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Addressing Communication Difficulties of Parents of Children of the Autism Spectrum

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1. Introduction

The autism spectrum includes major developmental disorders that, by definition, involve early and severe disorders in the areas of social, communicative and cognitive development. The resulting disorders are frequently severe and persistent with large individual variations. Therefore its impact on the families should not be overlooked.

On the other hand, the intervention aimed towards children with Autism Spectrum Disorders (ASD) should be comprehensive, intensive and long term. It leads to the notion that the families' participation in these processes should be a systematic focus of therapeutic proposals and studies involving children of the autism spectrum.

However, a recent literature review [1] about the papers published in three of the most important journals with specific focus on autism revealed a different reality. Only 0.7% of the papers published between 2005 and 2009 referred to studies about families with ASD children, comprising a total of 4883 participants. It is interesting to note that more than half of the papers about families with children of the autism spectrum were published in the last 18 months of the considered period. The themes of those studies involved issues about stress and emotional problems (13 papers); support groups and quality of life (7 papers); characterization of the families and their members (7 papers); intervention processes and their re-

sults (5 papers) and how the parents consider their children with autism spectrum disorders (8 papers).

The growing interest in the area may be a result of the recognition that families should be included in any plan for intervention designed towards ASD children. A recently published research [2] studied the experiences that were shared by families during the diagnostic process that identified an ASD. Reports about 16 children identified that there was an average 2-year lag between the first doubts about the child's development and the ASD diagnosis. These processes were more difficult and more painful to families of older children.

Another recent study [3] assessed schooling problems of ASD children and their families. The results confirmed the difficulties frequently observed in adaptation of ASD children in regular schools. The authors point out that opportunities for establishing friendship groups and peer acceptance seem to be the key elements to successful adaptations. [4] studied the opinion of parents of ASD children in the search for treatments - a process that often demands time, money and energy - in six different countries. The most significant issues that emerged were the effectiveness of treatments, relationships with professionals, access to treatments, costs, medication and stress. Early inclusion in a regular school, whenever possible, should be part of the resources provided for the development of children with autism spectrum disorders.

A Brazilian study [5] proposed a questionnaire to the identification of perceptions of caregivers of ASD children about the quality of their communication with their children, regardless of the concrete disorders presented by the child and the specific diagnosis within the spectrum. The questionnaire had a specific focus on the caregivers and was divided in four domains regarding their impressions about themselves, about other people, about their children and about their attitudes with their children. Caregivers report difficulties with other people's reactions to their children's behavior, communicative style of the adult-child dyad, concern about the child's future and the need for more information about their child communication and instructions on how to face their difficulties.

The atypical communication development of individuals with ASD is related to difficulties with the various communicative roles (as speaker and as listener); disorders in the use of the different communicative means; a restricted repertoire of communicative functions; lack or few demonstrations of communicative intent, imitation, joint attention and other disorders in the social cognitive and symbolic development and social communicative adaptation [6, 7].

Verbal communication may be absent. Language delays, discursive or narrative disorders may also be observed. Social impairments may also vary from lack of visual contact or social reciprocity to severe behavior disorders (including aggressive and disruptive behaviors and eating and sleeping idiosyncrasies).

The aim of this chapter is to present some specific points and strategies to cope with autistic children's communication inabilities and suggestions on how to improve opportunities for communicative development and improvement. Not all the suggestions will be useful to all parents at any moment of their child's development; but probably some of them will answer

to doubts of many parents at some point. Hopefully they will help parents and caregivers of ASD children to think about how their child communicates, which can be the key elements of successful communication experiences and the triggers of critical situations. This way they will be able to increase the occurrence of good and pleasant communication while decreasing the number of stressful situations. However, it should be remembered that some amount of misunderstanding and frustrating communicative situations is part of the everyday life of every person and therefore it is not reasonable to plan to completely eliminate them from the ASD child's communicative experiences.

2. Specific focus and action options

The broad themes considered address possible strategies to improve opportunities for communication, favor language development, improve social contact and improve the quality of communication with family and peers.

2.1. Improve opportunities for communication

Observing the communicative style of the ASD child parents may identify new ways of fostering the development of new abilities and their use in different situations or with different functions.

Identifying if there are specific situations when the child uses preferentially a certain communicative mean (speech, gestures, vocalizations, writing).

Showing the possibilities of expressing a certain meaning - or improving the communication's efficiency - by the use of alternative communicative means or by the combination of more than one mean.

Stimulating the use of new gestures, sounds or words in familiar situations.

Depending on the child's abilities, it may be important to exercise various situations and opportunities for expressing a certain content or intent.

In other situations it may be important to improve the creativity in communication. Sometimes it can be useful to show, in familiar situations, the various forms to express a certain message or intent.

Visual contact requires a delicate balance where the person must look at other people but shouldn't stare at them. Parents should be supportive in the development of strategies to improve social visual contact. Simple strategies, as being at the child's eye level, consistently maintaining and requesting eye contact and responding to the child's eye contact initiatives may produce significant results to the child's social adaptation.

Being aware of all the communication the child expresses, regardless of the communicative mean. Shouts, murmurs, vocalizations and gestures may convey meaningful contents and therefore lead to productive interactions. On the other hand, if a communicative attempt

made by the child is ignored it may send a confusing feedback about communication strategies and their results.

Exploring natural and routine situations (such as baths, meals, outings) to increase the repertoire of words and expressions that constitute the common ground for communication.

2.2. Stimulate language development

Simple but consistent activities and attitudes may have an important role in building an environment that will stimulate language development and provide comfortable contexts where the child may use his/her communication abilities.

Defining a time or a place to be with the child in a pleasant situation (playing, talking, exchanging impressions about something that happened during the day or planning a future event or activity). The situations should be simple enough so they can happen every day. Its duration may depend on the participants' interest, but should not vary too much, so the child may be comfortable, knowing what will happen next. If the mother has more time during daily routines, she can spend, for example, two fifteen-minute periods playing, talking or working on a project with the child. But if she is overwhelmed by the routine, the father may include these activities in his routine. If both parents are available, the three may be involved in the activities. Siblings and other relatives (even pets) may be included. What is essential is to consider that these short periods of time should be part of a routine that the whole family respects and enjoys.

Adapting adult's language to the child's level of understanding. Sometimes the ASD child present a speech level far superior to his/her understanding level. Parents should consider how well the child understands language and adapt their own language to it.

Associating language to actions (movements of body or objects) or sensorial experiences, such as sounds, smells or tactile sensations (especially those associated with extremes and graduations between them; for example, hot, warm, cold and freezing) will improve the whole experience and therefore increase its meaning.

Waiting for the child's own time to answer a question or perform a task. Also being aware to the fact that sometimes the child will perform a requested action or answer to a question after a quite large time-gap. It can be useful to retrieve the question or the request and show the child if it is still meaningful or if it lost its function. *For example: the mother is cooking, asks the child to get a spoon but when the child doesn't do it immediately she goes and get it - and it is reasonable that it should occur on a natural situation - ; if the child gets the spoon some minutes later the mother should appraise it, thank for the help, but also tell the child that she needed it a few minutes before, or the food would get burned.*

Using linguistic expressions in natural situations while enjoying an activity, such as *one, two, three, go!*; or *bye, bye*; or *pick-a-boo*. Using onomatopoeic sounds when playing with animals, vehicles or other objects with characteristic sounds, or when telling stories.

Use routine situations such as baths, meals or organizing a drawer to use known and new words and expressions, building a repertoire of words or expressions that will be always

used during these situations. For example, always saying *wash both feet* during the bath; *ate it all* when finishing a meal; *socks go together* when organizing a drawer. But also sometimes introducing new elements to familiar situations, for example saying *use your hands to wash both feet*, or *I ate it all, my belly is full* or *socks go together and boxers (or panties) on the other side*.

Use varied and even exaggerated facial expressions, associating them with communicative functions, demonstrating awareness to the child's facial expressions, commenting about them, identifying different facial expressions in pictures and films.

Stimulate the child to use language to express his/her own emotions.

2.3. Improve social contact

When the family engages in social activities and includes the ASD child in them, there are more opportunities for social interaction. Sharing social situations with their ASD child parents will be able to eventually identify focus of more difficulties and also productive strategies to help the child to cope with them.

Taking the child to parks and playgrounds and stimulating the child to interact with other children. Situations such as sharing a swing, respecting the line for the slide or playing on the sand along with other children, may provide interesting and pleasant experiences that can represent opportunities to experience communicative strategies and exercise recently acquired abilities. Parents should be aware however, that cooperative and competitive activities are frequently stressful and cause of major disagreement between children with normal development also. Said disagreements are also important experiences to the development of social and communicative repertoires as long as they are accompanied by a soothing and supportive attitude by the parents.

Including the child in family activities such as travels, outings, visits to different places and social activities. Planning these activities with the child will help him/her to prepare for new situations, talking about what to expect, how to react in specific contexts. Including relaxing time and places to unwind or calm down will probably be useful to the whole family and can be adjusted to each child's needs and rhythm.

Helping the child to cope with problematic places and situations. Do not avoid stressful situations but try to identify and reduce the stressing factors. They may be related to loud noises, flashing light, crowds, specific characters (such as clowns or Santa Claus) or previous unpleasant experiences. Parents should try gradual approximation to the situations, explaining the source of lights and sounds, increasing time or proximity according to the child's response.

Including the child in household routine activities. The child should share house chores as all other family members. Depending to his/her abilities and on the family's routine, the child may unpack shopping bags, organize a drawer, write the shopping list, sort out mailing, measure the dog's food or taking it for a walk. This routine should be part of the child's responsibilities as well as an opportunity to a feeling of accomplishment.

2.4. Improve the quality of interaction within the family and with peers

Attention to the child's interests, interactive strategies, communication breaks or triggers to disruptive behavior may enable parents to improve the quality of the family's interaction. All must be willing to proceed to changes in routines, responses and automatic reactions.

Observing and identifying child's interests, behaviour and communicative attempts are essential to attribute effective value to the interaction and to respond to it in a productive way, building contexts of joint attention and shared experiences.

Including the child in the family's dynamic means to comply with the same rules and limits that are applied to the other members. But close observation may also indicate that for some children more clear routines and limits may be useful. An agreement about a sequence of activities (such as choosing a toy or game, playing with it and storing it away when finished) may help the child to organize his/her expectations. Specific strategies may be needed to maintain the agreed procedure, but it may be essential to be consistent with it until the child can build his/her own rhythm and behavioural organization.

In the presence of peers (siblings, cousins, friends' children) take advantage of the opportunity to encourage the child to share objects and toys and to respect collective rules (waiting for his/her turn, complying with rules of specific games or sports).

Use unexpected situations to help the child to learn how to cope with them. Depending on the child's level, it can involve: searching for a lost item, fixing a broken toy, asking for help when needed or arguing a point of view.

Encourage the child to engage in organized activities or combinatorial play, such as building blocks, puzzles, logical sequences of pictures, narrating stories. Using concepts as time, space, rhythm and position.

Use and encourage the combined use of speech and gestures and facial expressions to improve communicative efficiency.

Try to adapt the length and complexity of phrases and language to the child's language level and to guarantee the child's attention (using eye contact, physical contact or other sensory clue to the communicative situation).

Be aware of the result of your communicative initiatives, as shown by the child's reactions or answers. Try to identify what are the most difficult points to the child's comprehension and be prepared to communicate breaks and alternatives to solve them.

3. Conclusions

The suggestions presented are mostly examples on how everyday life activities and routines can be used to increase the opportunities to improve the ASD child's communicative abilities and their creative use as an important part of the whole development.

The notion that the family's routine is an important part of the child's developmental environment, however, should not lead parents or other family members to transform it on a permanent training field. The best intentions and the undeniable stress involved in wishing to provide the better developmental opportunities to their ASD child may result on a stressful and over-stimulating situation. It will probably increase the stress level of the whole family decreasing the opportunities for relaxed, joyful interaction with affectively meaningful persons, which is also very important to the child's development.

The inclusion of parents and other family members in the education and intervention processes with ASD children should not be a responsibility attributed just to therapists or educators. Families can have an active part in it, by asking questions and demanding for instructions.

However, families can also need a "time-out" when they are not requested to collaborate on any structured activity. Each family should be allowed and encouraged to develop its own coping strategies and supported when a more direct approach is needed.

Groups of parents of children attending the same service or going to the same school can be very helpful in building a supportive network that includes persons that share similar problems and may also share some solutions.

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