

## **Constraints and challenges on inclusive education of children with Fragile X Syndrome**

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Fragile X syndrome is the most common inherited cause of intellectual disability and the most known genetic cause of autism. Children with this syndrome have a set of cognitive and behavioral features, which put serious challenges to their full inclusion in the educational system: intellectual disabilities, learning difficulties, hyperactivity, shyness and social anxiety. A qualitative study, using a Grounded Theory approach, was conducted to identify the main stages of the inclusion in mainstream schools and also the constraints experienced in each one of these moments. The findings show that problems relating to inclusion tend to be progressively more serious over the course of education, and schools and teachers often experience great difficulties in providing appropriate educational environment and activities. In kindergarten years the inclusion is easier, although very often an adequate diagnosis is not already made. In elementary school the best success in inclusion appears to occur when there is a high commitment of the school, teachers and family in building solutions that promote child development. To know the main constraints experienced by children and families can help schools, teachers and policymakers to find the adequate solutions to the inclusion of these children and young with a genetic syndrome that is more and more frequent.

*Keywords:* Fragile X Syndrome, Inclusion, Intellectual disability, autism, child development.

*Dificultades y retos en la educación inclusiva de los niños con Síndrome X Frágil.* El síndrome X frágil es la causa hereditaria más común de discapacidad intelectual y la causa genética más conocida de autismo. Los niños con este síndrome tienen características cognitivas y de comportamiento que ponen serios desafíos para su plena inclusión en el sistema educativo: discapacidad intelectual, dificultades de aprendizaje, hiperactividad, timidez y ansiedad social. Un estudio cualitativo, utilizando un enfoque de la *Grounded Theory*, se llevó a cabo para identificar las principales etapas de la inclusión en las escuelas regulares y también las limitaciones vividas en cada uno de estos momentos. Los resultados muestran que los problemas con la inclusión tienden a ser cada vez más graves en el transcurso de la educación y las escuelas y maestros a menudo experimentan grandes dificultades en el suministro de medio ambiente y actividades educativas apropiadas. En los años de jardín de infantes la inclusión es más fácil, aunque muy a menudo un diagnóstico adecuado no está hecho. En la escuela primaria el mejor éxito en la inclusión parece ocurrir cuando hay un alto compromiso de la escuela, maestros y familia en la construcción de soluciones que promuevan el desarrollo del niño. Conocer las principales limitaciones que sufren los niños y las familias puede ayudar a las escuelas, los profesores y los responsables políticos para encontrar las soluciones adecuadas para la inclusión de estos niños y jóvenes con un síndrome genético que es cada vez más frecuente.

*Palabras clave:* Síndrome X Frágil, inclusión, discapacidad intelectual, autismo, desarrollo infantil.

*Fragile X Syndrome*

Fragile X Syndrome (FXS) is the most common inherited cause of intellectual disability and the most known genetic cause of autism. It is a developmental disorder resulting from a mutation of the X chromosome at the level of the FMR1 gene (Fu *et al.*, 1991; Hagerman & Hagerman, 2002) and the name of the syndrome is related to the presence of a weakened region in the distal zone of the chromosome's long arm (Feinstein & Reiss, 1998).

This weakness is the result of a chromosomal expansion of trinucleotide repeat sequence cytosine-guanine-guanine (CGG) in the FMR-1 gene that inhibits the production of the protein FMRP (Fragile Mental Retardation Protein) responsible for cognitive development (Li, Pelletier, Perez & Carlen, 2002).

Currently it is accepted that the genetic sequence associated to the syndrome can have three states: normal, premutation and full mutation, depending on the number of CGG repetitions. The unaffected people have between 5 and 55 repetitions, while people with the premutation (carriers) have between 55 and 200 repetitions. Finally, people with 200 or more repetitions are described as having a full mutation (Kremer *et al.*, 1991). It is this expansion of DNA to a number exceeding 200 repetitions that gives to the "fragile X chromosome" this peculiar aspect (Jorge, 2013).

In individuals with premutation FMR1 gene function is not so affected and although there may be reduced levels of FMRP protein, the quantity available is enough for normal neurological development. The premutation tends to change size when it passes from one generation to the next, passing up unsteadily, and with different consequences depending on the descendant's sex. Most men and women with full mutation are affected, though the severity is generally softer in women due to the presence of a second X chromosome (Mazzocco, 2000).

Regarding the prevalence of the Fragile X Syndrome, the present data estimates that it lies from 1:4,000 to 1:6,000 for men and from 1:8.000 to 1:12.000 for women (Ribate, Pié & Fuentes, 2010). The premutation is quite common, and it has been identified in one to 130-259 women and in one to 250-813 men from the general population (Hagerman, 2008).

The phenotypic variability of individuals with FXS is quite large and includes physical, behavioral and cognitive features. Some physical characteristics as long face, prominent ears, macroorchidism and hyperextensible joints are very common (Hagerman, 2008). Regarding cognitive features it is widespread the existence of intellectual disability and learning difficulties. The most common behavioral features are poor eye contact, perseveration, hyperactivity, anxiety and hand flapping.

These characteristics, especially intellectual disability and autistic behaviors (30% have autism and other 30% have some autistic behaviors) may typify special

educational needs and add serious challenges to the education and the inclusion of children with FXS at school.

### *Inclusive education*

Children with cognitive impairments or behavioral problems have been sent, so far, to special schools. Nowadays, both in Europe and around the world there is a clear trend towards a broad inclusive practice according to the fundamental principles of the Salamanca Statement (UNESCO, 1994). This statement is the most important international consensus document on education and integration of children with disabilities, starting in the 90's the challenge of inclusion. It advocates an inclusive education at the level of principles, policies and practices, emphasizing the role of mainstream schools to combat discriminatory attitudes and promote inclusive societies, reaffirming the aim of achieving a school for everyone, which includes all the children, accepting differences, supporting the learning process and responding to individual needs.

Inclusive education *"is an ongoing process aimed at offering quality education for all while respecting diversity and the different needs and abilities, characteristics and learning expectations of the students and communities, eliminating all forms of discrimination"* (UNESCO, 2008, p. 3). In 2009 UNESCO added that Inclusive Education *"can be seen as a process of strengthening the capacity of an education system to reach out to all learners. It is, therefore, an overall principle that should guide all educational policies and practices, starting from the belief that education is a fundamental human right and the foundation for a more just society"*.

In this progressive development of the concept is this recognition that inclusive education is a continuous process resulting from an interaction of philosophical and pedagogical practices which aims to provide quality education for all, respecting diversity and different needs and abilities, characteristics and learning expectations of students and communities, eliminating all forms of discrimination and enabling the development of their full potential.

Inclusive education, as an education that adequately responds to the characteristics, needs and interests of each and every one (Ainscow, 2000; Ainscow, Booth & Dyson, 2006; César & Ainscow, 2006; Rodrigues, 2000, 2006, 2007) is based on valuing differences, reducing barriers to learning and promoting social cohesion and belonging. It is also based on promoting active participation in learning and in school activities, and on experiencing positive interactions with peers and other members of the school community. Schools and communities necessarily share these values and believe so that they value diversity, fostering the well-being and quality of learning of each of its members (Ainscow, Porter & Wang, 1997).

The fundamental principle of the inclusive school is that all children should learn together, wherever possible, regardless of the difficulties or differences they may have. The inclusive schools “*must recognize and respond to the diverse needs of their students, accommodating both different styles and rates of learning and ensuring quality education to all through appropriate curricula, organizational arrangements, teaching strategies, resource use and partnership with communities*” (UNESCO 1994, p. 11).

Inclusive education represents an educational reform that covers a very broad scope and different changes at several levels: concepts, methods, procedures, instruments and attitudes. Its aim is not just to facilitate the access of students with disabilities to mainstream school or curricular change, but involves a much deeper reform encompassing the values and practices of the entire education system (Rodrigues, 2001, 2003; Rodrigues & Rodrigues-Lima, 2011).

One of the main principles of inclusive education is the affirmation of an educational culture in which the schools are seen as multifaceted and multicultural places and where individual and social diversity is valued and celebrated (Porter, 1997; Marchesi, 2003; Rodrigues, 2006, 2007). As stated by the UNESCO in 1994, now it is the time to accept the challenge, so that Education for All is really for everyone, especially for the most vulnerable and most in need. So, one of the main challenges of inclusive education is to go from the elitist and segregating conceptions of education and school to a democratic conception, where diversity is recognized, embraced, valued and included (Hegarty, 2001; Rodrigues, 2006; Sanches, 2006).

However, despite the efforts of several countries and many international organizations to guarantee equal access to a quality education to people with special educational needs, some authors still emphasize that these persons do not yet see many of these rights recognized (César & Aisncow, 2006). This is due, not only to negative attitudes and prejudices towards them, but also to the lack of effective educational policies that value these people, guaranteeing them the right to education and to adequate life projects.

#### *Objectives of the study*

In a time where the educational system is confronted with change requirements so that the school may be more inclusive, it is expected that children with FXS can live different kinds of difficulties and constraints.

This study is part of a broader research on the life of children and teenagers with FXS (Franco, 2013), featuring the different stages and the most significant challenges of their inclusive trajectory. With this study we aim to contribute to a better understanding of the constraints and challenges of inclusive education, that is, how schools can organize themselves to receive, take care, educate and promote the development of children and teenagers with FXS.

## METHOD

In this qualitative and exploratory study, we adopted the procedures proposed in the literature for the use of grounded theory (Strauss & Corbin, 2008).

We interviewed 60 parents of boys aged between 4 and 31 years old with genetic evaluation of FXS full mutation, from Portugal. They were opened interviews with the following first question: "In your opinion, what were the most significant moments on the life of your son?"

## RESULTS

We can establish that the constraints and the challenges are related to the educational path of the boys with FXS in two different moments: preschool and basic education.

### *Kindergarten*

Attending Kindergarten is considered by parents to be very important and challenging due to the relationship with new professionals and peers. The separation process is significant for all the families, but when the child has special needs other changes are identified. In some cases, parents are actively involved in the search process for a kindergarten that is suited to the specific needs of the child. But this is not easy, particularly when educational institutions don't have adequate responsiveness.

Another kind of change is reflected on the routines, which are changed with the entry of the child in daycare. Other families also needed to make larger changes, like the place of residence, in order to have better resources and conditions for childcare or greater family support.

The global evaluation of the inclusive path in preschool period is generally positive. In some situations the entry in kindergarten and being together with other children was what definitely contributed to the diagnosis. The conditions seem to be more related to good adaptation and make the children feel happy and comfortable in kindergarten, with good relationships both with adults and other children: a) institution or services concerned with the welfare of the child; b) education facility with clear routines and appropriate educational practices; c) good adjustment of human resources; d) educators informed and concerned with the FXS; e) proximity among professionals and families, and having a close and warm personal relationship; f) Good relationship between the special education teacher and the class educator.

When this happens the children are described as being well and happy, and parents especially value good social relationships in the educational context, both with adults and with other children.

On the other hand, the difficulties experienced with the process of inclusion in daycare or kindergarten are related to: a) resistance of educational institutions in accepting the child when become aware that there is a problematic development; b) inadequacy of schedules of kindergarten; c) the short amount of time that specialized educators have to be in kindergarten and work with the child; d) the need of parents to find and pay for specialized interventions, such as therapies.

The problem of specialized interventions and support is very important for families and often they are not articulated because the doctors' appointments are widely spaced, the routine visits tend to be just for control (although private services express more availability to accompany the child) and therapies are generally insufficient (e.g., speech therapy). So, the private services end up having a greater role than the public services.

Regarding in particular the early intervention, although parents value it, they seem to agree that the response given to them was not always adequate. The support was occasional and limited, which led parents to seek specialized support; the intervention depends more on opportunities or on suggestions received than on a comprehensive plan of intervention to promote the child's development. Hence some families value private centers more because they have more adequate therapeutic responses.

#### *Basic Education*

Children with FXS enter the 1st cycle of basic education around age six, starting compulsory education. The entry into school is always a period described as distressing and, for many parents, the first confrontation with disabilities. More than anything else, to be with other children and facing the school goals is the basis of this first confrontation with the seriousness of having a child with FXS.

This brings major concerns to parents and also some concrete adaptation requirements, starting with the choice of the most appropriate school. Often this requires evaluation and raises many questions. If the transition was prepared by the kindergarten it seems it would be easier for the parents, the new school and the child. In many cases the parents are the ones who have to find a suitable school, and they value those schools with less students and with a professional who helps the teacher. In other circumstances, this adaptation to the new school and new rhythms may lead the parents to move or at least to change their routines, such as those related to family schedules and children's transportation.

The main changes described by parents regarding the entry into school, resulting from the new characteristics of the 1st cycle and that require a period of adaptability for the child are: a) more defined and structured tasks; b) more requirements that must be acknowledged according to the social rules; c) the demand for children to be focused and quiet.

These requirements are difficult for children with FXS, some at the behavioral level and some at the learning level. According to parents, the biggest challenges for their children are: language issues, hyperactivity, understanding and learning school subjects; motricity. Note that some children begin taking medication at this point to adjust their behavior to the demands of the school, particularly at the level of motor behavior.

Regarding the conditions of the school, the main difficulty identified by parents is the lack of specialized support, which does not exist or is very limited. The support of the special education teacher (who often has little information about the FXS) is usually one or two hours a week. This difficulty, in schools where the inclusion appears to have no adequate sustainability, leads many parents to have an attitude of "war against the school", claiming the minimum appropriate conditions to their children.

Regarding the overall evaluation of the inclusive process in this cycle there are cases where such inclusion resulted really well. These parents reported that the inclusion was better than they were expecting and mentioned that they were pleased with what their children had learned and that everyone at school liked them. This social dimension of good acceptance and social support in the educational context seems to be, for parents, the first inclusive criterion. The quality of inclusion binds mostly to the qualities of the child, and in particular to be sociable, which facilitates the relationship with teachers and peers. These children are described as being very well accepted and appreciated by everyone and are often key elements in the life of the school. Children who manage to be successful in the learning process are usually considered to have a more successful inclusion process, too.

In addition to the qualities of the child, it is crucial to the inclusion process the attitude of the school regarding the inclusion in general and towards the individual child, and also the amount and the nature of the support provided. However, in most situations, the process of inclusion of children with FXS in the 1st cycle is described negatively. The biggest problems lie on the teaching process which is considered by parents to be insufficient, even taking into account the children's difficulties. Some parents had to seek educational support outside the school, paying for it, and they believe that this extra help contributed more to their children's learning abilities than the activities performed at school. The parents also believe that the reasons for this failure occur because of the pedagogical organization and also due to some teachers' personal choices and actions. In many cases these children are referred to as being set aside, although within the room but in effective exclusion. It seems teachers are not familiar with the practice of the pedagogic differentiation advocated in the principles of inclusive education; instead, all the educational organization tends to be based on the existence (or not) of a specialized teacher to take care of the children with SEN.

Regarding teachers, the most frequent complaints concern the special education teachers. Their support is considered to be really insufficient, their work is criticized and often their dedication and motivation for the task is criticized. This leads to parents' dissatisfaction. For them the quality of inclusion is not dependent on the number of the professionals, resources, money, or a special equipped room, because, in fact, there are several examples of children being highly excluded in schools with these good conditions.

Regarding the importance of different persons at this stage, we find that the class teacher seems to be decisive for the quality of inclusion. In the most positive cases, they are described as dedicated, and it is established a direct relation between that commitment and the success of the educational process. The special education teacher is also decisive in the process: in the cases of good inclusion, these teachers study, are dedicated and make parents feel understood and supported. They contribute to the non-inclusion when they need to move to a different school (adapting to a new teacher is difficult and requires some or a lot of time) or when the dedication and the connection to the children is weak and erratic. It is of great importance the existence of a specialized and individualized educational plan, which often fails.

When the support received at school is not enough, given the ineffectiveness of Special Education or therapies received, parents often tend to look for external support. So, the support of the institutions is important in the development of the children, particularly in terms of pediatric consultations and access to therapies and activities appropriate to the child.

The progression from the 1st cycle to subsequent cycles of basic education is marked by differences in the structure of the educational context. While in the 1st cycle there is only one teacher per class, who is responsible for all the learning activities, from the 2nd cycle onwards there is a great diversity of subjects, one after the other along the day, each one with a different teacher and in a different classroom. The students aren't also the same, so the children with FXS have to adapt to a new group of colleagues.

Thus, the challenges in each cycle are different and as different is the level of development of students in each one. However, each transition brings new anxieties, especially for children with developmental difficulties or, as in the case of FXS, in those for whom the adaptation processes are slow and progressive and such changes involves difficulties and demands.

From the parents' perspective each transition is a new a headache because it requires restarting a process of adaptation and adjustment. This implies a new battle with new people and contexts, in the search for appropriate responses to the needs of their children.

The first barrier is when the opinion of the school (whether the main responsible or the teachers) is against the inclusion of children with such difficulties.

The main difficulties that may be encountered in that new cycle are related to: a) the child's stress towards the requirements of adaptation; b) the school organization, involving moving from room to room and timetables; c) teachers that are not sensitive to the inclusion of children with special needs; d) uncommitted special education teachers; e) peers cruelty; f) discouragement of parents facing new difficulties.

When the overall evaluation of the inclusive process is positive we find that the child is not mistaken in the halls and classrooms or gets lost. He is welcomed by leaders, teachers and peers and there are more professionals showing affection and providing better environment. Smaller schools with fewer students tend to be more inclusive. One of the biggest concerns of parents of older children with FXS occurs when they have to leave school. Until recently compulsory education in Portugal was up to the 9th grade. Thus, every teenager until 16 or 17 years old has his or her place in the educational system. Leaving school is, both for families and for teenagers, the most difficult and important milestone. For families because there are not many alternatives or social responses adjusted to the continuity of the inclusive process started in school. For teenagers because they risk staying at home, losing their friends and references.

The families of the teenagers who have had good experiences of inclusive education and loved to have been at school, prefer they remain there after the 9th grade. But when the school path ends up there are basically three alternatives: staying at home, going to an institution for people with disabilities, or having vocational training.

The alternative of entering into a special institution is frightening for families whose children had a fairly successful inclusion. The appreciation of not being segregated and develop good interpersonal relationships is very important. On the other hand the first representation of rehabilitation facilities is generally negative and confronts with disabilities and the exclusion of the social context. However, many families end up finding that institutions are not only the last alternative for their children, as some have qualities and advantages that they value, like: a) less peer pressure, b) the boy is between equals, c) he has more friends and d) he has more activities (like adapted sports) and therapies.

Regarding the vocational training, we found no cases of successful vocational or professional training in the school context. However, this is one of the main hopes and expectations of families, since almost all parents are able to identify areas in which their children could develop greater skills and autonomy. The referral to vocational training is therefore one of the possibilities within the rehabilitation institutions. Some of the young people were able to have access to vocational training and even successfully developed competence to perform tasks simpler or more complex. However, after a period of course, difficulties are aggravated when it comes to the stage and practice. Greater difficulties are on the transition from stage to employment. Parents report the huge frustration felt by young people when they see dashed employment expectations and

developed autonomy. The lack of professional or occupational alternatives can increase the risk of having young people very isolated at home. Mothers describe this situation as the risk of living inside a bubble. Besides, the issue of social inclusion is not limited to the occupation of young people from the time they leave school, it is simultaneously to the educational process and it has to do with different dimensions, often underestimated, and that we do not find in the narratives of parents, including cultural, sporting, recreational and interpersonal relationships and friendships.

## CONCLUSIONS

Listening to parents of boys with FXS allows us to be aware of the problems that arise along their educational path, identifying the constraints and challenges to their school inclusion. Although the legislation and the educational system point out to full inclusion in mainstream schools, this process does not always correspond appropriately to the needs of these children and families.

Inclusion in preschool is usually the best time of inclusive education and it seems to depend mainly on the existence of good teachers, with or without expertise in SEN. Early intervention, at this age, is fundamental for these children that should benefit from the several existing supports in a more frequent and substantial way.

Entering into the basic education is a huge concern for parents. The good inclusion at this stage is mainly related to the child social skills, the inclusive characteristics of the school and the commitment of the teachers. The progression to the different cycles of basic education brings new challenges resulting from changes in the educational organization. The inclusion problems are related to some features of teenagers with FXS and the presence of teachers not involved or sensitive to their needs. For many teenagers leaving school at the end of compulsory education is the end of the inclusive path, given the lack of vocational opportunities. So it is crucial to take the inclusion of children and teenagers with FXS into a life course perspective in which, for each age, appropriate responses for their full inclusion must be found.

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