**Autism and alternative care: building an independent life.**

Claudia Nicchiniello (Angsa Campania)

Alessandro Braccili (Fondazione Piccola Opera Charitas, Giulianova)

This proposal stems from a group of parents who consider it necessary to personally lead the de-institutionalization of their children, choosing for them the independent life that they cannot choose by themselves.

The following thesis is proposed: a child who is not qualified in the context of family and society will have very little chance of not being institutionalized.

 The Italian national health system already supports interventions for children in outpatient clinics and medical centres. Children, therefore, often move seamlessly from the rehabilitation centre to a centre (which is usually the same) with a semi-residential format and then to one with a completely residential format. We propose working in the family setting as soon as the diagnosis is made, to aid and promote the child’s care within the family.

The impact of the problems associated with autism for families, communities, and the social system cannot be underestimated.

Autism, generates a high amount of family stress on caregivers and siblings, and in particular, puts strain on the life of the child (and the future adult) affected by this problem.

We offer a summary of the current situation of autism care and the issues we identified:

• The diagnosis of autism is not always timely, leading to a delay in intervention.

• Even if family parents realize that their child has a problem related to autism, they are not adequately supported by their health system in daily life. Although deserving professionals may offer help at times, the intervention is fragmented at best, and fails to generate real improvements.

• School systems, despite their desire to include and support such ‘special’ students, do not have the means and are not equipped with the skills for achieving this goal. This situation leads to stress and dissatisfaction on the part of teachers, the subjective perception of failure and uselessness, and disagreements between the school and family. The last point of the discord between parents and the school’s professional figures is particularly concerning Both of these actors are motivated by the same ultimate goal (the well-being and improvement of the child’s ability) but end up opposing each other because neither of them is provided with the tools to effectively act in the face of such a complex problem.

• The health system offers services dedicated to autism that are highly variable in different territories and they oscillate from a clearly insufficient quality to a good and sometimes high quality. However, in case of the latter (not the most frequent, unfortunately), the resources in place do not allow for the actual ‘global care’ of the child and the family.

• What is worse is that these systems: schools, health centres, etc ... are almost always ‘monads’, suffering from a lack of mutual coordination. This creates a sense of confusion for parental figures, and in general, for the family of the child with autism.

• Furthermore, many ‘problem behaviours’ of the child originate specifically from the lack of constant guidance by the family and school. These behaviours disrupt the interaction of the child (and adult) affected by autism with their environment, interfere with their learning opportunities, with their chances of socialization with peers, and make it difficult for them to live in the family context. In fact, the daily management of the person with autism can become increasingly difficult and may require the removal of the subject from their environment. Once maladaptive behaviours have occurred consistently for an extended period, it becomes increasingly challenging to effectively decreased them. Therefore, the primary ‘tool’ we have in this regard is to prevent such behaviours as much as possible, offering all actors involved in the child’s life the tools to ensure that such behaviours do not occur in the first place.

We follow this concise ‘snapshot’ of the current situation with the proposal for a solution, which, although requires a change in some existing practices, is not out of the operational possibilities in this field.

The abundant scientific literature on interventions in autism establishes that interventions based on ABA (Applied Behaviour Analysis) are effective in autism, both for decreasing problem behaviours and teaching new skills. Within this framework, the following operational proposals can be summarized:

• When a family receives a diagnosis of autism regarding their child (even if it is not ‘certain’), it is necessary to immediately designate a specific person to take care of following the case in its entirety. This person must be a behaviour analyst (it is much better if they hold an international BCBA certification) with the theoretical and clinical skills to be able to: create an individualized program for the child, carry out a functional assessment for any problem behaviours, and give complete and effective training to family and school personnel. This person, who directly depends on the health system, needs to be assisted by a multidisciplinary team to support them in every step of their work. For the sake of brevity, we will call this person ‘supervisor’ from here onwards.

The family should receive high-quality training from the supervisor immediately after diagnosis. The objective of this training is to provide ‘basic behavioural education’ to parents to allow them to positively and profitably interact with their child, better understand their child’s behaviour, and know the correct way act in different situations of everyday life—how to stimulate their communication, how to manage problem behaviours, and how to prevent them from occurring. In short, they need to become the protagonists of their child’s development.

• This training needs to be very ‘hands-on’, with parents being asked to interact directly with their children under the supervisor’s direction. In this case, the Behaviour Skill Training model (an evidence-based training package effective in teaching new skill to staff and caregivers) can be very useful.

• This training needs to occur as early as possible, when the children are little and easier to manage and when the parents have the energy to follow the instructions. In fact, after months or years of interaction with their children without proper guidance, parents can become increasingly ‘worn out’ and their ability to apply the training may be impaired.

• Furthermore, as mentioned initially, early intervention reduces the future incidence of problem behaviours, causing them to either not manifest in the first place or to be present in less severe forms. It is essential to quickly inform parents that their child’s inappropriate behaviours (true for all behaviours) have a ‘meaning’ and are not senseless or random events.

• Training directed at the family is fundamental, but even when parental figures have the necessary energy to implement the training received, it is not easy to constantly and precisely apply the instructions, which is essential for their effectiveness. Therefore, parents must be supported for an adequate number of hours, directly in their home, by a behavioural technician (preferably with RBT certification) to help them implement the agreed program and to provide them with constant training by following the supervisor’s directives. It will also be the prerogative of the behavioural technician to implement the more complex and professional teaching procedures that are part of the program.

• In addition to the behavioural technician, it is essential to underline that families can be effectively assisted daily by less specialized figures, who can offer help, and at times, a ‘relief’ from family life. The essential condition is that these figures also need to be trained and monitored by the supervisor and behavioural technician in order to understand what needs to be done during various daily interactions with the child.

• The school must receive in-depth and high-quality teaching on autism and the logic behind interventions. This training must be carried out by specially appointed agencies, to meet stringent training requirements and must be assisted by the supervisor in charge of developing the program for the child. It is essential to ensure that the teaching is not only theoretical (which would be largely ineffective) but practical, with extensive use of role-playing and the consequent implementation, directly with the child, of the learned skills. The course provider and the supervisor in charge need to ensure that the teachers effectively learn and practice the procedures described in the program directly with the child, under their guidance. Each teacher has the right to possess the tools and skills to teach their student professionally and effectively: the training described above aims at providing these skills.

• The supervisor will also coordinate the child’s program offered in the health center. Here, the child can be supported by the same behavioural technician who follows them at home and/or others with the same training. If the centre has its own behaviour analyst, it should be easy to agree on actions and strategies with the supervisor. Additionally, the supervisor who supports the child at home will often be the same person who monitors their program at the centre.

• Carrying out part of the educational in a centre can be useful for several reasons: the supervisor can observe the child in a more ‘simple’ context than that present in daily life, and in the centre, there are materials and stimuli that can be used for teaching that can’t be found at home.

In addition to the points illustrated above, it is useful to list some general considerations that integrate the previous points:

• The supervisor: it is essential for them to have the authority to ‘direct’ the child’s program in every environment. Failing this requirement would lead to the current unstable situation, in which each actor carries out their actions independently from others. It should be remembered that the supervisor needs to be constantly assisted by a team, and that part of their training as a behaviour analyst involves the ability to include all actors in the application of the program, and to display openness to all proposals from the actors. Furthermore, in case the supervisor does not prove to be up to the task, they may be immediately replaced.

• Owing to the extensive infrastructure that needs to be created, truly addressing ‘life goals’ for the person with autism is possible. It is essential for the parents, assisted and advised by the supervisor and other figures involved with the child, to choose goals for the child. In other words, it is the parental figure who is primarily responsible for deciding what goals they set for their child, and it is up to all other actors to help them and their child to achieve this target. The goals should be clearly stated with intermediate objectives to make it easy to check if the program is having the desired effects.

• Together with the choice of goals, parents should be provided with a realistic and sincere picture of the child’s situation for them to choose achievable goals that improve their life without making unrealistic promises. At the same time, parents and other figures close to the child must be made aware of the direct relationship between the work and commitment dedicated to the program and the child’s progress. In other words, with their dedication, they can do a lot for the child.

• A further clarification should be made on the role of ‘medium and low specialization’ figures. The behavioural technician can be considered a medium-specialized figure, as they have theoretical and practical skills that allow them to implement the program of a supervisor. In other words, the ‘technician’ is a paraprofessional, that is, a professional who supports another professional (the supervisor). This person is particularly valuable because even though the necessary training is not particularly onerous, their effectiveness of interventions is very high as, according to the rules of the profession, they can only operate upon receiving constant and direct supervision from the supervisor. In this way, the supervisor’s intervention can ‘multiply’ thanks to the action of the technician while maintaining the quality. This ‘division of labour’, is somewhat innovative compared to the current practices in this field, and the efficiency of this way of operating is not always immediately appreciated. This is one of the cornerstones of the system just described: a program well designed by a professional with years of experience, with training effectively implemented by people especially trained for this purpose, even if these people only possess a fraction of the skills of the supervisor.

• Finally, the ‘low training’ figures mentioned above need to be considered, referring to people who do not have specific training. They can be vital to the proposed system, as the practical and direct training they receive from the supervisor can enable them to have a positive relationship with the child. In other words: there is not always a need for highly specialized figures with years of training to support a child (or an adult) with autism. What matters is ensuring that these figures personally know the child for some time, and for them to be capable of giving ‘direct’ training to non-specialized figures. In this way, the whole system becomes less demanding and offers, as an accidental but virtuous consequence, the possibility of employment for less trained figures.

References:

Cohen, H., Amerine-Dickens, M., & Smith, T. (2006). Early intensive behavioral treatment: Replication of the UCLA model in a community setting. *Developmental and Behavioral Pediatrics, 27,* S145-S155.

Eikeseth, S. (2009). Outcome of comprehensive psycho-educational interventions for young children with autism. *Research in Developmental Disabilities, 30,* 158-178.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism: A 1-year comparison controlled study. *Behavior Modification, 26,* 46-68.

Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2010). Using participant data to extend the evidence base for intensive behavioral intervention for children with autism. *American Journal on Intellectual and Developmental Disabilities, 115,* 381-405.

Eldevik, S., Hastings, R. P., Hughes, J. C., Jahr, E., Eikeseth, S., & Cross, S. (2009). Analysis of early intensive behavioral intervention for children with autism. *Journal of Clinical Child and Adolescent Psychology, 38,* 439-450.

Foxx, R. M. (2008). Applied behavior analysis treatment of autism: The state of the art. *Child and Adolescent Psychiatric Clinics of North America, 17,* 821-834.

Green, G., Brennan, L. C., & Fein, D. (2002). Intensive behavioral treatment for a toddler at high risk for autism. *Behavior Modification, 26,* 69-102.

Hanley, G. P., Iwata, B. A., & McCord, B. E. (2003). Functional analysis of problem behavior: A review. *Journal of Applied Behavior Analysis, 36,* 147-185.

Howard, J. S., Sparkman, C. R., Cohen, H. G., Green, G., & Stanislaw, H. (2005). A comparison of intensive behavior analytic and eclectic treatments for young children with autism. *Research in Developmental Disabilities, 26,* 359-383.

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55,* 3-9.

Matson, J. L., Benavidez, D. A., Compton, L. S., Paclawskyj, T., & Baglio, C. (1996). Behavioral treatment of autistic persons: A review of research from 1980 to the present. *Research in Developmental Disabilities, 17,* 433-465.

McEachin, J. J., Smith, T., & Lovaas, O. I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation, 97,* 359-372.

Sallows, G. O., & Graupner, T. D. (2005). Intensive behavioral treatment for children with autism: Four-year outcome and predictors. *American Journal on Mental Retardation, 110,* 417-438.

Virués-Ortega, J. (2010). Applied behavior analytic intervention for autism in early childhood: Meta-analysis, metaregression and dose–response meta-analysis of multiple outcomes. *Clinical Psychology Review, 30,* 387-399.

Wong, C., Odom, S. L., Hume, K., Cox, A. W., Fettig, A., Kucharczyk, S. et al. (2013). *Evidence-based practices for children, youth, and young adults with autism spectrum disorder.* Chapel Hill, NC: The University of North Carolina, Frank Porter Graham Child DevelopmentInstitute, Autism Evidence-Based Practice Review Group.