

# Addressing Stress for Adults with Autism Spectrum Disorder through a Multi-Semester Investment by Interior Design Faculty and Students

**Author** Seb Prohn, PhD and Staci Carr, PhD.

*Rehabilitation Research & Training Center, Virginia Commonwealth University*

## Project Background

In late 2015 a New York Times contributor with an aging brother with autism wrote that there “is virtually no current substantive national discussion on the fate of middle-aged or elderly autistic people” (Gottlieb). In Richmond, the discussion occurs daily at A Grace Place (AGP). Through family discussions or record analysis, executive staff at AGP strive to better understand older adults with autism spectrum disorder (ASD). Individualized and therapeutic approaches have yielded some successes, but it became clear to the staff at AGP that more perspectives would be needed to make the changes they wished to see at their organization.

Meanwhile, at Virginia Commonwealth University (VCU), faculty in the Department of Gerontology and the Rehabilitation Research and Training Centers were asking the same questions as AGP. Their respective fields had yet to develop any foundational knowledge about middle-age and older adults with ASD. They wanted to look to the community of practitioners to understand current, pragmatic discussions about supporting adults with autism. In October, 2015, Drs. Carr, Gendron, and Prohn reached out to the CEO of A Grace Place to expand their understanding. A partnership began to emerge from mutual need and shared problem.

VCU Gerontology, Rehabilitation Research and Training Center, and A Grace Place were unified by similar practices and also through the recognition of a common problem: the absence of clear, systematically rendered practices for appropriately and respectfully serving and supporting older adults with ASD. With a prevalence rate higher than that of Down syndrome and cerebral palsy combined, individuals with ASD are reaching adulthood in great numbers and often require supports throughout the lifespan. These challenges compelled us to join as partners and construct a pathway that will lead to research-guided practices best supporting the needs of (older) adults with autism.

We know that individuals with ASD are not static. Impairments tend to shift longitudinally, both improving and declining (Smith, Maenner, & Seltzer, 2012). As partners, we were guided by a belief in the capacity for neurological, social, and emotional plasticity over the lifespan. Such development, we hypothesized, required a host of contextual changes to care staff practices and client opportunities. The physical environment also needed consideration and restructuring. The team, informed by clients and families, proposed some changes in physical environments, but to actually design new environments that meet all the sensory needs of adults with ASD, we asked VCU’s Department of Interior Design to actualize individual specifications. Pragmatic and cost effective changes required considerable thought, investment, and expertise from all partners. What is more, a process for melding group strengths to encourage meaningful change for all our stakeholders will take careful planning and additional resources.

## The Science of Team Science

Autism spectrum disorder has earned the attention of multiple academic disciplines. To be certain, any single method or theoretical approach fails to adequately address ASD's various impacts on language, behavior, intellectual functioning, social interaction and skills for daily living. Diagnosis alone requires interdisciplinary assessment conducted by neurologists, psychologist and language and speech pathologists.

While the value of many scientific perspectives is clear, the configuration of academic teams deserves additional attention. Researchers on interdisciplinary and multidisciplinary teams tend to make successive, independent contributions to a project while remaining relatively entrenched in the respective frameworks and methods of their fields (Rosenfield, 1992). These additive processes require a degree of collaboration and promote a convergence of perspectives to develop a more complete understanding of a phenomenon or disorder in the case of ASD.

Transdisciplinary teams have also shown promise a more pluralistic approach for strengthening and translating research for the benefit of individuals with ASD. For instance, a team of educationalists and neuroscientists identified and negotiated methodological, language and value differences to develop common group identity and perspective to address specific social skills in a theatre-based intervention (Ravet & Williams, 2017). Transdisciplinary research is based on a shared, and often co-constructed, conceptual framework informed by multiple academic disciplines (Stokols, 2006). Essential to the concept is highly integrated collaboration. In this brief we will 1) describe the development of a transdisciplinary team and 2) explain the usefulness of a transdisciplinary action research process for collaboratively identifying salient problems for adults, including older adults, with ASD who participated in a therapeutic adult day center.

The value of team science for developing solutions to complex problems has been nationally recognized in the United States and validated by way of government funded field guides and for strengthening collaboration and communication among scientists while mitigating challenges (Bennett, Gadlin, Levine-Findley, Collaboration & Team Science: A Field Guide; National Research Council-Enhancing the Effectiveness of Team Science, 2015). Similarly, institutions of higher education are creating internal funding sources to promote the disciplinary cross-pollination to create healthier communities.

Our team viewed science as an action oriented, multidisciplinary endeavor that is accountable to multiple stakeholders. To reach our scientific aims, we knew that our first goal would be to strengthen our partnership. As a group, we developed a vision, mission, and values statements that clarify the team's "head and heart" (see table 1). We built a shared understanding of our common values that subsequently inform the project's research agenda. By overtly communicating cohesive plans we hope to build trust, communication, and increase the likelihood of synthesizing our perspectives to meet our goals (Suarez-Balcazar, 2003; Vogel, Stipelman, Hall, Nebeling, Stokols, & Spruijt-Metz, 2014).

After clearly identifying group identity and purpose, we made permeable group boundaries, inviting community knowledge to strengthen the team and research planning. We invited feedback from AGP staff and caregivers of individuals who attend day support at AGP. The two groups vetted our goals and research plans and inform us of additional needs. By the end of our first year, we participated in

comprehensive cross-discipline training. The graduate students and design faculty shared their expertise in interior design and creating spaces that address all of our senses. The psychologists shared their knowledge of adults with autism, sensory differences, and intervention practices.

## **Project Activities**

Our transdisciplinary team, the Partnership for Aging with Autism Research Core (PAARC), observed AGP's service environment, physical space (i.e., floorplans), and enlisted the creative energy of VCU interior design students and, in concert with clearly defined parameters, we further defined the scope of needs and a genesis for proposed solutions.

We found that adults with autism receiving services at AGP exhibited support needs for stress reduction and active engagement in learning and leisure. Stress, often displayed as anxiety, is one of the most common comorbid mental health conditions for individuals with autism (White, Ollendick, Scahill, Oswald & Albano, 2009). Engagement, often described as attention, was also a commonly cited challenge, and tends to decline in older age (Taylor & Mailick, 2014).

*Table 1. PAARC Vision, Mission and Core Values*

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### **Mission**

PAARC will conduct quality research to develop appropriate, innovative, and flexible best practices and support services for people aging with autism.

### **Vision**

PAARC will become a transdisciplinary core of person-centered support services for adults aging with autism and their caregivers. Our research focus will promote dignity and respect and will demystify fears to foster accepting of all diversity.

### **Core Values**

#### Compassion and Respect

- We treat everyone fairly with understanding, dignity and respect.
- We trust each other and others and seek to build trustful relationships.
- We base all decisions and actions with compassion for others and understanding of human dignity.
- We strive for an open and honest communication with all stakeholders.

#### Transparency

- We involve all stakeholders through clear dissemination of information.
- We welcome participation of all stakeholders.

## Integrity

- We strive to create value for all stakeholders.
  - We comply with all laws, regulations, policies, procedures, and protocols to ensure safety and welfare of all stakeholders.
  - We strive to be honest, moral, truthful, and sincere in our collaboration with all stakeholders.
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## Understanding the individual.

An estimated 95% of individuals with autism experience challenges with sensory processing which includes receiving, integrating, interpreting and responding to sense related stimuli (Baker, Lan, Angley & Young, 2008). Congruence between sensory processing preferences and the physical environment can reduce stress responses and improve behavior, including attention and participation. Familiar AGP staff completed Dunn's (1999) Adult Sensory Profile, and a caregiver completed the Caregiver version of Dunn's (1999) Adult Sensory Profile. Preliminary results revealed that all participants' showed probable or definite sensory differences in sensory registration, seeking and sensitivity, and all but one participant showed definite differences in sensory avoiding behaviors. All sensory differences deviated from the norm in the higher direction, meaning for example, participants sought sensation and avoided sensation at greater than average rates. They were also more likely to be under-sensitive and over-sensitive, showing general sensory processing impairments across dimensions. These results confirmed that the study's focus on the impact of the sensory environment was relevant to the experiences of the targeted group.

We compared results of each profile to determine sensory processing preferences for each participant. We followed up with focus groups of caregivers to gain addition stress and sensory information that was not gleaned from the profiles. Table 2 provides examples of some commonly occurring sensory preferences and sensory stressors.

Table 2. Sensory Themes from Caregiver Focus Groups

Sought Sensory Options	Avoided Sensory Options
1. <i>Active hands</i> : Hand grips, stress balls, pom-poms, spinners, tv remotes, keys to shake, inserting keys to keyholes (like starting a car, resulting noise would be great), cards to shift and shuffle, holding, tapping, clicking, rattlers/percussive shakers, ball and paddle, clapper,	1. <i>Touch</i> : of any sort; Invasiveness (unwanted touch, poking, prodding); Prolonged physical contact/being touched at length- long hugs, etc. 2. <i>Loud, sudden sounds</i> : alarms, sirens, unexpected horns, etc.

- clapping, bouncing balloons, feathers/feather boas,
  - 2. *White noise* (tv in background, lawnmower in distance, conversations among others, etc.)
  - 3. *Colors*: pink, purple, bright/vibrant colors,
  - 4. *Temperature*: Ice/cold sensation; warmth- like sun through a window;
  - 5. *Texture*: fake fur; plants/fake plants
- 3. *Headgear*: headphones, hats, anything on head
  - 4. *Feeling enclosed/trapped*: Crowds, close proximity to other people;
  - 5. *Isolation*: solitude; being ignored

Two groups of interior design students also had opportunities to observe and directly interact with the adults served at AGP. From their interactions and observations they began designing solutions. The first group created environments that would promote engagement in activities such as musical exploration, gardening, cooking and art. A second set of students designed interactive furniture to serve as a primary vehicle for meeting various sensory needs and preferences of adults with ASD. Design parameters were established from results of caregiver focus groups that showed the way participants were soothed by some sensory opportunities in any given environment and agitated by others. The holistic and more narrowly focused designs were to reduce stress and increase participation. Design considerations were considered by AGP and used to develop an intervention that we hope to implement in the near future.

### **The Social Environment.**

AGP staff know participants better than most, including communication styles, preferences and triggers. It is logical, therefore, for staff to receive training to enhance support and co-develop interventions and facilitate the implementation of the interaction wall and sensory bins.

The PARRC research team trained paraprofessional staff using a variety of pedagogical techniques including, but not limited to, instruction, role modeling, role playing and feedback from observations. The first training broadly focused on autism, engagement, stress reduction and choice making. The second training shared the intent of the intervention. The third workshop provided detailed instruction, role playing opportunities and manuals for facilitating participant engagement in the respective interventions.

### **Future Activities**

Our early data collection efforts confirmed that adults with ASD process sensory information differently than most. Caretakers were able to clearly describe the contexts under which certain sensitivities emerged. With support from VCU interior design staff and students we developed interventions to reduced stress and increase participation.

The first intervention (Intervention A) to alter the physical environment is an age appropriate, interactive structure. An amalgam of concepts from interior design students with the appearance of furniture, the piece will reside in an open space in a recreation room and will be responsive to multiple

preferred textures, sounds, scents, and surfaces. The vehicle, which is currently under construction, also includes different types of games, instruments, and creative expression activities. Through the structure each participant will have access to multiple modalities for meeting sensory needs while reducing stress and increasing engagement in activities of leisure, learning or expression.

The second intervention (Intervention B) is developed from participants' sensory preferences, but unlike the larger structure which meets multiple needs, it will be entirely individualized. Interactive sensory boxes have long been used for calming and educational effects they have on children with autism. The boxes (i.e., 10 gallon bins), stored within the structure designed for intervention A, are filled with various age-appropriate interactive tools, games and devices that satisfy personal preferences and sensory needs. For example, one box might include items such as weighted lap pads, a jewelry making kit, headphones with options for music or white noise, and a meditative sand garden. The bins will provide opportunities for choice making and include activities that can be social, creative or educational, each with the goal of reducing stress and maintaining attention. The bins will be easily stored, labeled, and transported from room to room or from building to building. We hypothesize that through the systematic delivery of these two interventions, we will see an increase in engagement and participation while behaviors of stress decrease.

To accurately document stress and engagement behavior, AGP staff created lists of observable behaviors, for each participant, indicative of stress and non-attending. Two researchers will collect data at baseline, intervention A and intervention B using individualized partial interval recording forms (see appendix A). Data will be analyzed for trends using Friedman's ANOVA. These results will be shared with AGP and all team members.

## **Benefits and Sustainability**

Our research will remain committed to engaging VCU's interior design students in our research agenda while expanding their exposure, knowledge, understanding, and acceptance of aging adults with autism. They will have opportunities to learn about adults with autism in an applied setting and learn to communicate differently, engage clients effectively, and to explore unique sensory accommodations for stress reduction.

AGP staff, while compassionate and dedicated, are dependent upon additional training to meet the needs of adults with autism. With access to support strategies, clients will benefit but AGP staff will also be safer and healthier while performing their jobs. The benefit of our research to the community reaches beyond A Grace Place. Adults with autism are a growing population, yet communities are ill-prepared to address the unique challenges this group has. Our research will address many of these needs, reaching beyond AGP to other adult care centers, nursing facilities, and group homes in the future.

## **Commitment to Community Engaged Research**

Engagement is a central and defining characteristic for successful community partnership research. Virginia Commonwealth University's commitment to community engagement is readily apparent

through its statements of university mission, goals, values, vision, and strategic directions. This commitment to community engagement is consistent with both emerging and already implemented university-community partnerships throughout metro Richmond. Consistent with overall mission of the University, the VCU-AGP partnership will continue to focus on development, cooperation and negotiation, and commitment to addressing local issues of concern regarding aging adults with an autism diagnosis. Through this partnership we are committed to collaboration in many different ways, including defining the problem(s), planning the research, making decisions about elements of intervention implementation, and sharing the presentation of the research results. We strive to develop a sustainable, long lasting, partnership that will continue to investigate best practices to meet the needs of the autism community while securing funding to support such work.

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## APPENDIX A

### *SAMPLE PAARC Partial Interval Recording Form*

**Participant code:** 1463

**Observer:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Intervention type:**  baseline;  "wall";  bin



Behavior	Definition	Individualized examples	Individualized non-examples
Stress	Behaviors associated with uncomfortable emotional experiences; change in normal behavior as response of a stressor	Hitting/punching self or others; crying; yelling; hitting furniture	Waving arms; smiling; pacing; walking back and forth; excited vocalizations
Attending; engaging ("attend")	Persistent effort, attention, participation and involvement in a task; focus on task/stimulus	Use gestures/fingers to communicate; nodding head; grunting responses to prompts	Walks around room/away from activity; ignores prompts; walks away from supports;

Observe participant for 10 minutes at 20 second intervals. Denote the occurrence of a behavior with an "X" and non-occurrence with an "O".

Start **time**: \_\_\_\_\_

	20 s	40 s	1m	1m 20s	1m 40 s	2m	2m 20s	2m 40s	3m	3m 20s
Stress										
Attend										

	3m 40s	4m	4m 20s	4m 40s	5m	5m 20s	5m 40s	6m	6m 20s	6m 40s
Stress										
Attend										

	7m	7m 20s	7m 40s	8m	8m 20s	8m 40s	9m	9m 20s	9m 40s	10m
Stress										

Attend										
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Please report examples of the types of behaviors that occurred during your 10 minute observation: