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RESEARCH AT TEACCH PAGES 3-5



TEACCH'S NEW ONLINE COURSES PAGE 5



ENGAGEMENT IDEAS FOR YOUNG CHILDREN PAGE 6



# **TEACCH** Autism Program

Services Across the Lifespan

# A Message from the Director...



Happy Holidays from TEACCH,

I always look forward to writing this end of year letter so that I can celebrate some of the exciting accomplishments at TEACCH in the past year. Thanks to our fabulous training team (Lee Marcus, Kathy Hearsey and Jill Thompson) we have some innovative new training programs at TEACCH. We have created our first online TEACCH training program (http://ahecconnect.com/teacch/). This course, Structured TEACCHing Individualized Schedules, uses a combination of lectures, vignettes, videos, and quizzes to teach participants strategies for creating and using visual schedules effectively. Through our partnership with AHEC, we are offering this one-hour continuing education course to professionals and caregivers in North Carolina and across the world.

Our TEACCH outpatient clinics are joining the University of North Carolina Healthcare System. This means that our medical record keeping will be linked across the state and to other UNC Healthcare providers. Clinics at UNC can now work collaboratively with TEACCH through joint record keeping. In these challenging economic times, we are continuing to charge for some of our services. Joining the UNC Healthcare System will allow us to accept insurance for covered services. We will continue to provide some services at no or reduced costs. This is a HUGE change for our Centers and the families whom we serve. We thank everyone for their patience as we make this transition.

We were thrilled this year to welcome Dr. Michele Villalobos as the new Clinical Director of our TEACCH Center in Asheville. She comes to TEACCH from the Children's Hospital in Philadelphia and has a particular expertise in early screening and diagnosis of autism in infants and toddlers. We also wish a "happy retirement" to two longtime members of the TEACCH family: Dr. Judy Pope (Director of the Greensboro TEACCH Center) and Susan Boswell (Director of our preschool services in Chapel Hill). We honored Dr. Gary Mesibov, former TEACCH Executive Director, at our annual conference this past May with the "Eric Schopler Lifetime Achievement Award" in acknowledgement of his incredible commitment to research, teaching, and clinical service on behalf of individuals with autism and their families.

Last, I want to thank our many donors and sponsors of fundraising activities during the past year. With your support, we are working hard to continue to meet the needs of 1 in 70 individuals in the state of North Carolina with ASD.

Best wishes for a Happy Holiday Season!

Laura Klinger

## Dr. Gary Mesibov Awarded Lifetime Achievement Award and Retirement Party



Dr. Gary Mesibov, former Director of TEACCH received the University of North Carolina TEACCH Autism Program Lifetime Achievement Award for his exemplary leadership and enduring contributions to the field of Autism.

We also created a new fundraising initiative to support our adult services programs at TEACCH. Gary has always supported adults with autism and college

students learning about autism, and therefore we plan to honor both commitments using this fund to create a college support program for students with ASD attending the University of North Carolina.

He was honored and roasted by colleagues and friends at a gala in May. We celebrated by hosting a traditional TEACCH "roast" where we shared many hilarious memories with Gary.



#### **Cutting the Ribbon**

Dr. Laura Klinger and Dr. Nancy Reichle, (left to right) cut the ribbon on the new greenhouse.



# A New Greenhouse for TEACCH's Carolina Living and Learning Center

The Carolina Living and Learning Center (CLLC) dedicated its new greenhouse at the annual family and friends' picnic held in October. The greenhouse was dedicated in memory of Al Costanzo. Mr. Costanzo and his daughter, Mary Balliet, and grandson, Bryan Balliet have been long-term supporters of the CLLC. Their generosity has enhanced the



lives of the adults with autism who live and work at the CLLC including supporting the addition of the versatile and substantial greenhouse. TEACCH Autism Program and the CLLC are extremely grateful for the contributions from the Costanzo family.

The CLLC currently plans on utilizing the greenhouse for year-round container gardening in order to grow chemical-free crops, such as greens and tomatoes. The greenhouse will also be used to expand the variety of herbs, spices, and flowers grown for the soaps, potpourri, and cards made by the residents. Plants to be transplanted in the CLLC garden in the spring will also be started in the new greenhouse. Staff and residents are very excited about the abundant possibilities for use of the greenhouse and the ability to garden year round.

## **RESEARCH AT TEACCH: Understanding Autism in Adulthood**

The research team at TEACCH is excited to find out how the clients who came to TEACCH in the 1960's, 70's, 80's, and 90's are doing as adults! Professionals know a lot about children and adolescents with Autism Spectrum Disorder (ASD), but very little research reveals what happens to people with ASD as they age. One of our missions at TEACCH is to provide services to a growing population of adults with ASD. In order to achieve this goal, it will be necessary to know the challenges faced by adults with ASD and the services and supports that they need.

Thanks to funding from Autism Speaks and Foundation of Hope, TEACCH has a unique opportunity to learn more about the lives of adults with ASD. We are looking for adults who were diagnosed with autism, Asperger's syndrome, or pervasive developmental disorder during childhood by the UNC TEACCH Autism Program between 1965 and 2000.



#### There are two phases of this research project:

**Phase 1:** 400 adults with ASD and/or their caregivers will complete a survey about education, employment, and social opportunities and what current services are needed. The survey can be completed online or a copy can be sent to you.

**Phase 2:** 100 adults with ASD who participated in Phase 1 will complete several in-person activities. The research team is interested in learning how ASD symptoms, language ability, and independent living skills have changed from childhood into adulthood.

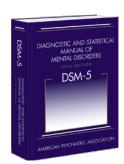
We believe that the information gathered from the surveys and in-person assessments has the potential to make a significant impact on legislative and community service agency decisions that will contribute to improved quality of life for adults with ASD. This information will not only give a better understanding of the current challenges faced by adults with ASD, but will help determine what TEACCH can do to better assist adults!

This study is currently underway and the research team would love to hear from you! To learn more about this research study, please contact Sarah Carlisle, Project Coordinator, at: TEACCH Research@med.unc.edu or 919-962-3303.

#### RESEARCH AT TEACCH

The TEACCH research team is hard at work on a number of other exciting research projects! Here are just a few highlights:

#### DSM-5 (Diagnostic & Statistical Manual-5)



With the recent publication of the diagnostic manual used by professionals to make diagnoses, such as Autism Spectrum Disorder (ASD), TEACCH has been conducting research on the impact of changes to diagnostic criteria on clinical practice. There have been concerns that these individuals may no longer meet diagnostic criteria using DSM-5. TEACCH researchers (Mary Van Bourgondien, Tamara Dawkins and Allison Meyer) compared diagnostic data from five TEACCH Centers across North Carolina. They found that the majority of children and adults who met DSM-IV criteria for autism also met criteria for a diagnosis of ASD by DSM-5 criteria, suggesting that the majority of people receiving

diagnoses are not likely to be affected by the changes in the DSM-5. These findings were presented in May 2013 at the International Meeting for Autism Research in Barcelona, Spain.

### Independent Living Skills Across the Lifespan



Thanks to many families who have allowed TEACCH to use their child's evaluation data for research purposes, it is possible to see how skills change across the lifespan and to identify where the focus for interventions need to be. Across more than 150 evaluations, it was found that in early childhood (2 to 9 years), independent living skills increased as expected by each child's cognitive skills. From age 9 to 18 years, adolescents showed a more shallow trajectory – they gained skills but more slowly than expected. As individuals with ASD entered adulthood, evidence for decreased skills was found. This research suggests the importance of teaching independent living skills to adolescents and young adults to prevent a decline in these skills after leaving school. The

research team (Allison Meyer, Patrick Powell and Mark Klinger) presented this important research in May 2013 at the International Meeting for Autism Research in Barcelona, Spain.

#### **Treating Anxiety in ASD**



TEACCH continues to partner with Judy Reaven at the University of Colorado, Denver on a National Institute of Health funded project called "Fighting Worries and Facing Your Fears." This group intervention is for children between the ages of 8-14 with high functioning ASD and/or anxiety symptoms, and their parents. The research team has completed six groups and is currently recruiting for the last two groups. The team (Allison Meyer and Laura Klinger) and TEACCH therapists are having a great time working with all of the families—from squashing worry bugs to making movies. TEACCH is an ideal place to do treatment outcome research and the research team is eager to continue this intervention research in the future. Stay tuned to hear about the results!

#### Job Coach Training Program .....



TEACCH is interested in creating an online job coach training program to improve transition from school to employment. As a first step, funds were received from the Ireland Family Foundation to conduct focus groups and a survey to identify needed content for this curriculum. The team (Signe Naftel, Mark Klinger, and Michael Chapman) will launch the survey soon and are hoping to hear from adults with ASD, families, job coaches, and employers about what can be done to train more qualified employment service professionals.

#### Attention and Learning Research .....



In order to create new intervention programs, TEACCH needs to learn more about how people with ASD learn. Allison Meyer, a clinical psychology graduate student at TEACCH, is studying how children with ASD learn new categories – she is using exciting eye tracking techniques to see where children are looking when they are learning. Patrick Powell, a psychology graduate student at TEACCH, is studying whether children with ASD have trouble learning things automatically or whether it take more effort for them to learn.

If you're interested in finding out more about any of the TEACCH research projects, please contact our research team at <a href="mailto:TEACCH\_Research@med.unc.edu">TEACCH\_Research@med.unc.edu</a> or 919.962.3303

# On-Line Course: Structured TEACCHing: Individualized Schedules

by Kathy Hearsey, Assistant Director of Training, TEACCH Autism Program

TEACCH is developing a series of on-line courses for parents and professionals working with individuals with Autism Spectrum Disorder (ASD) with the sponsorship of North Carolina AHEC (Area Health Education Center). On-line courses will help TEACCH educate people who are unable to attend a training in-person due to funding, distance or time. TEACCH is very excited about this endeavor and appreciative of the support from NC-AHEC.

The five-part series of on-line courses will be available over the next 18 months and will address: TEACCH and Learning Styles in Autism, Physical Organization, Individualized Schedules, and Work Systems and Visual Structure with Materials. The first of this series; Structured TEACCHing: Individualized Schedules is available online. This course introduces the process of creating individualized schedules and the advantages as well as strategies for

incorporating these schedules into the daily routine of students with ASD. <u>Click here</u> for more information about this on-line course then click on "courses" in upper right hand corner).

Please Note: For all non-US citizens and/or if you do not have a Social Security number, use any four numbers to create your PIN. <a href="http://aheconnect.com/teacch/">http://aheconnect.com/teacch/</a>

# **AUTISM SPECIALIST TOOLBOX**

#### **ENGAGEMENT IDEAS FOR YOUNG CHILDREN**

by Betsy McCormick and Kaia Mates - Autism Specialists, Wilmington TEACCH Center

Typically, eye contact, facial expressions, sharing/showing, joint attention, and shared enjoyment all work together to support success in socially reciprocal interactions. However, these skills are very challenging for young children with ASD. In our work together with preschool children we have found these activities to be some of our very favorite and most successful for the teaching and development of these skills. We developed some of these activities and we gathered others from parents and other professionals. The materials can be store bought or homemade. In general, stabilizing and organizing the materials makes a big difference in both the child's attention and their success with the activity.



# What's in the Bag?

**Materials Needed:** cloth pouch, items of interest- examples include a rapper snapper, birthday horn, wind-up toy, animal (with squeeze noise).

**Goal of Activity:** Social engagement, practice sharing and showing.

**How:** Place several objects of interest in the pouch. Guide the child to reach in and pull out an object. Encourage "show and share" by helping to hold it up as it is pulled out of the bag – label and then activate the toy. Place the toy in finished basket and encourage the child to reach in and get another toy. Change the materials in the bag so the activity remains novel.



## Feeding the Puppet

**Materials Needed:** Puppet with a hole cut out in the mouth, a sock sewn in, and pretend cookies/food.

**Goal of Activity:** Engage in shared activity, begin working on building pretend play, opportunity for language stimulation and communication.

**How:** Have the pretend "cookies" in a container or box (a small egg carton is nice for separating the "cookies"). Model feeding the puppet a cookie, (make eating and yum yum sounds). Encourage the child to feed the puppet the rest of the cookies.

**Moving On:** Adding a few other pretend objects such as a cup, toothbrush, or small towel or blanket can expand this activity. When finished eating the cookies, guide the child to give the puppet a drink, brush its teeth, wipe its face, or put it to bed.



#### Knock Knock Book

**Materials needed:** Laminated book with pages and "doors," photos of family members, favorite characters, or toys/activities. Cut out forms in photos to highlight the person/item in the photo.

**Goal of activity:** To build interest in books by introducing a format where the activity is short, manipulative, and uses an area of interest. Establish a joint activity routine that can encourage social anticipation, sharing, and language development.

**How:** Begin by showing the book and modeling knocking on the "door". Help the child open the door to find the picture. Label the picture, guide the child to pull off the picture and place into a container. Keep the language simple and establish a verbal routine that the child can begin to predict – for example, "Knock Knock – look it's Woody!" Help turn the page to show the next door. This book can also be placed on a "book box" and pictures can be placed into the box as pulled off.



"Book Box" - book is Velcroed@ on top, hole is cut for pictures to be placed into.



#### **AUTISM SPECIALIST TOOLBOX**

## **Using Visual Structure for Medical Appointments**

by Keri Waldrop, Residential Supervisor, Carolina Living and Learning Center

As a residential facility for 15 adults with autism, the Carolina Living and Learning Center staff frequently accompany the residents to various medical appointments. These visits could be for something as straightforward as an annual physical exam or routine dental cleaning, or a more complex procedure such as having a cavity filled, getting an immunization, or even undergoing a surgical procedure. Medical appointments often involve exams that can be lengthy and/or physically invasive, which can be confusing and challenging for someone with autism to understand and tolerate.

Entering a doctor's office can be overwhelming for someone who doesn't know what to expect or may have had a previous negative experience. One strategy for decreasing anxiety during medical appointments is the use of a visual schedules/checklists. These checklists show the individual with autism a step by step sequence of events for what will happen during the visit. Schedules can include pictures and/or words to explain what will occur, individualizing to the person's level of understanding. By using a checklist, the individual with

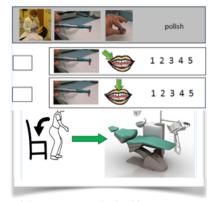


autism begins to rely on the visual information presented on their schedule and becomes more secure that what is depicted is actually what will occur during the visit.

A typical schedule may include photos or words to depict: sitting in the waiting room, weight and blood pressure checked, sitting/laying on examination table, nurse and doctor, any tools or exam instruments the physician or nurse will use, body parts the doctor will look at, and when the individual can leave the office and return to the car. As each step is completed, it is marked off (or removed/ turned over) to indicate that it is finished. It is important to highlight when the appointment will be done. Additionally, a special treat is often offered for completing a schedule or a certain portion. This should be something that motivates the individual, such as a sticker, small toy, soda or preferred activity.

CLLC residents who were frightened of the dentist's office and as a result were physically aggressive during appointments, have learned over the course of several visits to tolerate a thorough dental exam and cleaning through the use of visual schedules. This was accomplished by starting with small goals for tolerating a portion of the procedure in order to get the individual comfortable with the basics of a visit. Over time, additional steps can be added to the checklist and visuals are continually modified to clarify the expectations. During dental cleanings, it is helpful for the individual to see exactly what section of their mouth the dental hygienist will be cleaning. The hygienist counts to five, as

quickly or slowly as needed to clean that section. When the hygienist reaches "5" that section is finished and may be checked off on the visual schedule.



While some visual checklists are very detailed, others can be basic and focus on one particular aspect of the visit. For immunizations, a simple "first, then" visual is often used that shows a picture of someone getting a shot, followed by a picture of the reward they will receive afterwards. For example, "First, shot. Then, soda." Using an internet search engine such as Google Images is a quick way to find photographs of just about anything that may be needed on a schedule for a medical appointment, such as, images of instruments, procedures, and even the facility or doctor. Taking a smartphone or camera along to the appointment can provide more exact photos (waiting rooms, medical staff, or specific equipment) for future appointments.

Using visuals during medical appointments is a very valuable tool that makes the entire experience more successful and less stressful for individuals with ASD as well as their families.

# **A PARENT'S PERSPECTIVE**

## A Transfer of Care; a Transfer of Trust by Catherine Jones

James needed to have his wisdom teeth removed. What a typical thing to happen to a young adult. This was an easy decision. I knew it would be best for him to have this done in a hospital instead of a dentist office. He can handle a regular appointment but this was a big deal. Wait a minute; he did not need to know that this was a big deal. I was so conflicted.



James with his mother Catherine, Office Manager at the Chapel Hill TEACCH Center

James has been in a group home for almost two years. I remember how it was two years ago, making a major decision about my son's future. I knew that this was the best thing for our family, but it was still hard for me and my husband. Okay, it has always been harder for my husband to let go (just ask my daughter). He is better now and can see how this choice that was once so painful has changed everything in such a positive way. We are so happy and grateful that James was able to move to a group home. The group home's caring staff has made such a difference in my son's life and our lives as well.

James' oral surgery was coming up and I had to decide if I needed to go with him or let the staff take care of him. I drew strength from a mom from a TEACCH support group

many years ago. Nan told us about meeting her son and his group home caregiver for a doctor's appointment. After the appointment she turned to watch her son walking away with his worker. She was overwhelmed by a sense of peace. She had witnessed a transfer of trust. She knew that he would be okay without her one day. James was very young then but I knew that one day it would be me, watching my son walk away.

I knew that James would one day live in a group home. I thought about what I would need to do to make this future possible. I had to make sure that he had the tools and skills needed in order to live his own life. I wanted him to be in a group home with staff that understood autism and how to make James's life have a purpose. James is doing well in his day program and gets along with his housemates and staff. I am always glad when he comes home for a visit but I confess I am just as glad to take him back. I will never forget the before and after of this story.

Now the day had come. He did not need to think this was a big deal and I knew that if I went with him that could trigger a lot of anxiety, making the whole ordeal more challenging than it already was. I trusted that his staff would prepare him and support him. They knew how to do this with stories and using his schedule. I knew he would have a long wait at the hospital but he was in good hands. He came through it like a trooper. I knew he would. He is an awesome guy. He had staff that he trusted with him. So, why did I cry when I heard how well he had done? Why do I cry as I am writing this? It is very emotional to feel the transfer of trust. A weight I didn't really know that I was still carrying has been lifted from my shoulders and I know that everything is going to be alright for James. I understand, Nan. Thank you for your wisdom many years ago.



The University of North Carolina TEACCH Autism Program would like to recognize the people who made donations in the past year. These contributions have enabled TEACCH to improve clinical services for individuals with ASD and their families across the state of North Carolina, provide financial assistance to families seeking services, enhance the lives of the residents at the CLLC, and provide professional development opportunities. As a University-based program, all donations made to TEACCH are tax deductible. Thank you for your generous support.

For anyone interested in making an on-line donation to TEACCH, <u>click here</u>.

All other donations, payable to TEACCH, can be mailed to the TEACCH Autism Program, Attn: Development Office, CB# 7180, University of North Carolina at Chapel Hill, Chapel Hill, NC 27599

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