

L'intervento di CAA integrato di territorio: verso un modello di rete partecipata

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Summary

The gap between users needs and service resources represents one of the most critical points in service delivery.

We will describe the transformations in service delivery that have taken place in the last 15 years in two AAC centres that are part of child neuropsychiatric services in Italy, and that started with very little resources, insufficient to answer to children and families needs.

In order to reorganize the service, the barriers in attitudes and practices in child neuropsychiatric services, schools and community in the two territories has been analyzed. The first need appeared that of a strong cultural change in the community, and the Centres therefore invested in local information and awareness through integrated and participated training of families, teachers and professionals. The next emerging need has been that of thinking of AAC instruments for early intervention that could be used directly by families and teachers of children that were still on the waiting list, easy to use, with little training needed and that could have a high impact on life context by naturally teaching the communication partners the dynamics of AAC and preparing for intervention that may unfortunately start many months later.

It is well known that service delivery plays a critical role in efficacy and cost of interventions in health care and in rehabilitation, but this is even more so in AAC.

In the beginning of our experience in AAC, almost 15 years ago, in a child neuropsychiatric public service in Italy that dealt with a population of 120.000 inhabitants in a rural area not too far from the city of Milano, we used to work directly with the children, separately from parents and school staff. We had very little human resources, worked very hard, but outcomes were unsatisfactory. We decided therefore that we needed to analyze in depth what was not working, and how to optimize our efforts.

The first and most relevant aspect was the existence of barriers in attitudes and practices in the community. AAC was not known by the general population, and was considered by colleagues, teachers and families as something to try only when all other interventions had failed. Children arrived to the AAC service in their teens, and building the intervention with the environment was very difficult.

The first step we took was therefore diffusing information and awareness between health staff, teachers and families, through monthly meetings. In the beginning, the meetings were kept separate for each group, and access was possible only for families and professionals that already had a child that was starting an AAC intervention. Attendance was much higher than expected, we begun to

have externs asking to come and in the meantime we realized that having people involved in the same child in groups working in parallel was increasing misunderstandings. In one year time we had to rethink the whole thing again.

Meeting became every 15 days on Monday, in early afternoon so that children could be at school, included teachers, families and interprofessional health staff (speech language pathologists, physiotherapists, psychologists, child neuropsychiatrists, special educators etc), and were open to anyone from the community that was interested. They included 3 annual editions of a general introduction to AAC, that had a wide diffusion, and then a calendar of specific themes. The latter always included a practical part in which groups had to work together.

In those years, the idea of putting together staff, teachers and families was very unusual for Italy, and in the beginning was strongly criticised. But the experience went very well, attendance was absolutely unexpected and extraordinary for a small reality like ours (an average of 80-100 people for every meeting), many people began to arrive on their own and followed the meeting long before an intervention could be put in place for their child. Shortly, this forced us towards two more passages.

One regarded our way of working, that at this point had to complete its transformation towards a participated and family-centred model. The other regarded the procedures to access service and deal with waiting lists: the increased awareness in our territory had strongly improved our work, but our waiting list was becoming much longer.

Now our work was mainly with schools and families together, very little with the child alone, mainly on the context and its barriers and facilitators. Assessment included the presence of all significant persons for the child (at least of those that could come) and was discussed together, and the project was made with the participation of all those involved, including when possible the user itself. Also, assessment was no more the entry point of the system, as it used to be before.

Our new procedures of access asked that some "environmental prerequisites" were dealt with first: staff, teachers and families had to participate to the introduction to AAC, in order to know what they were going to put themselves in, and find an agreement between them on the need of an AAC intervention and their willingness to participate to the project that we would then build together. We did not want to exclude anybody through these procedure, but needed to find ways to start interventions when we really had a group ready to work, in order to optimize the very few resources that we had. Putting the teams together was very hard in the beginning, and a very unusual request, but slowly became more usual and less hard. Before assessment, people started spontaneously to follow other meetings, in particular those on early communication, and begun AAC intervention as a group well before we could possibly organize to evaluate the child. We realized that these were the interventions that were going better, and the age of the children for whom we were asked to make an AAC project dropped dramatically, with many referrals made at age two, even spontaneously by the families.

Our problem now was to think on how to better support the children and the working groups that were on the waiting list. We started making very practical training laboratories. The first training laboratory regarded "books on measure". At that time, "books on measure" production was a small part of our AAC intervention, that was usually introduced late as part of an advanced intervention, in older children with a full AAC system already running. But under the pressure of families and teachers it was quickly moving towards early booksharing. We came to realize that reading aloud books with a complete text in symbols was a very powerful early intervention instrument for the child and the environment, because it was very easy and natural for everybody to learn how to use it (reading aloud and modelling the symbols, no testing, error-free, full amusement and emotion sharing, rich and complete vocabulary, phrases structure adapted to specific child, strongly appreciated by other children in the context...) and it prepared very well the child and the environment for the AAC intervention that would follow. It also allowed the child to be exposed to a wide symbol vocabulary receptively before introducing CAA output instruments that need much more training for the communication partners.

The laboratory structure has changed in time, and now is organized on two full days, with 5 or 10 teams of 8-10 peoples each, of which 2-4 are tightly connected to the child for whom books will be produced in the laboratory. The first day is on the production of a personalized book (a completely new book, created for a single child, that makes a personal story from positive or negative emotional experiences of that specific child), and the second day is on the production of a modified book (a commercial book and modified it in order to make it fully accessible, including introducing full text in symbols). This forces each group to become a team by focusing on the specificity of the child and not on the theory of the book. It also forces parents, teachers and professionals to share their different viewpoints on the child and then find together where the child is, and the things that really interest and activate him. For most adults, it is usually much easier thinking on what the child can or can't do than thinking on what he likes, while this can be an important point of alliance building by experiencing very practically that what could be good for one child may not be adequate for another, and that "on measure" means exactly what it says: made on measure for that specific child, like a tailor's dress. It is not standard, first it has to be thought "on measure", and only after it can be built "on measure", and that this will be the guideline for the future AAC intervention.

The specificity of the model of service delivery that is now used both in the original AAC rural Centre and in the twin centre that has been structured in centre town Milano is in fact on the "pre-assessment" steps, that include the immediate constitution of a team (parents, teachers and professionals) around the child, the participation of the team to an introductory seminar on AAC, the participation to the "book on measure" laboratory and at least three months of books on measure use.

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