-to-read guide for people with autism spectrum disorder and their families. Make decisions that protect our legal interests.
Tutelary foundations. An alternative to favor the legal protection of people with autism spectrum disorder.
II. Stories

“Enjoy” Collection of Visual Learners
The little pink bird. https://aprendicesvisuales.com/p/pajaritorosa
The dragon chef. https://aprendicesvisuales.com/p/el_dragon_chef
The pirate frog. https://aprendicesvisuales.com/p/la_rana_pirata
The explorer smell. https://aprendicesvisuales.com/p/el_oleedor_explorador
The fluff moves out of the house. https://aprendicesvisuales.com/p/las_pelusas_se_mudan_de_casa

“Aprende” Collection of Visual Learners
Various stories to enhance self-care, learn routines and become aware of emotions.
https://aprendicesvisuales.com/p/ Tales_aprendicesvisuales/

Stories online
The ugly Duckling.
https://www.pictoTIES.com/el-patito-feo

The concert.
https://www.facebook.com/Asociaci%C3%B3n-Navarra-de-Autismo-ANA-267996259925713/photos/a.1082400681818592.1073742049.267996259925713/1082400721818592

Stories focused on siblings
My brother has autism. An explanatory book for children between 4 and 5 years old.

My brother has autism. An explanatory book for children between 6 and 7 years old.
What happens to your brother?

https://www.plenainclusion.org/publicaciones/buscador/que-le-pasa-a-tu-hermano/

My sister Lola.

https://www.plenainclusion.org/publicaciones/buscador/mi-hermana-lola/

Unique beings.


Stories on paper

*Kalakandra and BATA*. Editorial Kalandraka, in collaboration with the Association for the Treatment of Autism BATA, launches a collection of stories especially aimed at children with special educational needs under the name of Malakiño.

https://www.kalandraka.com/authors/bata

"Maria and I". María y yo is an important work, both for the subject it deals with, autism, and for the delicate, sensitive and funny look with which Miguel Gallardo shows us his happy relationship with his daughter, María.

https://www.astiberri.com/products/maria-y-yo

"Maria turns 20". Seven and a half years after the publication of María y yo, Miguel Gallardo once again shows us the look of his daughter, now in her twenties, and her relationship with the world.

https://www.astiberri.com/products/maria-cumple-20-anos

III. Short films

*My little brother from the moon*. My little brother from the moon is a short film that shows us, from a girl's point of view, the symptoms of autism in her younger brother. With the simple way that children have to explain things to us, we see how, despite not understanding very well what is happening to her brother, she makes an effort to overcome barriers and connect with him.

https://www.youtube.com/watch?v=IO85pTSvg7c

*Academy of specialists*. Academy of specialists shows in a fun and entertaining way the special abilities that many people with autism have and that are not always understood when viewed from the outside.

https://www.youtube.com/watch?v=fCoBk1tWYEs
**Float.** In this Pixar short, a father discovers that his son is different from other children in a very unusual way.

[https://www.youtube.com/watch?v=MnU1hHFsGQc&ab_channel=MellowDropMedia](https://www.youtube.com/watch?v=MnU1hHFsGQc&ab_channel=MellowDropMedia)

**Strings.** It shows the story of a beautiful friendship and the importance of coexistence from an early age.

[https://www.youtube.com/watch?v=4lNwx_tmTKw&ab_channel=StringShortFilmOficial](https://www.youtube.com/watch?v=4lNwx_tmTKw&ab_channel=StringShortFilmOficial)

**Lorenzo's saucepan.** Talk metaphorically about differences. It shows the overcoming of day-to-day activities.

[https://www.youtube.com/watch?v=4lNwx_tmTKw&ab_channel=StringShortFilmOficial](https://www.youtube.com/watch?v=4lNwx_tmTKw&ab_channel=StringShortFilmOficial)

**The gift.** This short makes us reflect on the acceptance and affection towards our person.

[https://www.youtube.com/watch?v=2A5WhsRjoCQ&ab_channel=DanielMolina](https://www.youtube.com/watch?v=2A5WhsRjoCQ&ab_channel=DanielMolina)

IV.  **Series, movies and others**

**Series**

**Atypical.** Atypical revolves around the life of Sam, a not exactly popular 18-year-old boy diagnosed with autism spectrum disorder who, being quite intelligent, has learned tools to interact appropriately with others. Sam has decided that it is time to have a girlfriend and experience his first relationships with girls. [Available on Netflix.](https://www.netflix.com)

**Everything will be alright.** An unresponsible twentysomething who travels to the United States to see his father and his little stepsisters receives news that will turn his life upside down: his father is about to die and he must take care of the two girls as their legal guardian; Matilda, a girl on the autism spectrum about to finish high school, and Genevieve, a witty and scathing girl on the verge of puberty. [Available in Movistar Plus.](https://www.movistarplus.com)

**Parenthood.** The Bravermans are a macro-family. Four grown brothers with their respective families. Children of all ages with all kinds of problems. Among them

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20The EDITEA team does not enter into assessing the different representations that are shown within the collective with ASD in the films and series shown. I just knowseeks to show those formats that have decided to give visibility to the group, all from a respectful perspective.
is Max, an eight-year-old boy with Asperger's syndrome. Available on Amazon Prime.

*Young Sheldon.* Sheldon Cooper is 9 years old and skips four grades to go straight to high school along with his older brother, less clever than him. Life in her will not be easy, since her classmates, her parents and her neighbors do not understand Sheldon.Available in Movistar Plus.

*The Good Doctor.* A young autistic surgeon with sage syndrome begins work at a prestigious hospital. There he will have to overcome the skepticism with which his colleagues receive him. Available on Netflix.


*The computer engineers.* Moss works in the IT department of a company. He has a great logical-mathematical ability but no interpersonal intelligence and no capacity for improvisation. Your most suitable job would be as a programmer, but instead you have to be in charge of technical support to users, which causes multiple conflicts. Available on Netflix.

### Films.

*The lighthouse of the orcas.* Lola travels with her autistic son, Tristán, to the end of the world to meet Beto, a wildlife ranger who has a very special relationship with wild killer whales in Argentine Patagonia. The reason for the trip: Tristán has shown a strange empathy and response to stimuli at the sight of orcas. Available on Netflix.

*Temple grandin.* Film that portrays the life of Temple Grandin, a woman who, regardless of her life condition, becomes one of the most brilliant scientists of her time, a teacher and an expert in zootechnics. One of the most classic films when it comes to autism. Available on HBO.

*Long life and prosperity.* It features a bright young woman with autism who escapes from her nursing home and sets out on a road trip to deliver a script at a Hollywood competition. Available on Amazon Prime.

*Rain man.* A greedy young man develops a rare relationship with the autistic brother he never knew, who inherited his father's fortune. Available on Amazon Prime.
Others

Love on the spectrum. It is an Australian reality show starring people with autism trying to find the love of their life. Available on Netflix.

Asperger's are us. Four comedic friends, all with autism spectrum disorder, prepare for their last big performance before parting ways. Available on Netflix.

The beginning of life. Documentary in which scientists and parents analyze how correct attention to the earliest needs of children can shape the future of society. Available on Netflix.

Documentary "María y yo". María Gallardo, a teenager with autism, lives with her mother in the Canary Islands. Her father Miguel Gallardo lives in Barcelona, who takes her on vacation to a tourist center in the south of Gran Canaria. During one of these trips, it is shown what it is like to live with a person with autism, their peculiarities and their ways of understanding the environment. Available here: https://www.rtve.es/play/videos/el-documental/documental-maria-yo/2060907/

One round. This short breaks new ground by creating Pixar's first autistic character. In it, two children in a canoeing camp end up adrift in a lake, unable to continue until they find a way to connect and see the world through each other's eyes. Available on Disney +.

V. Apps

Jose Learns. José Aprende, a collection of stories adapted to pictograms to learn while having fun, designed for Visual Learners by a team of collaborators, illustrators, psychologists and specialized professionals, which has the support of the Orange Foundation.


Azahar Project - Orange Foundation. Azahar is a set of free downloadable communication, leisure and planning applications that, run through tablets, computers or smartphones, help improve the quality of life and autonomy of people with autism and/or intellectual disabilities.

http://www.proyectoazahar.org/azahar/whatis.do

TEA doctor. The Foundation for Biomedical Research of the Hospital Gregorio Marañón and the Orange Foundation have created this space with the aim of facilitating visits to the doctor of people with ASD and that they become familiar with environments to which they are not normally accustomed.

http://www.doctortea.org/
**PictoTEA.** Specially designed to help people who have ASD (Autism Spectrum Disorder), PDD (Generalized Developmental Disorder), or any condition that affects social and communication skills to communicate.


**MITA.** MITA is an early intervention app for children with autism, maturational delay, and learning difficulties. The app includes interactive activities designed to help children learn how to mentally integrate multiple objects.


**PictoBoard.** PictoBoard - It is an application to improve speech skills in people who are receiving speech therapy.


**PROJECT.** Using a Web and Android application, a virtual agenda is developed that represents daily activities with pictograms and images for the use of children with ASD. This App substitutes in a practical and agile way the physical agendas and, in addition, it enhances the interaction between the adult and the child.


**Day to day.** Day by day works as a simple calendar in which we can save and review all daily activities in a visual and structured way. In addition to photographs, it also supports video and the recording of recurring activities to always have them available and to be able to work on them in advance.


**Dictate Picto.** It allows to pass the information of voice to images of immediate form. The translation of speech to pictograms occurs automatically from a spoken phrase of the user, initially converting it into text and, from there, into the pictograms / images that represent the words.


**EmoPLAY.** It is an application that uses either a webcam or an integrated camera, to work with different emotions such as joy, sadness or anger, in a simple way.

VI. Wellness

**MindfulTEA.** Emotional regulation program adapted during confinement for people with ASD. Each video of the session consists of two parts: first a short introduction where a Mindfulness expert from the collaborating entities of the program briefly explains the purpose of the practice and the necessary material, and then the development of the total session accompanied by the corresponding visual aids.

https://fespau.es/practicas-adaptadas-del-programa-mindfultea/

How to organize the weekly children’s menu. Help and tools when organizing and preparing meals during the week.

https://www.educo.org/Blog/como-organizar-el-menu-infantil-semanal

Collection of activities and materials to work at home with children with autism.

https://www.imageneseducativas.com/estupenda-coleccion-de-actividades-y-materiales-para-trabajar-con-ninos-y-ninas-autistas/

"Game of Emotional Faces". Learn to identify emotions with the Color Monster.

http://www.mundoderukkia.com/2016/04/juego.caritas.monstruo.colores.html?m=1

101 ideas to do at home when school is out.
