



Fundación "Hay alguien allí"

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"Voluntary Contribution to the Second Cycle of the Universal Periodic Review of the Bolivarian Republic of Venezuela, for the 26th Session of the Working Group on the Universal Periodic Review Universal"

Review Period 2012 - 2016

Complementary Report of the Foundation "Hay Alguien Allí" (There is someone there)

The Foundation "There is someone there" is a non profit organization created in February 2016, as a result of the experience in production and supply of the first Venezuelan full length Documentary on Autism: "Is Anybody There" in years 2014 and 2015. This feature film was made aimed at sensitizing the Venezuelan population on this condition and also on awakening awareness of the society, the governments and the State on the guarantee of the human rights of people and families with autism. It was premiered in movie theaters in November 2014.

In 2015 it celebrated a national tour with film projections focused on a social perspective, through cinema forums and street projections totally for free. The objective: To generate a reflection, dialogue and action towards the issue. "There is someone there" was projected in 20 out of the 24 states of Venezuela. Likewise, the publication "I'm a person, I have autism" was made, and given totally for free to the participants of these activities.

The main objective of the Foundation "There is someone there" **is developing actions to spread the word on the multiple forms of disabilities, differentiated abilities and/or functional diversity, focused on autism and mental-intellectual disability, aimed at contributing on the promotion of the social, family and community integration of people with disabilities, differentiated abilities and/or functional diversity, with the integral protection of their human rights, guarantees and duties, as well as the construction of a culture of respect to their human dignity in conditions of equality and non discrimination.**

Currently, framed within April 02nd as the World Autism Awareness Day, the Foundation "Is Anybody There", prepares a set of actions to be impelled on this date: a) Audiovisual campaign "breaking the silence on autism" (12 spots with Venezuelan musicians), b) Cinema forums c) Premiere of the film on TV D) Release of the film for free on the Web, subtitled in three languages (English, French, Portuguese), with audio description for sight impaired and closed caption for hearing impaired people. e) Social Distribution of the film on DVD in public schools of special education, as well as public and private specialized centers of attention to autism and disability.

The Constitution of the Bolivarian Republic of Venezuela establishes in Article 81: "Every person with a disability or special needs has the right to the full and autonomous exercise of his/her abilities and community and family. The State, with the solidary participation of the families and society, will guarantee the respect to his/her human dignity, fostering opportunities, satisfactory labor conditions and it will foster him/her formation, education, and access to work according to his/her conditions...". Progress in the Bolivarian Republic of Venezuela has been accomplished regarding the recognition and guarantee of rights to the people with disabilities, as well as the construction of a culture of respect and good treatment. However, it is acknowledged, even by diverse public institutions, that in the specific area of autism and people with intellectual – mental disabilities, little progress has been accomplished, and needs and requirements of families are increasingly compelling.

The current report presents a balance of actions impelled by the Bolivarian Republic of Venezuela on attention and integral inclusion of people and families with autism: Accomplishments, results and challenges still in force.



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Information on Autism:

Based on the last Census of Population and Housing, impelled by the rector entity of statistics in Venezuela, from the total Venezuelan population, 27,019,815 people, a meaningful proportion (5,38%) declares to have a disability. That is, 1,454,845 people. 130,731 Venezuelan citizens have a mental-intellectual disability (autism, down syndrome, cerebral palsy, mental retardation, etcetera). That is, 0,48% of the Venezuelan population. From this amount, 44,79% (58,584) is of female gender and 55,21% (72,177) of male gender. This tendency of distribution per gender is evidenced in the 24 Venezuelan states¹.

Regarding the composition of age groups, 37,21% (48,733) of the people with mental-intellectual disability in Venezuela are children and adolescents of 0 to 19 years old. 16,44% (21,490) is above 54 years old, comprising the group of seniors. 17,78% (23,249) is comprised by young adults between 20 and 29 years old. 28,5% (37,259) are adults between 30 and 54 years old².

From the total of people with intellectual-mental disability, 33% (40,614) of the autistic people live in situation of poverty, whereas 9% (6,097) is currently in situation of extreme poverty in Venezuela³.

It is important to stress that there are no specific demographic, educational, socioeconomic data on the population with Autism in Venezuela. The autism is compiled in the category above mentioned -mental-intellectual disability-, together to other disabilities. There are not any studies that contribute with a better understanding of this problem yet and, thus, a better guidance towards the formulation of public policies neither.

Recommendations:

- **To foster the specific development of statistics for the measurement of autism in differentiated way, so that the data compiled contributes in the specific formulation of public policies.**
- **To develop quantitative and qualitative studies to favor the understanding, analysis and formulation of public policies on autism issues.**

The Right to Health

The Ministry of People's Power for Health (MPPS) impels the Program of Integral Attention to People with Disability (PASDIS in its Spanish acronym) and specifically the **Autism Units**. They are multi-disciplinary medical attention centers for children and adolescents, within the autistic spectrum disorder. The protocol of attention comprises medical, nutritional, educational psychology, language and family therapy approach.

These units are a positive initiative by the national Venezuelan government to guarantee the right of this sector from an integral perspective. Nevertheless, the scope is still limited. There are currently only two units in function in the capital region and eight multi-disciplinary practices and services⁴ (they're involved in different medical and technical specialities to assist autism, though not in the same facility) in Venezuela. One of the main difficulties The Ministry of People's Power for Health (MPPS in its Spanish Acronym) faces to boost these multi-disciplinary units and practices is the lack of qualified and prepared personnel for the different requirements of this condition. The situation in most Venezuelan states where families have no specialized public health center for integral assistance to their relatives is alarming.

¹ Source: National Institute of Statistics INE, in its Spanish acronym. Census 2011 (Own Processing)

² Source: National Institute of Statistics INE, in its Spanish acronym. Census 2011 (Own Processing)

³ Source: National Institute of Statistics INE, in its Spanish acronym. Census 2011 (Own Processing)

⁴ Source: Ministry of People's Power for Health. Program of Integral Attention to People with Disabilities (PASDIS, in its Spanish Acronym)



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Recommendations

The integral medical attention to people with autism is core along every stage of their lives: The balance in health will directly affect every possibility of development and progress in all dimension of their lives. In this sense, an optimal guarantee for the right to health in every person with autism in Venezuela is recommended.

- **To continue the creation of public centers for attention of autism along the national territory, at least in the 24 Venezuelan states. Increase the search and training for the required staff, and to guarantee the interconnection of the medical and therapeutical disciplines involved: psychology, psychiatry, neurology, gastroenterology, immunology, nutrition, occupational therapy, speech therapy, developmental therapy, behavioral therapy, among others. Also, associated services: Laboratory, specialized tests, dentistry, etcetera.**
- **To summon the incorporation of majoralties and govenances to impel these integral autism attention centers (together with MPPS). Likewise, the National Council for People with Disabilities (CONAPDIS).**
- **To foster The medical and therapeutical service to people with autism be considered for every stage of their development: Childhood, youth, adulthood and eld.**
- **To foster the curricular university inclusion of specialized formation in autism in health disciplines with incidence on attention to autism.**
- **To stimulate the free and preference access to medicines, vitamins and nutritional supplements requireds for this condition.**

The Right to Education

The guarantee to the right to education to the people with autism in every stage of their lives is a core issue for families. Possibilities of development, improvement and integral social inclusion of these people lie on the regular attention in this regard.

There are 408 schools that assist the population with special educational needs in Venezuela. There are also 491 specialized services in attention to the population with special educational needs. From them, there are 20 CAIPA (Centers for Integral Autism Centers), 3746 integrated classrooms (support service for the regular school that assists the integrated autistic population)⁵. There is no information of public access on the specific amount of people with autism within the public education system . CAIPAs provide specialized attention. However, the demand surpasses the actual capacity.

In the educational consultation made by the Ministry of People's Power for Education (MPPE in its Spanish acronym), the special education had a special critical view regarding limitations still present to guarantee a satisfactory integration of people with special educational needs, including people with autism: *"A lack of qualified personnel, interdisciplinary support team, resources for adapted learning, adequate facilities is observed. In the moment of integrating students in the field, they are not prepared to respond to the demands of regular schools. Likewise, the high fee per classroom complicates the individualized attention. The presence of attitudinal barriers identified by the ideas, perceptions, beliefs or opinions, that lead them to be biased or with little positive attitude; this is one of the major problems and challenges students with special educational needs face"*⁶.

While progress and efforts in special education issues are recognized, families of people with autism consider many children, adolescents and adults with autism are specially stigmatized. Their rights amidst the public educational system are vulnerated, even worse than in other conditions. In order to face and transform this reality, a boost for public policies in special education to accelerate better conditions for all the population with special educational needs is urgent. Autism is the most vulnerated condition regarding exclusion.

⁵ Source: Ministry of People's Power for Education. National Direction of Special Education.

⁶ Source: Ministry of People's Power for Education: "Opinions and Views from the Special Education". Bulletin of the Consultation of Special Education, 2014. (Attached)



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Recommendations:

- To continue the formation of practicing teachers in psychoeducational techniques for the approach and inclusion of people with autism in the regular classroom (Courses and workshops).
- To favor the inclusion of curricular changes in careers education and pedagogy; also, incorporating the study of autism and specific pedagogical techniques, as currently not the case in Venezuela. Teachers graduate with no knowledge of autism.
- To foster the development of fourth level studies on autism, in public universities nationwide. The few offers available are private and expensive.
- To continue the urgent improvement of infrastructure and supply conditions, both in special integrating schools and classrooms as well as services of the educational population with special educational needs.
- To grant the reduction of the overall enrollment for an effective integration, beginning with schools and classrooms with integrated students.
- To continue the creation of new CAIPA and integral strengthening of the ones existing regarding: Infrastructure, supply and personnel with the necessary technical equipment (psychology, language therapy, occupational therapy, social work, pedagogy), for an effective response to the demand of every state where operative.
- Design and creation of sensitization campaigns within the MPPE structure on human rights of people with special educational needs, good treatment, bullying prevention and approach, and others.

Right for the Integral Protection of People with Autism with High Level of Dependence, their Families and Specially Women

There are many degrees and complexities in autism. The construction of higher levels of autonomy and independence of autistic people must be fostered. However, a meaningful group of this population requires high levels of care along their lifetime. They are in a situation of vulnerability and dependence. Therefore, they require higher levels of protection. Likewise, as a consequence of the patriarchal culture, care labors are entitled specially to women, generating this a strong impact in their quality of life, health and guarantee of their rights.

The situation of autistic adults with high dependence is alarming. There are no public policies for this group, and they end up in situations of "family confinement", or they end institutionalized in psychiatric centers not suitable for the autism treatment. One of the strongest concerns in parents is related with the attention to their children once they grow old and die, and there are no other family members involved in their care and protection.

The Venezuelan law for people with disabilities establishes in Article 14: *"The State will grant appropriate assistance and support forms, such as : Guides, caregivers... as part of the integral attention to people with disabilities. Such attention will be granted through the National Council for People with Disabilities"*. However, there is no public policy for caregivers to autistic people with high level of dependence.

The arrival of autism to a family is brings not only a strong emotional and psychological impact, but also a strong economic impact. The public offer of attention is Little or non existant in many Venezuelan states. Also, the cost of private services is high, as well as the cost of medicines, vitamins, special food and nutritional supplements. Finally, high periods invested in their attention impact in the reducton of incomes and precarious forms of work.



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Recommendations:

- To foster the creation of daytime integral attention centers for autistic adults.
- To foster the creation of residential centers for autistic adults, specially aimed when parents and/or caregivers grow old or die.
- To foster the inclusion of autistic people to the system of social security (pensions).
- To foster the development of a public national policy of caregivers who help families in the attention of people with autism of high level of dependance.
- To foster the development of family support and guidance programs.
- To foster socio-economic support to families.
- To foster the flexibility and diversification of working forms for parents and other relatives and people responsible for autistic people with high levels of dependence (Schedule modalities, work from home, etcetera.).

OTHER GENERAL RECOMMENDATIONS

- The Legislative approval of the Organic Law for People with Disabilities or Special Needs, impelled by the Ombudsoffice (The People's Defensory of Venezuela), with a wide and democratic consultation to organizations of the Venezuelan civil society of multiple types of disabilities. This project incorporates demands of the sector autism and other disabilities (Project attached).
- To continue impelling the development of national communicational campaigns to sensitize and inform the population on the condition of autism and fostering the construction of a culture of respect to the human dignity to people with autism in conditions of equality and non discrimination.
- To continue to guarantee of the preference Access to food incorporated within the diet clinically for people with autism: Gluten, casein, sugar-free food, etc.
- To foster the development of the national production and the gluten, casein an sugar free food industry.