PHYSICAL THERAPY AND OCCUPATIONAL THERAPY BEST PRACTICES

angelman SYNDROME FOUNDATION

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WITH YOU FOR THE JOURNEY.

Physical and Occupational Therapy Best Practices, Tips & Tricks, Equipment and Resources for those living with Angelman syndrome

This resource was created by a group of certified physical and occupational therapists that have a history of working with individuals with AS. This document is intended to be a support document that you can take to your team to support their efforts with your individual with AS. If your PT or OT would like to talk with anyone from this team for support, please have them reach out to info@angelman.org. Please note that this is NOT a complete list or a standard of care for AS, but a resource created by passionate individuals experienced in this area.

BEST PRACTICES

There are many theoretical approaches to physical therapy e.g., neurodevelopmental, activity based, systems theory, dynamic systems. Most therapists, I hope, would support exploration (a mix of trial and error and guidance) with an environmental set-up to assure optimal learning of motor skills. This may include special equipment to facilitate optimal motor learning. (see the Appendix for related pictures & videos) The following are areas to prioritize:

- Assess and identify sensory processing patterns to include assessing and identifying supports and barriers to basic daily activities- including sleep, feeding, toileting, etc. Rule out medical complications for any barriers or difficulties identified, and then develop supportive interventions for these areas. Activities: Sign Up EARLY (months to years before child ready as usually there are waiting lists) such as hippotherapy and aquatic therapy. (figs 26,27,28,29)
- Appropriate sensory inputs into your intervention. For example, proprioceptive and deep tactile input (input to joints- pushing, pulling, hugging, squeezing, jumping) can be calming, while vestibular input (swinging, rocking, head movements, bouncing) can have both calming and dysregulating affects that may support or hinder regulation. Walz & Baranek (2007)1 found high rates of sensory processing variability and dysfunction in children with Angelman syndrome.
- When needed for schools, The Peabody Developmental Motor Scales II (PDMSII) evaluation tool is composed of six subtests that measure interrelated abilities in early motor development. It is designed to assess gross and fine motor skills in children from birth through five years of age. When needed for insurance or schools, some people use PDMSII to capture videos and pictures of functional gains to show progress to parents. For more information check out this website:

Quotes from a few therapists who have worked with individuals with Angelman syndrome

"Being flexible to match the child's mood and willingness to participate while still reaching their goals is a fundamental of pediatric therapy."

"Being creative and being able to work on the fly."

*"Being persistent and patient, no, really P*E*R*S*I*S*T*E*N*T AND P*A*T*I*E*N*T...could be a month of dedicated time to allow the infant/child to own 1 skill."*

"Making all therapy functional so parents can tweak their support/hand placement and positioning for: p... diaper changing."

FOCUS POINTS

MOTIVATION

- Depends on what captures your child's attention and what keeps their attention. In the case of some it could be their favorite things like magazines, musical toys, light up toys, build magnets, or specific people. Keep these toys "special" to use only during engaged parent play or therapist play, not during independent play time.

ENVIRONMENT

- Static (consistent) environment to master skill, then dynamic (same location with distractions added) environment, then novel (new location) static then novel dynamic (new location with distractions added).
- Limit flat play time to playpen, not open floor. This will allow child to get input seeking when rolled into sides of playpen. Fix toys/motivation from at the top on side out of reach or across the middle. It also encourages pushing up on hands to view and eventually pulling to stand, rather than rolling.
- When growing playpen space, make space with a "play-yard" a narrow rectangle to facilitate moving forward, not rolling sideways (fig.1). Focus on toy placement at nipple level (not eye level) to engage eyes in downward gaze to engage tummy muscles for back play, playpen, crib mobiles, car seats and, supported sitting.
- Obstacle Course: when leaving child for safe free play, set up environment so that child needs to problem solve to get their favorite toy drawer/closet/bin (rather than placing toy on lap) (fig.2).
- Limit toy selection to a choice of 2 held separately for focus playtime (fig.3).
- Increase body awareness by hiding favorite soft toys under shirt (start with front move to back, shorts leg then pant-leg) for free play time challenge (fig.4).
- Once up and walking, even with support, get all play up off the floor using supported tall kneeling (fig.5,6,7,8), dynamic standing support, or sitting in a chair reaching in a bucket on the floor.

STABILIZE

- Very early on, stabilize as much of the body as you can, including the neck, to get control of eye gaze. I have found being at the head of the infant, having an infant on back with a weighted blanket, engaging in face to face while infant locks upward eye gaze is a fun game for infants with parents and siblings.
- Restrict joints and provide an "external skeleton" (bracing as much as possible). Use elbow splints early to get weight bearing through hands in 4 point supported sitting and then supported quadruped (fig. 9,10).
- Start very early eliciting balance reactions(fig.11) in functional ways as well as getting the hand position as low on the trunk as possible, with the goal of all support at diaper level.
- A favorite: Hold the infant at the trunk, sit the infant on changing table facing you, rolling to the side, then to the back to change the diaper. Then rolling the infant to the side, to sitting facing you, then picking up from the changing table. (Focus on 3: "SIT SIDE BACK" then "BACK SIDE SIT" to slow yourself down.) Be sure to change head placement from one end of table to the other so that you engage both the left and right sides of the trunk. As the infant develops you are looking for hand to go out, as a side protective reaction.
- When moving to standing, use elbow splints (elbow& knee splints are interchangeable at this age) on knees to get weight bearing, as you hold child at waist from behind (fig.19).
- Then, start to remove one brace at a time, keeping bracing on the stronger side rather than weaker for neurological training. Then use support at the trunk moving down the legs with support as control improves, then to combine with variable input support, to allow a safe environment to explore and find midline.
- Using lit/musical toys to facilitate crossing midline (i.e., use of left hand to reach to right to grab toy) and reaching to get additional trunk rotation in various positions including lying down, sitting, kneeling and standing. Also provides weight shift stabilization needed for higher level activities.

SUPPORT

- Our hands show the child where support will come from: our tendency is to hold the child up. BUT focus rather on slightly pushing child's feet down into the surface, to allow them to gain a better understanding of where their support surface is coming from.
- Use support from behind the child with all activities such as tall kneeling and standing during dedicated engaged play as children will naturally get support from surfaces in front of them.

- Sitting infants in cross-leg sitting with support at ankles and with no other trunk support (fig.12).
- Inside corner support in standing (fig.13).
- Allow for variable non-human support, such as flexible rope draped at variable heights. The tighter the rope the more support and the looser the rope the more the child needs to react with trunk muscles to maintain upright (fig.14,15,16,17,18,19,20).
- When walking, get away from handheld as soon as possible and try using variable hand input to shoulder; try holding a firm toy while the child holds the other side progressing to floppy toy in the same manner.
- Walking in chest level in water, input at the pelvis in the beginning, possible weighted vests to keep legs down and feet on floor (fig.26).
- Walking on a treadmill with variable support including up to a Lite-Gait type support.
- Walking while carrying objects first in 1 hand and progressing to 2 hands, as able.

CORE (Ask therapist for more details to start core work early)
- Use of breathing facilitation to improve diaphragm function and core musculature to improve balance.
- Rib mobilizations and myofascial work to improve trunk mobility, breathing patterns,

EQUIPMENT

It is imperative to have set ups in the home to facilitate movement with proper balance of guidance and just the right challenge. Individuals with Angelman syndrome may take a longer period of repetitive positioning, movement and/or choice limitation to own the experience. The equipment suggestions may carry over into next area of development depending on the individual.

For Infants

All postures, appropriate toy selection with early isolation of toys to the choice of 2, early opportunities for emerging infant motor skills such as prone progression, rolling, sitting, kneeling and crawling. Aids for transitioning such as wedges, foam steps, proper table heights for pull to kneeling or standing etc.; may include such garments as a SPIO.

- **SPIO of varying support levels (figs.6,10,21)**
  The SPIO is ideal for children with poor core muscle activation, stabilization or weakness.
  Provides shoulder-trunk-hip stability and midline orientation and increases body awareness. Both tops and bottoms. www.spioworks.com

- **Bath Ring**
  Once sitting with support at trunk, the bath ring allows an individual to have more autonomy in the bath, while building trunk strength and control of freedoms of movement within the ring. It supports play and body stability training. See product example on Amazon.

- **Elbow Extension Splints (for elbows and/or knees) (figs.9,10,19)**
  An elbow or knee extension splint provides an extra set of hands while giving joint control to allow for isolated joint control work. Gives you an extra pair of hands to challenge individual with AS without hand support for continued body control development during workout sessions.
  See the BraceAbility Elbow Immobilizer on Amazon

- **Weighted Blankets/Vests (figs.23,24)**
  Helps to control bodies by providing firm pressure. Individuals are provided with increased sensory feedback to help with body control and awareness. Please check with therapist about appropriate weight of blanket for your individual. www.lunablanket.com/products/luna-weighted-blanket

For Toddlers

Emerging walking with necessary supports but adequate challenge to reach independence (walkers as needed, orthoses), swimming and climbing, early fine motor skills. Repeating simple phrases such as, “Give me” when taking an object and continuing daily through elementary.

- **Wall mounted toys**
  Allow for motivation for pushing vs. pulling training

- **Crawling Aid**
  Very helpful to keep children of any age moving independently on hands and knees if walking is not yet attained. See FLAGHOUSE Adjustable Crawler on Amazon

- **Spiral Orthoses (Show the attached images to your orthotist and physical therapist.)**
  Can provide just the right amount of stability and support to engage the individual's larger muscle/motor control. Can help by giving intermittent input into legs and improving walking abilities. Orthotist and PT’s may not recommend this type of support, but for individuals with Angelman syndrome, spiral orthoses are game changers. Individuals with Angelman syndrome have the strength, so they don’t need fixed support, but they do need the support to learn where midline is, and the spiral orthoses gives this variable input.



- **BILLY Shoes**
  Orthopedic footwear for individuals with ankle foot orthosis (AFO).
  billyfootwear.com

- **Safety**
  o Enclosed Beds: Safety Sleeper by Abram’s Nation
  o For Travel: Safe Place Bedding
  o Dutch Door (1/2 door) (fig.25): See product at Home Depot

For Elementary

Addressing higher motor skills- adaptive bike, running and engagement in group motor activities, especially for the school-aged child who will be in class and working with school staff to make choices, etc.

Bikes

- Adaptive Bikes: designed specifically to the individual. The bikes are designed for mobility, therapy, recreation, and fun!
  - o Rifton
  - o Freedom Concepts
  - o Worksman

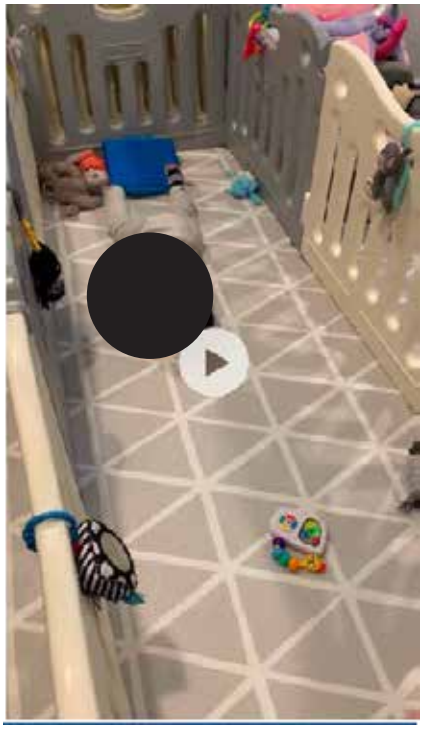
- **Ride-Alongs / Trailers**
  Weehoo

- **Safety Helmet (fig.22)**
  - o If walking balance and independence are at odds a safety helmet can aid in progress.

References

1. Walz, N. C., & Baranek, G. T. (2006). Sensory processing patterns in persons with Angelman syndrome. American Journal of Occupational Therapy, 60(4), 472-479.
https://www.orpha.net/data/patho/Pro/en/AngelmanGuidelines2011.pdf

APPENDIX OF PICTURES & VIDEOS



FREE TIME PLAY:
Play-yard rectangle: to encourage movement forward place toys out of reach.

Obstacle Course: when leaving child for safe free play, set up environment so that child needs to problem solve to get to favorite toy draw/closet/bin.

Limit Choice of toys during focused playtime.

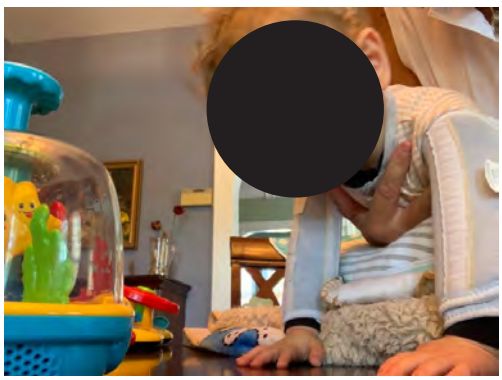
Hide soft toys under clothes: start front of shirt, move to back of shirt, shorts leg, then pant legs.

PLAY POSITIONS

Kneeling at Slant Toy

Kneeling with Trunk Rotation (SPIO on with Extra Back Support)

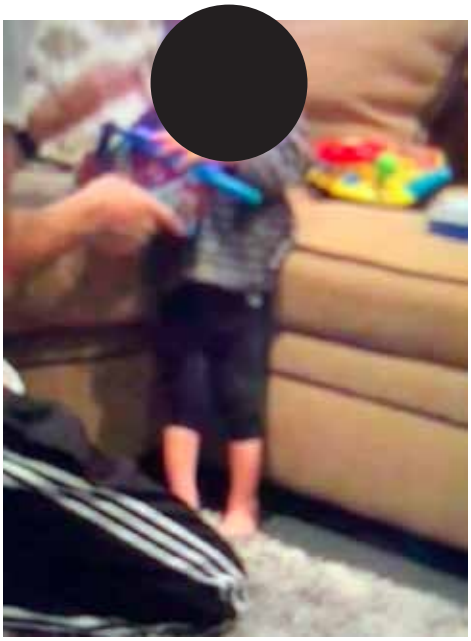
Tall Kneeling with Posterior Support



All Fours with Elbow Braces

One Protective Reaction:
right hand out to side

Crossed legs sitting with
Support at Ankles

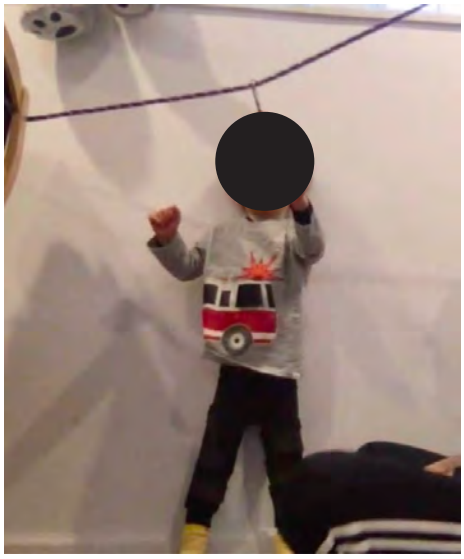


Posterior support standing
on inside corner

Rope draped at adjustable heights for dynamic support play: Walking or Static Standing

Dynamic Support of Bolster & Rope

Tall kneeling with Rope



Rope with wall support. Knee Brace on Stronger Leg Only.

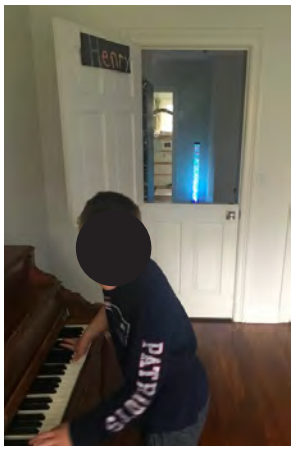
Home Made Dynamic Surface Support of Light Saber & Swiffer ;)

EQUIPMENT

Full SPIO suit on:

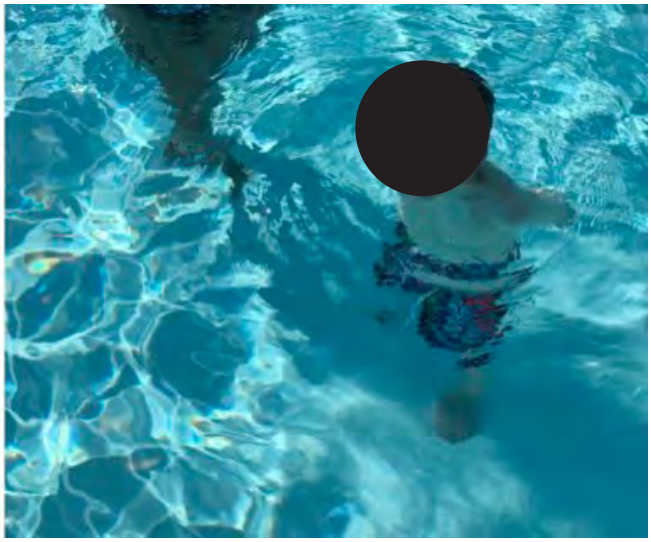
Helmet for increased safety with walking

Weighted Blankets of Various Sizes



Dutch(1/2) Door

EXTRA FUN ACTIVITIES:
Sign Up EARLY (months to years before child ready as usually there are waiting lists)



Walking in shoulder high water: may use weighted vest or weights at waist to keep feet on ground.

Hippo-therapy and/or Therapeutic Riding

Skiing feeling the wind in my face

Buddy Surfing