

## Families and information: What makes a professional's information or suggestion on AAC adoptable and usable?

Or with other words:  
*What makes it tick?*

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The correct answer is: We do not know.

What we all know: AAC is working the best if parents and professionals are in agreement regarding its aims, means and everyday practice. We are all also aware of the importance of mutual respect, empathy, and a strong will to cooperate with each other in the best interest of the AAC-using person.

What does the research tell about it?

Cooperation should not mean that mothers are forced to become their child's therapist: children need mothers AND therapists, thus finding the "optimal mixture" is really important<sup>1</sup>.

Quite often an interesting phenomenon might be hidden behind the mutual misunderstandings between parents and professionals, the so-called "embrace of paradox" described by Larson (1998)<sup>2</sup>. This paradox means the mothers have mixed and contradictory feelings regarding their child's disability, like grief and joy. While the presence of such contradictory feelings helps them to battle the situation, at the same time it causes confusion for the professionals. So Larson says it's important to acknowledge and embrace these contradictory feelings.

Another study emphasizes that beside empathic and trustful behavior toward parents the most convincing trait is the authenticity: instead of mainly complying with administrative requirements of an institutional framework, a professional should prioritize families' value systems in order to be able to work effectively together<sup>3</sup>.

A further study calls attention to the importance of sharing knowledge between home and school thus making the transition between the two smooth and advantageous instead of creating a new hindrance<sup>4</sup>.

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<sup>1</sup> Leiter, V. 2004: Dilemmas in sharing care: maternal provision of professionally driven therapy for children with disabilities, *Social Science & Medicine*, 58. 837–849.

<sup>2</sup> Larson, E. 1998: Reframing the meaning of disability to families: the embrace of paradox *Soc. Sci. Med.* 47/7, 86, 5–875.

<sup>3</sup> Lindblad, B.M., Rasmussen, B. H., Sandman, P. O., 2005: Being in Tune with Oneself, Children, and Parents: Meanings of Being a Supporter to Families with Children who have Disabilities as Narrated by Parent-Selected Professionals, *Journal of Pediatric Nursing*, 20/3, 214–223.

<sup>4</sup> Böttcher, L. 2014: Transition between home and school in children with severe disabilities — Parents' possibilities for influencing their children's learning environment. *Learning, Culture and Social Interaction*, 3/3. 195-201.

It is a pity though that knowing or even understanding something won't mean that somebody will be able automatically to act accordingly.

The Hungarian Bliss Foundation founded the first AAC Center in the Eastern and Central European region in 1986. From a very early point on we were faced with the difficulties of the cooperation between parents and professionals. There were quite a few studies, papers and presentations published dealing with these concerns, even a full book was written about it in Hungarian<sup>5</sup>. We learnt a lot about emotional phases of parents discovering the disability of their child; we also realized their need for partnership and enough information, but still. The everyday practice showed that advice and information provided by professionals are not easy to accept, even less to adopt into the family life, and almost impossible to follow through in the hectic schedule of an average weekday. Just recently as an answer to their request we held a sex-education program for parents concerning their prepubertal AAC using children. Half a year later a follow up study showed that none of the advices and suggestions happily accepted on the spot, were followed through, or perceived as possible solutions for the families.

So we had to think again about our original question from the eighties: what makes a professional advice, suggestion or information acceptable and adoptable for a parent or put it simply: *What makes it tick?*

An interesting idea was to apply Rogers' *Diffusion of Innovations Theory*<sup>6</sup> for the acceptance issues surrounding AAC.

This Spring we tried to test this theory, asking both parents and professionals in focus groups what they thought about the *relative advantages*, *compatibility* with the family's life, *complexity* of use, *accessibility of trials* and *observability* of AAC methods: all concepts from DIT. If we consider any information, an instruction, an advice, a device, a method etc. suggested by an AAC instructor as an „innovation” in the life of the family, we thought that Rogers' five components could easily decide whether something could or would be accepted.

#### Method

In two parents' and one professionals' focus groups we asked the same prepared questions, with one group leader and one observer present. The interviews were taped, transcribed, and thematically analyzed by two investigators: one was the observer and the other who was not present at the interviews, but knew the participants. The results of the two analyses were cross-matched and discussed with the group leader. Discussions were led until full agreement.

#### Questions

- Tell us an example about an AAC related success be it a new method, a new equipment, a good idea, anything that worked in your family / that you experienced with a student.
- Tell us an example about an AAC related failure when something definitely didn't work in your family / in your practice.

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<sup>5</sup> Kalman, Zs. (2006) [1994]. *Bánatkő (Road of Sorrow)*. Budapest, Hungarian Bliss Foundation

<sup>6</sup> Rogers, E. M. 2003. [1962]. *Diffusion of innovations* (5th edition). Free Press, New York, NY

- In your mind what is influencing the adoptability of a new AAC-related idea or method into your family / into the life of the family you are working with?
  - o Is it possible that AAC is not the real answer for the basic problems or its advantages cannot be seen?
  - o Is it possible that the usual demands related to the use of AAC cannot be built into the life of the family?
  - o Do you think that sometimes AAC seems too complicated?
  - o Could it mean an obstacle that even in order to try it one has to learn and to practice a lot?
  - o Could it be a negatively influencing factor that there is hardly any way to see how it works in reality, whether it is truly effective in other families, in other settings?
- An extra question was asked only in the professionals' group: What do you think what could make your information, suggestion or advice really effective?

*Results of the parental focus group*

| <b>Themes</b>  |
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| <b>I am a lone fighter for my child's right to express himself</b>   |
| <b>The unrelenting driving force: I will never give up looking for the perfect therapeutic setting for my child in an imperfect system</b> |
| <b>The communication dilemma: I understand my child anyway and am not sure I need or could manage more than that</b>                       |
| <b>Forces, needs, hopes promising possible advantages of AAC: A time might come when Yes and No might not be enough anymore</b>            |
| <b>Parents and professionals: we live in two separate worlds with fragile bridges in need of ongoing construction</b>                      |

**Theme One: I am a lone fighter for my child's right to express himself**

„It would have worked only in case of everybody using her little booklet, her pictures, the communicators. But the other half of the family is simply not able to grasp the idea of this whole issue.”

**Theme Two: The unrelenting driving force: I will never give up looking for the perfect therapeutic setting for my child in an imperfect system**

„How in the name of God could one look for a place where you don't find this and that, all wrong, because I will not let him go to a place which is worse than what I can offer at home... One is certainly willing to pay, if it depends on it, but in that case I want to know that he is in a good place. But you won't find that in Hungary.”

**Theme Three: The communication dilemma: I understand my child anyway and am not sure I need or could manage more than that**

„We don't really use it /=AAC/, we rather keep asking him, and he decides with hemming whether it is yes or no. We are watching his face, what are his reactions, and based on these we know exactly what he wants.”

„She is my child, I know all of her whiffles (?), smallest signals, so we don't use it.”

„There is a time element as well. For us it is much faster to ask her questions than waiting for her pointing from her board what she wanted. It is not working for us because of the lack of time.”

**Theme Four: Forces, needs, hopes promising possible advantages of AAC: A time might come when Yes and No might not be enough anymore**

„It is getting more and more difficult nowadays since he has more sophisticated needs than eating, sleeping, peeing and what not, and we parents have difficulties with understanding these needs.”

„I know I will get it, though not tomorrow, but once he will suggest things, make choices, or will have differentiated opinions about certain qualities... Sometimes this is rather frightening.”

**Theme five: Parents and professionals: we live in two separate worlds with fragile bridges in need of ongoing construction**

„If there is a basic trust, meaning not that I am the therapist, and you are just a parent, who is entitled only to humble herself (or to look small?), this is the only chance to meet halfway.”

„We asked them to try it. Let's try it, let's do it, why not? Don't tell us that the child is not able to do it, the method should be found which would make it possible to teach it.”

„If I experience that they really started doing it, and it is done every week, I would see in this case that she /the teacher/ listened to what I wanted to be done.”

*Results of the professionals' focus group*

| <b>Themes</b>  |
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| <b>Ever-evolving AAC: sometimes it works and sometimes one has to try it again and again</b> |
| <b>Taking on the challenge: building cooperation despite different perceptions and hopes</b> |
| <b>Complicated components of creating real partnership</b>                                   |

**Theme One: Ever-evolving AAC: sometimes it works and sometimes one has to try it again and again**

„It was really shocking that in his second year once he picked his cousin's photo from his album and he explained with another picture and gestures that he wanted his cousin to be invited to their cottage.”

„We have two failures with X and Y. We couldn't reach anything with them regarding AAC, because – despite their totally unintelligible speech – they had such a deep opposition against any kind of augmenting communication that there was no way. None.”

## Theme Two: **Taking on the challenge: building cooperation despite different perceptions and hopes**

„The idea is that whatever we show them, it should be present in their home. Without this nothing is working.”

„I am stuck with this child, she does nothing here. I encouraged the mother to try it at home. She came back telling that out of 10 cases the child did correctly 9 times: for me out of 10 none. How come she could choose so perfectly at home?”

„She tells me that her son is able to recognize letters and build words. OK, I called her in and placed certain letters in front of the child. Show me please, how it works. But the mother couldn't see the child's face, and his arms were crossed in front of him, how could she see what the child was looking at. Sometimes I have the feeling that the mother already made his choices instead of him.”

## Theme Three: **Complicated components of creating real partnership**

„I think age is a strong influencing factor. And the experience. They accept advices from somebody who already has a child, and knows certain situations from life. But it was not enough that I told them what I learnt at the college, real good things, they didn't take me seriously.”

„When parents are talking about their children, they try not to minimize, but look at the child's disability in a comprehensive way, namely not to realize its real severity. This might be a survival strategy on their part in order to have strength to the everyday struggles. ”

„We must be very persistent and authentic while understanding the parent's thoughts about her own child when she asks why she should need all these devices when she knows exactly what her child wants.”

### *Discussion*

It has become evident early on that the original viewpoints of Rogers' DIT were important, but far not sufficient to the acceptance of AAC into the family.

If we look at the families' and professionals' focus groups it seems that everybody wants only the best for the AAC using person, but each of them trusts different routes. When the parent says that she wants to ensure the best possible developmental path for her child, and will try again and again everything in order to reach this goal, it is exactly the same when the professional says that she tried many-many things and even though it took two years, the child made the first important steps toward his personal growth. When a parent says that she realizes the need for a more sophisticated communication, it is in harmony with the teachers' opinion that one needs to be able to tell things to the world and not only to the mother.

So somewhere during the developmental process both parents and professionals realize that without each other it is not possible to do a good job. But to find the right and trustworthy bridges between the two worlds is not easy. Both parties are dreaming of idealized partners. Parents picture a professional who is not only empathically listening, but she is duly following whatever and whenever the parents' suggestions. The ideal parent for a teacher is open for the professionals' advices, listens to the information and even though it is all right to add her own observations, she still should do her best to follow through every suggestion.

This paradox is embodied in certain reflections.

Parent: Why can't you see what I as a parent see?

Professional: Why can't you let me see what I'm trained to see?

A particularly close bond between parent and child reveals more than the professional could ever hope for. This dual-union very often prevents the professional entering their world.

Parent: She should have literacy training, she is already 8!

Professional: First she would need at least a proper, consistent yes and no answers.

Differences experienced in the child's abilities and capabilities result in highly different expectations on both parts

Parent: I want to be involved!

Professional: You should be involved!

The parents would like to pull in the professional into their world of "unrealities" as perceived by the professional, while the professional would like to cooperate with the parents on their own terms experienced in their world of perceived realities.

### *Conclusion*

Under these strained circumstances it is extremely difficult to give an acceptable advice, make a suggestion or convey an information to a struggling, tired parent, or to accept one from a frustrated professional, both seemingly living in an entirely different world. The parent and the professional both feel the same bitter taste of failure. The miracle of meeting despite of all of these hindering circumstances happens usually if the parent had a *eureka* /AHA/ experience: she saw her child's opening up and had the opportunity to enjoy it. To make it happen is one of the greatest challenges – and dream – of an AAC instructor.

Better knowledge of these separate but interdependent worlds and a strong will to meet might help to construct stronger bridges. Good service delivery of good, useful services might certainly help, and an ongoing discussion with constant, mutual feedback between parent and professional could also do a lot for it. This long process takes time and needs individual endeavor, some resilience, persistence and lots of patience from everybody involved.