

Welcome to the module entitled, *Use AAC At Home*, the tenth module in the POWER: AAC training.

POWER: AAC is a project sponsored by the ***Pennsylvania Training and Technology Assistance Network (PaTTAN)***. This training is one of a series of modules designed to build the capacity of local educational agencies to serve students with complex communication needs who require the use of augmentative and alternative communication systems.

Module 10 will help you support parents and families as they use their child's AAC system and core vocabulary at home.

Training in the POWER: AAC Project is primarily self-directed. Each module is presented in a variety of formats, including a video format, PowerPoint presentation format and a print version of the PowerPoint with transcript notes. Some of the modules include supplemental presentation materials. Each module includes a pre and post test assessment.

Please complete the pre-test before starting this module.

Parents and the family are the constant in a child's life. Schools, therapists, teachers, and instructional assistants change, but for most children, parents and families are always there. And nowhere are there more natural or motivating opportunities for communicating than when the child is riding to or from school, visiting grandpa and grandma, at home playing with friends, helping dad cook, or reading a book with mom.

In this module, the focus is on the role of parents and the family in their child's AAC communication program.

While a student spends a lot of time in school, home is where real-life happens. The communication skills that the student is learning at school are intended to enhance his or her life at home and in the community. So, how do you help a family use an AAC system at home? How can you move a family along the pathway to becoming a POWER: AAC home?

The information in this module will help you answer those questions. However, the information in this module is provided with the acknowledgement that becoming a POWER: AAC home is a gradual process; and also that ***no two families are alike***. The ***involvement level*** of and the ***skills presented by*** parents and families in their child's AAC program is dependent on many factors that reflect realities of family life. These realities include things like the number of siblings and other family members in the home, the languages spoken in the home, the parent's coping mechanisms for dealing with challenges or stress, and work demands of the parents.

So, when discussing the roles of the family and the use of AAC at home, it is done with the awareness that not all recommendations or strategies presented in this module are going to be a good fit for every family. But the recommendations and strategies are made with the assumption that school personnel respect and value the role of parents and families and are committed to cultivating parent and family involvement.

Several exceptional postings in the PrAACticalAAC blog have addressed the general topic of the use of AAC at home. In the December 19, 2012 posting, Dr. Carole Zangari reflected on how we can best work with a family so that their child using AAC will do well, and the physical and emotional cost to the family

is not excessive. She covered the idea of respecting the culture of the family; and to aim for slow and sustainable changes with the family in their use of AAC.

In the May 5<sup>th</sup>, 2014 posting, Dr. Zangari, through the use of case examples, reminds us that our approach to supporting families has to reflect who they are and how they function as a family. Dr. Zangari presented valuable insight on the need to support families in the way they need to be supported, remembering that each family is as unique as their child who uses an AAC system.

There is no one-size-fits-all approach to family supports.

Many parents have their own way of communicating with their child. Parents are allowed to understand their child and do not need to pretend that they don't in order to force use of the AAC system. However, understanding their child can become the "seed" upon which AAC skills are grown. For example, if their child vocalizes while looking at the door, the parents can acknowledge that their child is asking to go. The parents could use their child's AAC system to model "go" while saying, "okay, let's go." Or, if the AAC system is not near by, the parents could say, "you want to go. Go is a green word on your board." In this example, the parents aren't sabotaging or pretending not to understand, nor are the parents forcing use of an AAC when there was no real communication breakdown. Yet, by modeling on or mentioning their child's AAC system, they are "watering the seed," so to speak, for AAC use in situations with communication partners that do not understand their child as well as they do.

Parents often view aided AAC systems as being too "something" to use at home. Maybe the parents see AAC as too hard, or too cumbersome, or too time consuming to be practical at home. Addressing the parents' perception of AAC starts with being honest about aided AAC. Parents may find it helpful to meet with other parents of children using AAC to openly discuss concerns and solutions. Other parents may benefit from seeing video of how their child successfully interacts using the AAC system while at school. And other parents may change their view of AAC by talking with adults who use AAC systems. Look for ways to show how the benefits of using AAC outweigh the challenges.

So, assuming that the parents are open to use of their child's AAC system at home, what are some ways in which parents participate in their child's AAC program?

In May 2014, at the Speech-Language & Audiology Canada Conference in Ottawa, Canada, Anne Guillemette and Ann Sutton presented information on the roles of parents, as viewed in current AAC literature. They identified 4 main roles: Collaborator, Informant, Research Participant, and Intervention Agent.

They identified six ways that parents collaborate with AAC experts and educational or medical professionals. They collaborate with the school teams to participate in goal setting, identify priorities for intervention, evaluate AAC options, assist with vocabulary selection and programming, maintain the AAC system, and make the AAC system accessible to their child.

The parents of the child using an AAC system in a public school setting participates in goal setting through the IEP process. The parents shoulder the daily responsibilities of the medical, behavioral, and emotional challenges of their child. They are concerned with not only the educational and communication needs of their child, but also their child's well being, safety, and happiness.

As the parents state their goals for their child, tie communication objectives to their goals. In the examples listed on this slide, developing communication skills is essential for being happy and healthy, having friends, living safely in the community, going to college, or getting a job. The AAC intervention program reflects the steps along the way for reaching these long-term, holistic goals.

Imagine that you have collaborated with the parents to set the following three communication goals for their child who is at the beginning stages of using an AAC system.

Bobby is a student who has behavioral, as well as communication challenges. Each of his goals replaces a current behavior with a communication goal. These three goals are very broad, but are the first steps in working toward the parents' goals for Bobby.

Next, the parents and AAC intervention team identify priorities in the communication intervention program.

We like to think that ALL of the communication goals that we set are a #1 priority, but in the example of Bobby, his parents choose goal #1 as the number 1 priority because their son is self-abusing and they choose goal #3 as another first priority in order to reduce or eliminate his screaming behaviors. They are the goals they are going to work on now. That doesn't mean that the parents don't value goal number 2 of playing nicely with peers, but it is not as high of a priority right now.

Third, the parents collaborate with the school to assess and choose AAC options that are appropriate for their child. If you are not currently involving parents in this process, review Module 3 and consider specific strategies for including parents as collaborators in the AAC assessment and selection process.

As more and more parents are privately purchasing mobile technologies and AAC apps for their children, is it important to remember that AAC assessment is a process which produces the best results when no one assumes a solo role as gate keeper for the selection of the AAC system.

When the collaborative process breaks down, it is possible that the student may end up with one AAC system used at school and another, entirely different AAC system used at home. It is beyond the scope of this module to address this complicated issue other than to remind everyone that it is rarely in the student's best interest to have these types of conflicts between the parents and the school system.

While a one-size-fits-all AAC system does not fit all students, I would suggest that a one-size-fits-all AAC system may not fit all communication situations, settings, or partners of a student who uses AAC. Let me explain.

When collaborating with parents to assess AAC options, the AAC system, as it is used at home and in the community, might be a variation of the AAC system used at school. I want to stress the word "variation," which in this discussion means that the school system and home system are related, similar, and supportive of each other.

First, when at home, the student might require alternative access methods. Many students who are well positioned in a wheelchair or other types of seating at school use one access method at school, but when at home they need a different access method because they are not always in their chair. Jonah is one of those students. At school, he uses eye gaze to access his speech generating device, but at home when he is out of his chair, he uses a manual communication board with partner assisted scanning. His

manual board is a print-out of what is in his speech generating device, so he is using the same words, same pictures, and same vocabulary organization. The only thing different is the access method.

Next, some students need different designs for different environments. Taylor is one of those students. She is ambulatory and uses a mobile device with a communication app at school. Because she is very active in her community, she has a manual communication board, designed as a purse, which is light, can't get broken like a mobile device and, if accidentally left somewhere in the community, it isn't a huge financial loss. Her purse communication system has similar pictures, but less vocabulary than her mobile app.

Jonathan is another student who has different designs for different environments. He uses a speech generating device mounted on the front of his wheelchair accessed with two switches mounted by his head. He frequently goes to theme parks to ride roller coasters. A speech generating device isn't something you want to take on a roller coaster, nor is it something you want to leave behind in an unsecured location while riding the roller coaster. So, when going to these types of community settings, Jonathan's parents carry a small, foldable eye-gaze word and spelling board. This board parallels the vocabulary in his speech generating device.

Finally, you may need a variation of the child's AAC system when there are family members who do not speak the language of the classroom. For many students, that might involve having a manual communication board with words for both languages written above the pictures on the communication board.

The fourth area of collaboration is in selection and programming of vocabulary. In the collaboration process, it is essential to explain the power and purpose of core vocabulary. However, we also want parents to understand that core vocabulary isn't the only words needed in their child's AAC system. The parents can supply a list of essential extended vocabulary words, such as family names, favorite objects, and favorite places.

Create a plan for managing the programming of a speech generating device, mobile technology app, or even a manual communication board. It is recommended that one person be designated the official programmer. If multiple people are programming vocabulary into a device or app, the vocabulary organization can quickly become disorganized and jumbled, frustrating the student as well as other team members. The official programmer should be a person who not only understands the operation of the technology, but is also versed in the organization of the vocabulary.

Create a plan for how the family and members of the school team can communicate requests for new vocabulary; as well as a plan for how the official programmer will inform the family and school team about how and where the new vocabulary was added to the device or app.

The parents will also collaborate with the school team to maintain the AAC system. Maintenance tasks may be done on a daily, weekly, or as-needed basis.

Daily, parents collaborate when they take responsibility for charging and cleaning their child's AAC system. For Heather, who has significant health concerns, every night her parents use sanitizing wipes on the surface of her low-tech device and paper displays that go on her device. This significantly reduces her exposure to bacteria. Then, once a month, they change the two, double A batteries in the

device and check all the parts of the mounting system that attaches Heather's device to her wheelchair. If she used switches, I'm sure they would also be checking those too.

Maintenance of the AAC system also includes documenting the vocabulary programmed in the AAC system. The programmer may be the person who maintains the electronic or paper documentation of the vocabulary in the device or app, as well as the person who conducts regular memory back-ups of the vocabulary. The parents should have access to the electronic or paper documentation, as well as the memory backup to their child's device or app.

As a team, discuss any issues related to the upgrading of any software in the device or app, as well as the plan and policy for the repair or replacement of damaged or broken equipment, such as a switch or cable.

Finally, the parents as collaborators involves making the AAC system available to their child. As stated earlier, the parents and school team will collaborate to resolve any barriers which may prevent the child from being able to use an AAC system. That includes discussion of the use of alternative access methods, design variations for different environments, and modified systems for different languages spoken in the home or community. It might also include teaching the parents how to make adjustments to the settings of the device for different environments. This was key for Jordan and his family. They were not taking his AAC device with them to church because they didn't want Jordan to disrupt the service by saying messages loudly with his speech output device. By teaching them to turn the speech way down, or even off and read the display, they saw how they could make the AAC system available to Jordan while in church and other quiet environments.

Then there is Kyle who uses auditory scanning to access his device. In loud environments, like at his brother's basketball games, his family didn't bring Kyle's AAC device with them because Kyle couldn't hear the auditory scan output. But by providing him with headphones and teaching them to change the settings in the device, Kyle has his AAC device available to him for the three or more hours they are at the basketball game.

Next, let's consider the role of the parents as informants.

When given the opportunity to express their opinions, worries, and thoughts to educational or therapeutic team members, parents add details to the overall picture of their child's communication patterns, needs, and competence. For this to happen, there needs to be regular communication back and forth between the parents and the educational or therapeutic team.

Teachers have many informal strategies for communicating back and forth with the parents of their students. Teachers gather information from parents and parents express concerns to teachers through home and school books that are set back and forth every day. Some teachers have weekly or monthly live chats with parents when they need to collect information. And most teachers and schools have newsletters or websites which can be a means to communicate with the parents about their child's communication program.

There are also formal tools which can be used with parents to collect information about their child's AAC and communication development. Many school districts develop their own information inventories to formally collect information from parents during the AAC assessment process and for on-going assessment to measure student progress. Module 11 includes information about collecting evidence to

measure progress. There are also a variety of non-device specific AAC products developed to measure student communication skills and guide communication intervention. One tool is the Augmentative and Alternative Communication Profile: A Continuum of Learning by Tracy Kovach, available from LinguiSystems. Another popular tool to use with beginning communicators is the Communication Matrix by Charity Rowland, available at [communicationmatrix.org](http://communicationmatrix.org). Both of these tools are useful when working with parents as informants.

Now, let's consider the role of parents as research participants in their child's AAC system.

In a school-based setting, we don't usually think about parents as research participants. But in a broad sense, parents are research participants any time the parents collaborate to set goals, collect data on a goal, and then discuss their child's progress.

Consider how you can collaborate with parents to collect information on their child, focusing on information which is not usually available to the school team. In the day of smart phones, parents can document their child's real-life AAC use at home, in the community, and with different communication partners with a quick, short video of their child. The family can also document the strategies they use at home when they are modeling the AAC system, communicating in the car, or when siblings are interacting with each other using the AAC system.

Finally, many high tech AAC systems have automated data logging features, which record when something was said with the device or app, what was said, and how it was said. This information is very valuable in tracking a student's skills and showing progress over time, especially with students who make progress slowly. The data collected can be analyzed manually or through available software. Parents need to be aware of and in support of this feature in their child's AAC system.

Contact device manufacturers and their representatives to learn whether or not any devices you are using with your students have an automated data logging and analysis feature.

We've covered the parents as collaborators, informants, and research participants. Finally and most importantly, let's consider the role of parents as intervention agents for their child.

As intervention agents, sometimes the parents are the communication partners. Like everyone on the intervention team, the parents need to be comfortable with the ins and outs of being an effective AAC communication partner. Module 7 covered communication partner skills, and included information on creating and engineering communication opportunities, prompting use of the AAC system, responding to the student's communication attempts, and asking questions which encourage use of the AAC system. Share this information with parents in ways which makes it do-able for them at home.

The parents and siblings are also models in the use of the AAC system. The family is encouraged to use the AAC system to talk to their child. Module 7 covered modeling as a specific communication partner skill. Working with the family, develop strategies that are do-able for them to learn how to talk with the AAC system so they can be role models for their son, daughter, sister, or brother.

Finally, the family might be called upon to conduct specific activities or lessons at home, acting as teachers in the reinforcement of specific learning objectives. For example, the classroom teacher might send home a storybook with symbolized text, asking the parents to have their child read the book to them. The teacher might send home a script that includes symbolized text which the parents say with

the AAC device, providing a role model as they read the book. Then, as their child reads and re-reads the book to them, they help their child say the vocabulary and sentences featured in the book. Module 8 included information on vocabulary teaching strategies, which included information on how parents can be involved in teaching the target vocabulary at home.

There are no specific rules for helping a family implement an AAC system at home. What might work for one family may not work with another family. However, in most cases, implementation of AAC at home involves a significant change for the family. The pathway to effective AAC change involves having realistic reasons to change, supporting sustainable changes, maintaining communication, and then celebrating successes.

First, create in the minds of the parents a compelling picture – a vision – of how things could be better when their child is communicating with an AAC system. In other words, give the family something to change for – a realistic picture of what can be expected. These expectations should be aligned with the goals and objectives established for their child.

Sharing a short, motivating video of a child using an AAC system – or better yet – their child using the AAC system successfully - could be what it takes to give the parents a reason to change. Many parents may ask to meet competent AAC users with and without similar challenges as their child. Some parents may need to meet other parents to talk through their concerns, hear about the experiences of others, or talk through ideas that did and did not work for them.

Second, be conscious of what it takes to make changes that are sustainable. A sustainable AAC change is a change which can be maintained and kept up by the family. Anyone who has ever tried to lose weight or start an exercise program knows how hard it is to make a sustainable change. The secret for making a change that is sustainable is to start in your comfort zone where you have the most confidence in your success.

If the goal is for the parents to model on their child's AAC system, present ideas and options for how much, when, and where they could start modeling. Start slowly with small steps and with small demands and expectations. Could mom model for 2 minutes? Could dad model for a minute when he comes home from work? Could a sibling learn to model a couple of sentences?

Next, ask parents what would work for them and encourage them to present options, suggestions, and strategies to fit their family life situation.

If you ask the parents to act as "teacher," choose activities which are already familiar to the student and which the student has had some success with at school. We want the beginning success from school to extend to success at home. The efforts of the parents can help strengthen and turn those emerging skills into mastered skills. When that happens, parents get the pleasure of seeing their child master a skill and knowing they contributed to it.

Families are more likely to make sustainable change when the intervention we ask them to do is integrated into authentic, home-life activities. Rather than add to the demands and activities of their household, we want to slide some AAC use into activities that are already part of their family routine. Find out from the parents as to which activities are the easiest ones for them to start implementing some AAC strategies or which would make the highest, authentic impact in their family.

If you are asking the parents to do specific tasks, make sure that the parents have easy access to the materials needed to do the task at home. Send home symbolized materials which are specific to the AAC system used by their child. One teacher made short 2 or 3 minute videos explaining and demonstrating the materials she was sending home to parents. Then she posted that video to her classroom website and sent a video link to the parents showing them how to use the materials she sent home. This strategy greatly increased parental implementation of AAC at home.

The third item on the pathway to change is on-going communication. Communication is essential to maintain enthusiasm and to build accountability. Encourage balanced two-way communication. Share ideas and stories with parents, and encourage them to share stories, pictures, and videos with you. How often you communicate about the student's AAC program is based on personal style of both the parents and the teacher. But, short, frequent communication is typically the most effective.

Short, frequent communication can be managed through pictures or videos of teaching procedures, phone or video conferencing, short notes or text messages, and even through classroom or school websites.

Finally, create an atmosphere where parents feel safe to report on what is and isn't working for them. You need their honest, constructive feedback to trouble shoot problems and modify the home AAC program. Rather than blame parents for not using the AAC system at home, we need to better understand the hurdles they are facing and consider what changes are necessary to make use of AAC at home more do-able for the family.

The last item on the pathway to change is celebration. The family needs to be reinforced for their efforts, as well as their successes. Verbal reinforcement is good and written reinforcement is even better. One parent in a school in Florida was thrilled to receive a written, mailed note from her son's speech-language pathologist, thanking her for her efforts and praising her for the work she did to make sure her son was successful in school. In the note there was also a refrigerator magnet with a motivational saying.

This parent was also invited by the classroom team to attend and co-present with them at a local AAC conference. While this parent didn't feel comfortable presenting at a conference, she was in attendance at the presentation and her role in her son's AAC success was publically acknowledged. This encouraged her to take new steps to develop her skills as her son's communication partner, role model, and teacher.

Celebrating efforts and successes with the parents also helps them see themselves as partners with the school AAC team. A sense of partnership helps fuel parental empowerment in families with children who use AAC systems.

Finally, partnership and success usually stimulates a desire to learn more and become more involved in the AAC community. This is a good time to approach the parents and the family to find out what kind of additional training they want and need.

While most initial interaction with families and implementation by parents usually involves training specific to and tailor-made to their child, many parents seek out additional, general information about AAC and then learn to apply that information to their child.

Based on the parent training opportunities at your school, regional center, or local area, explore small and large group training activities which might be interesting to the parents and family. The list of small and large group training options listed on this slide are just a few of many possibilities which might appeal to parents and families. Inviting parents to any of these types of events encourages them to continue to explore ways that they can use AAC at home with their child.

You are encouraged, following this module, to apply what you have learned. First, review the two PrAACtical AAC postings that were mentioned on slide 7. Print out the postings and share with other colleagues and parents, as appropriate.

Then, print out a copy of the POWER: AAC Home-School Planner. This Planner is a working document, intended to help develop your skills in helping a family implement AAC at home. Print out a copy of the document and do a role-play activity with a colleague, such as the classroom instructional assistant, another teacher or another therapist. Have that colleague play the role of the parent of a child in your classroom. Together, think through possible reactions of the parent to questions on the Home-School Planner. Modify the Planner, as needed, to suit the students in your classroom.

For more information about parents and the use of AAC at home, consider reading some of the journal articles listed on this slide.

Please complete the post-test for this module. Thank you.