Education

As indicated elsewhere in this document, children with Angelman Syndrome (AS) present many unique physical, social, educational, cognitive, and communicative challenges which require interventions to be comprehensive in nature and scope. Educators, including teachers and related service providers (e.g. occupational therapists, physical therapists, speech‑language pathologists), must have sufficient expertise in the area of severe disabilities (in general) and Angelman Syndrome (in particular) to meet these challenges and provide appropriate educational programs. Students' individualized programs should be aligned with the general education curriculum to the greatest extent possible, consistent with federal regulations (IDEA: Individuals with Disabilities Education Act).

Also consistent with IDEA, education should occur in the Least Restrictive Environment (LRE) in which individualized and appropriate instruction can be provided. For many students, this is a general education classroom where they learn along with children without disabilities. Other students may spend part of their day in a resource room, moving between this setting and the general education classroom. Other options include a self‑contained classroom, where students are grouped with other children with special needs, and a separate school for children with special needs.

Decisions about the most appropriate placement for students with AS should follow much deliberation among the team, including the family. No particular placement is optimal for every student with AS. The appropriate placement is the least restrictive environment in which the student's needs can be effectively met and in which there are reasonable expectations the child can make meaningful progress. It is essential that students' educational needs and corresponding goals are determined first, with discussions about placement following. We must not work in reverse, determining where a child will be placed and then building goals around that placement. Finally, irrespective of where a student spends most of his or her time, whether it be an inclusive or a self‑contained classroom, it is important that administrators and all staff share a common mission for all students, those with as well as those without disabilities.

For children receiving some or all instruction in general education classrooms, it is essential that necessary types and levels of support are made available not only to students but also classroom teachers. This entails systematic and ongoing collaborations between special educators and general educators, with additional input from related service providers and, of course, parents. The team determines curriculum modifications and special accommodations that are necessary to meet each child's instructional needs. These are based on comprehensive evaluations conducted by a diagnostic team at school and/or in a specialized center. Families should play a central role in the selection of assessment instruments, interpretation of results and, perhaps most importantly, selection of instructional goals. Educators should engage parents in discussions about visions and dreams for their children post‑graduation. Educational goals should be aligned with these aspirations, irrespective of students' educational placements.

Source: 7th edition Facts about Angelman Syndrome by Charles A. Williams, M.D., Sarika U. Peters, Ph.D., Stephen N. Calculator, Ph.D. in 2009

The resulting educational program should be conceived in a manner that enables students to derive benefit and demonstrate reasonable educational gains in relation to the general education curriculum. At the same time, it must also provide sufficient opportunities to address other skills noted in the child's Individual Education Plan (IEP) or, in the case of early intervention programs, Individual and Family Service Plan (IFSP).

Children with AS typically require a variety of related services, most commonly physical therapy, occupational therapy, and communication therapy (particularly Augmentative and Alternative Communication). It should be kept in mind that educators are expected to provide programs that are appropriate and not, necessarily ideal. Additional services such as adapted physical education, therapeutic recreation, behavioral interventions, music therapy, aquatics, and hippotherapy may be appropriate on a case by case basis. Related services enhance children's abilities to access and participate actively in the general education curriculum. This usually requires significant modifications of classroom instruction; academic expectations; and dual emphases on academic learning and the acquisition of functional skills (e.g. indicating food preferences to a cafeteria employee).

Children with AS typically require one on one instructional support from an aide or paraprofessional. Aides should work under the direction of general education and special education teachers, and related service providers. Although Aides may carry out programs, it is the responsibility of other professionals (Teachers, SLPs, etc.) to determine what is to be worked on, when, and in what manner and to monitor aides' implementation of programs on a regular basis. Similarly, although Aides may collect performance data, it is the responsibility of teachers and others to interpret these data and then make additional program recommendations.

Aides must be used in that capacity, as Aides, and not as teachers or other specialists. This requires sufficient levels of support from other staff. Team input is critical in identifying accommodations and modifications that must be made for students' frequent laughing, hypermotoric behavior, shortened attention span, and other disabilities commonly seen in AS. Modifications should also play into children's strengths, which often include a pleasant disposition, interest in people and social interactions; movement, and active engagement.

Calculator and others provide rationale as well as practical strategies for targeting students' IEP goals in the context of the general education curriculum using integrated models of service delivery in the classroom and other natural settings. For example, rather than pulling a child out of the classroom to work on 'walking' in a therapy room, the Physical Therapist consults with the Aide and teachers and instructs them, through role release, how to foster acquisition of this skill in the context of the child's getting from one meaningful location to another. This could involve walking from the classroom to the gym for a PE class or navigating around the playground during recess. Similarly, rather than working with a speech -language pathologist on a choice making program, the Aide, teachers and others are taught and encouraged to instead integrate opportunities for children to make meaningful choices such as with whom they wish to play, whom they wish to be seated next to, and where they wish to play, throughout the day. Dressing skills can be worked on when the child arrives

and leaves school and needs to put on and take off a coat, uses the bathroom, and changes in and out of gym clothes for a physical education class. In order for an integrated model to be effective, assistive technology such as mobility aides and AAC devices must be available to students and educators at all times. Assistive technology needs are determined by multiple team members who seek to maximize students' independence and participation in a full range of meaningful activities throughout the day. School personnel should be trained how to use and maintain this equipment in good working order.

As discussed in another section of this document, Applied Behavior Analysis (ABA) has been found to be an effective instructional method for many children with AS. Programs employing other teaching methods, such as those found in general education instruction, often incorporate behavioral methods such as reinforcement, modeling, shaping, multiple trials, and so forth. Skills targeted should be appropriate chronologically and developmentally. For example, puzzles intended for preschoolers should be used with preschoolers and not older children despite their perhaps being perceived to exhibit skills typically associated with preschool aged children. For example, an adolescent who is learning to make meaningful choices might be given an opportunity to select one of two books a classmate is prepared to read to him/her during silent reading, rather than choosing between bubbles and a pinwheel in a play setting.

Academic skills should be supplemented with attention paid to fostering independence and self‑determination (i.e. students having maximum control over their lives, making choices and decisions). Whenever possible, functional skills should be integrated within the curriculum, as previously discussed.

Students with AS usually require high levels of assistance, such as physical prompting, when learning new skills. Verbal prompts should be kept to a minimum as these are very difficult to fade and often result in children's overly relying on them in order to act. This is referred to as prompt dependence. The goal should always be spontaneous behavior, with minimal reliance on prompts and cues.

Many children with AS demonstrate difficulties orienting to and then sustaining attention on task. This relates directly to students' levels of active engagement, interest and motivation. Unless instructional content and delivery appeal to students, and they value the consequences of this instruction, students may be distracted and/or seek stimulation elsewhere. Conversely, when meaningfully and actively engaged in activities as active, and not passive, learners students with AS can remain on task for up to an hour or more. The use of picture schedules and other aids that cue students to transitions from one activity to the next are often helpful in keeping students oriented and on task.

Amounts and rates of learning vary greatly in students with AS. Some students may complete school still highly dependent on others in most life skills, using relatively simple communication aids that enable them to express basic wants and needs, with a limited range of leisure interests, and requiring high levels of support to participate in their communities. Other students, particularly those without large deletions, may possess life

skills that enable them to be more independent at school, home, and in the community, with less reliance on prompts and other external supports. They may utilize complex voice output communication aids (i.e. speech generating devices) to express hundreds of different meanings with a variety of listeners in numerous settings. Regardless of the severity of their disabilities, employment and a happy life can be a goal for all individuals with AS, so long as the necessary types and levels of support are readily available.

Finally, it is important that educators, families, and others set and maintain high expectations for all students with AS. It is preferable to provide students with opportunities to experience and succeed rather than withholding instruction in anticipation of failure.

Source: 7th edition Facts about Angelman Syndrome by Charles A. Williams, M.D., Sarika U. Peters, Ph.D., Stephen N. Calculator, Ph.D. in 2009