Experience Design for the New Autism Nation

Implications and Applications in Heath Care

IOWA STATE UNIVERSITY
OF SCIENCE AND TECHNOLOGY

In•Site Research Group

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Experience Design for the

New Autism Nation

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With between 1 and 1.5 million Americans affected, autism is the fastest growing disability in the United States.

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Sixty percent of these costs are in adult services.

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Therefore, to meet the needs of people living with autism, the health care design industry must better understand the unique and complex issues that face this consumer group.

Preparing healthcare for

Autism in Society

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While autism was once considered a childhood disorder, it is now known to be a chronic illness that will affect these individuals over the course of their lives.

It is also known that 70% of the people with autism are highly likely to be productive members of society.

Preparing healthcare for

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Preparing healthcare for

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The high functioning people with ASD do not consider themselves to be different or disabled.

In fact, they will become our most gifted engineers, artists, musicians, and computer programmers.

Preparing healthcare for

Autism in Society

They will get married, raise families, and contribute to our economy. They will use the Internet, attend universities, buy consumer products, live in our communities, and access health care.

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They will get married, raise families, and contribute to our economy. They will use the Internet, attend universities, buy consumer products, live in our communities, and access health care.

People with ASD will have all of the daily living and quality of life needs and desires as every member of society.

Understanding the unique needs of

Persons with Autism

People with ASD do; however, have a unique and identifiable set of preferences and accessibility needs.

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People with ASD do; however, have a unique and identifiable set of preferences and accessibility needs.

By understanding these needs and introducing them into design specifications, products and services can be optimized to best meet the expectations of all persons with autism.

Understanding the

New Autism Nation

In•Site conducted two studies during spring 2013:

1. “Children with Neurodevelopmental Disorders: Comparison of Parent and Teacher Perceptions” and

2. “Autism Spectrum Disorder: The Potential Presence in Online College Communities.”

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New Autism Nation

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1. "Children with Neurodevelopmental Disorders: Comparison of Parent and Teacher Perceptions" and

2. "Autism Spectrum Disorder: The Potential Presence in Online College Communities."

These two studies show both the impact of ASD on children as perceived by their families and educators and the later career implications for HFA in college communities.

Autism Associated Issues

Facing ASD Children

The literature indicates that children with autism experience significant differences in communication, socialization, and behavior as compared to typically developing peers.

Autism Associated Issues

Facing ASD Children

For the first study, a series of 5-focus groups were conducted to identify parents and teachers perceptions regarding the main deficits in social skills, communication skills, and behavioral skills that negatively impact a child with neurodevelopmental disorders.

Autism Associated Issues

Facing ASD Children

A second set of parents (n=84), siblings (n=26) and teachers (n=84) were asked to complete a mixed-method survey. The survey was administered to Iowa State University faculty, staff and students.

E-mail invitations were also sent to teachers and special education professionals identified through internet searches.

A Snow-balling technique was done to increase the number of respondents. Data came from 31 communities across Iowa and a total of 15 states in the US.

Autism Associated Issues

Facing ASD Children

Hypotheses for Study 1:

H1 Children with neurodevelopmental disorders exhibit social, communication, and behavioral traits that potentially contribute to functional difficulties.

H2 Parents and teachers may have differing perceptions of the relative importance of the impact of these social, communication, and behavioral traits.

Facing ASD Children

Measure of social skill:
(1 factor; 53% of variance; Cronbach's alpha= .815)

The ability to make friends.
The ability to maintain friendships.
The ability to understand social situations.
The ability to understand that other people have feelings.
The ability to "fit in" socially with their peer group.
The ability to participate in age-appropriate activities with their peers.

Autism Associated Issues

Facing ASD Children

Measure of communication skill:
(1 factor; 55% of variance; Cronbach's alpha= .861)

The ability to use age appropriate speech and/or language for communication.
The ability to understand the thoughts, words and communication of other people.
The ability to initiate conversations with peers.
The ability to carry on a discussion with peers without monopolizing the conversation.
The ability to understand body language or non-verbal cues.
The ability to show their emotions.
The ability to understand emotions in other people.

Autism Associated Issues

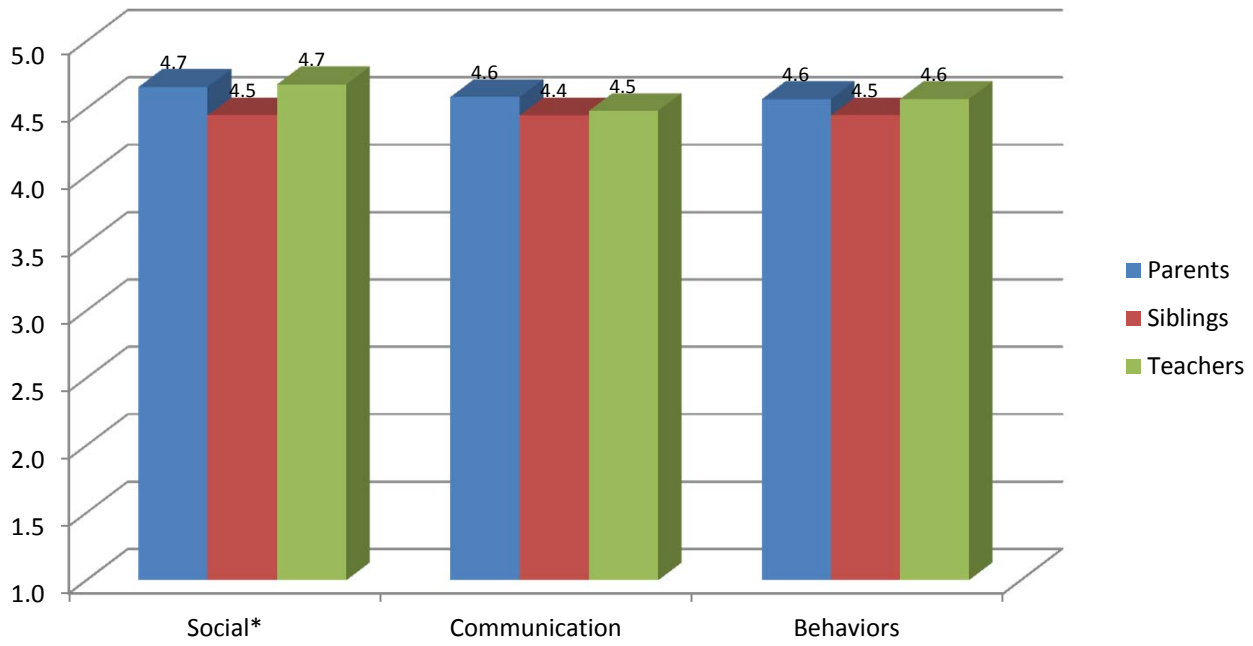
Facing ASD Children

Measure of behavioral skill:
(1 factor; 46% of variance; Cronbach's alpha= .796)

The ability to tolerate change in routines.
The ability to tolerate new environments.
The ability to tolerate loud or over stimulating environments.
The ability to avoid or control "melt downs" or "acting out."
The ability to control excessively loud or abrupt vocalizations.
The ability to understand personal space, boundaries or limits.
The ability to understand and respect boundaries when objects or things or places belong to someone else.

Autism Associated Issues

Facing ASD Children



Results

There were no significant differences in comparing the perceptions among parents, siblings and teachers on communication and behavioral skills. However, there is a significant differences in terms of social skills which are perceived to be more important to teachers, followed by parents and then siblings.

Autism Associated Traits

In our Society

Study 2: “Autism Spectrum Disorder: The Potential Presence in Online College Communities.”

Over the five year period it was noted that while taking an online course with a project on autism, one or two students per semester in the HCI program both self-identified as suspecting they had ASD and seemed to exhibit personality traits associated with ASD.

The Ritvo Autism Asperger Diagnostic Scale-Revised (RAADS-R) was used in this study. It is an 80 question scale to assist in the self-assessment of ASD in adults.

Autism Associated Traits

In our Society

H1: Some graduate students will have RAADS-R scores of 65 and higher indicating a presence of ASD associated personality traits.

H2: Graduate students in Graphic Design and HCI will exhibit unique and definable personality traits based on a RAADS-R scale and those traits will vary predictably by degree programs.

H3: Students will exhibit different preferences in course delivery methods based on two groups as identified by the RAADS-R of those scoring at or above the research-validated threshold of 65 vs. below.

Autism Associated Traits

In our Society

Approximately 100 students were contacted for possible inclusion in this study.

Two clusters were established:

1) Meets or exceeds RAADS –R threshold of 65, and
2) below RAADS-R threshold.

The study population was also divided into groups:

(a) those who took ARTGR672 and/or HCI595x (n=6),
(b) general population (n=23),
(c) HCI students (n=10), and
(d) Graphic design students (n=7).

Autism Associated Traits

In our Society

Each participant was asked to evaluate their preference in the course that they took terms of:

1. delivery methods (i.e. face-to-face, online, group discussion, video recording, etc.),

2. type of assignments (i.e. individual vs. group, topic selection, who determines the timeline and completion of assignments), and

3. student learning evaluation techniques.

Autism Associated Traits

In our Society

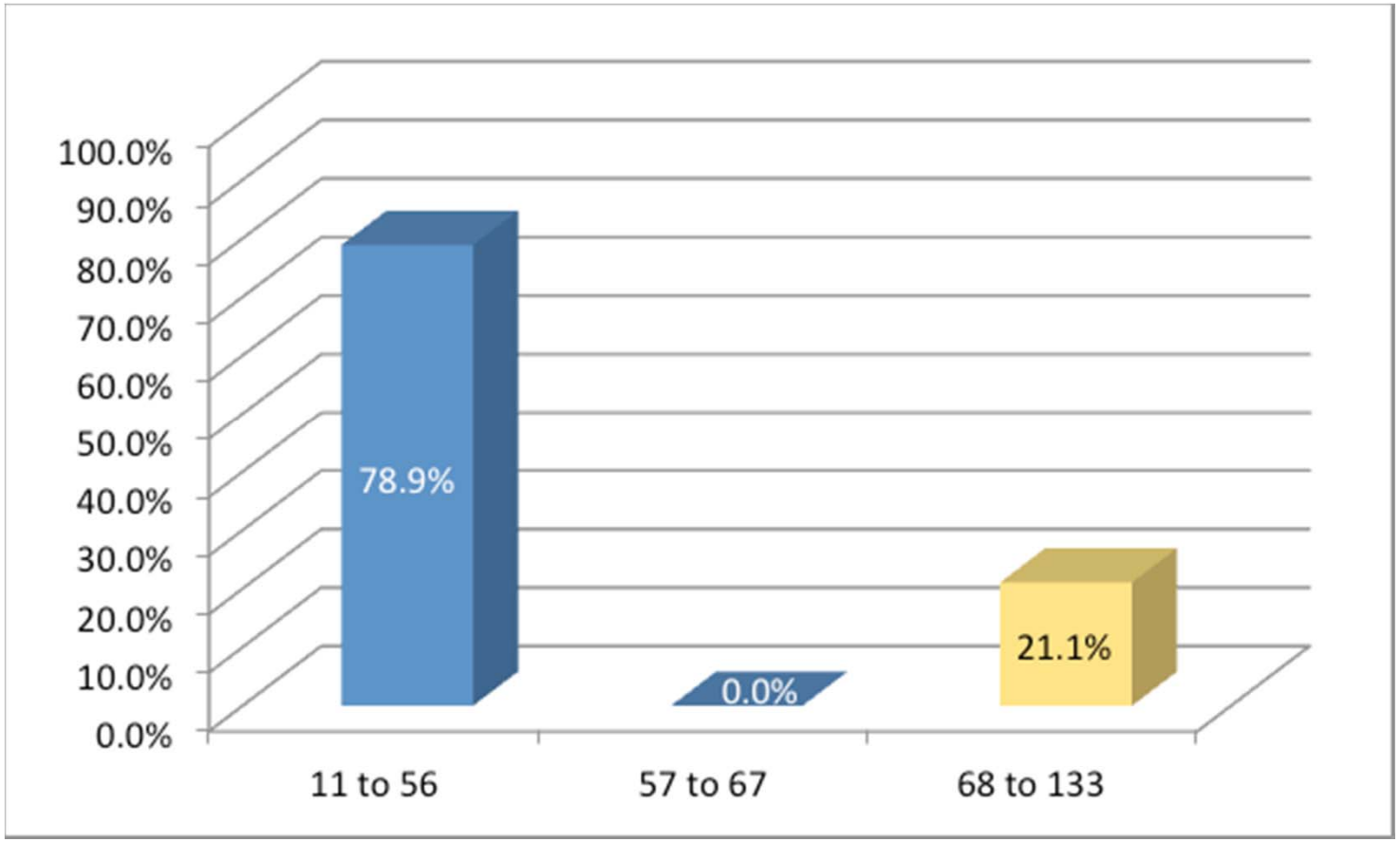
Students were also asked to complete a self-assessment via the RAADS-R with 63 symptom-based questions and 17 non-symptom based.

The overall Cronbach's alpha reliability test was .924, which is highly acceptable.

Based on the original RAADS-R publication, a score of 65 and higher is consistent with probable ASD in a specific student/participant.

Autism Associated Traits

In our Society



Based on RAADS-R scores, 78.9% (n=15) of respondents fell below the 65 threshold and 21.2% (n=4) of the respondents scored above with scores between 68 and 133.

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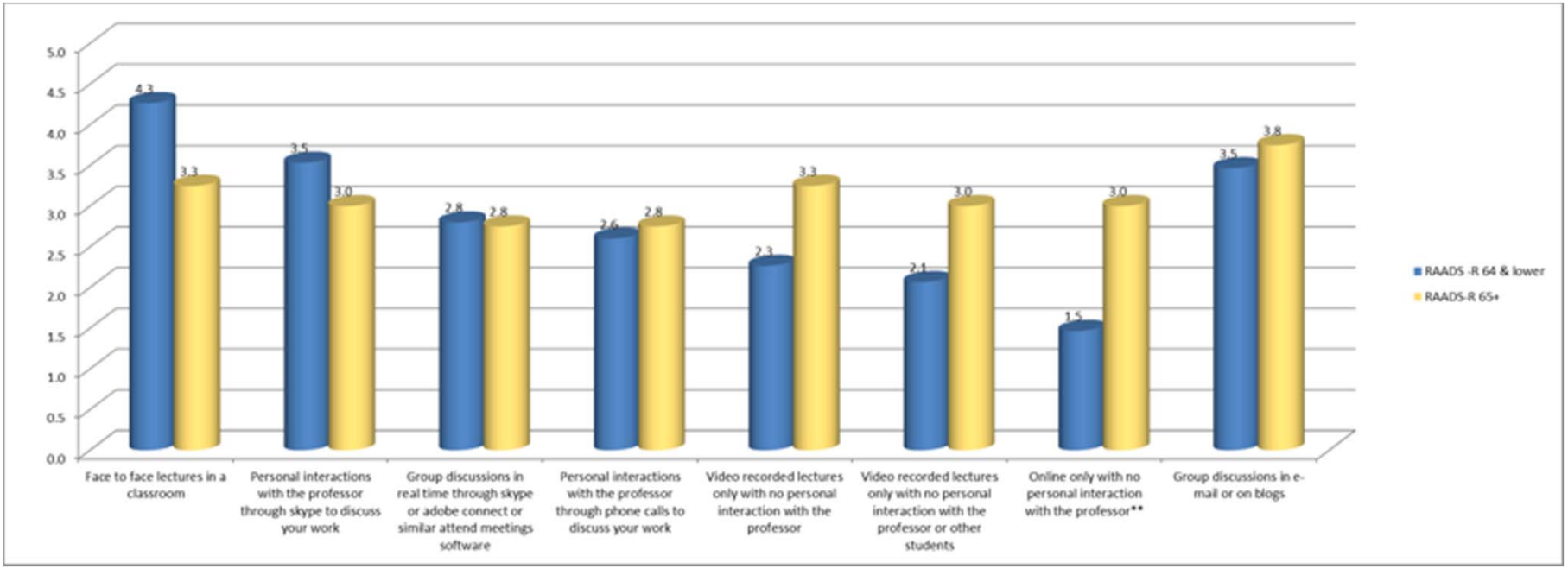

Those students with a RAADS-R score 64 and lower showed higher preferences for face to face lectures in a classroom and personal interactions with the professor to discuss work.

Both groups indicated a similar neutral response to group discussions, phone calls with the professor to discuss online coursework, and group discussions through e-mail or blogs.

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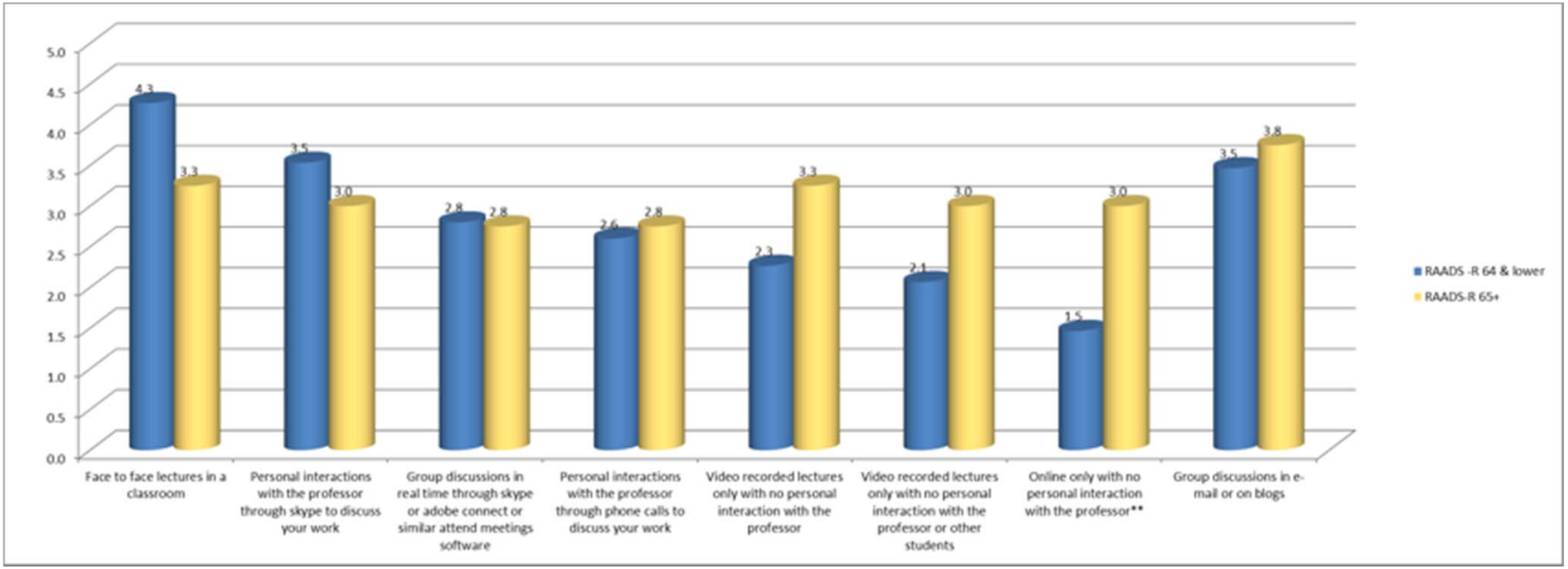

Students with RAADS-R scores of 65 and above showed more preference for video recorded class content with no personal interaction either with the professor or with other students.

Students with a RAADS-R score of 65 and above showed a statistically significant preference (.01 level) over the students scoring 64 and below for online course delivery with no interaction with the professor.

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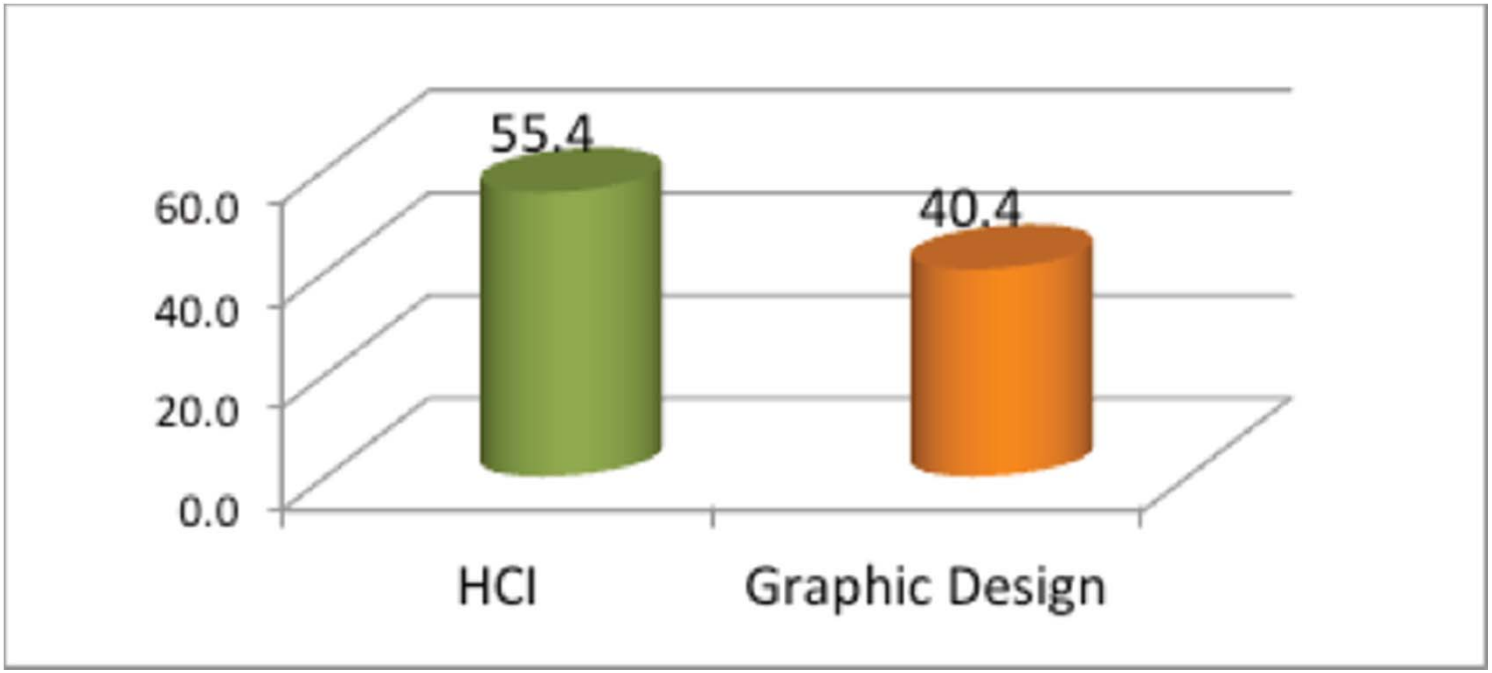

The mean RAADS-R score for students in the HCI discipline was 55.4 compared to a mean score of 40.4 in graphic design.

Although not statistically significant with the current pilot n, this 15-point difference is suggestive of discipline-related tendencies between the two groups specifically in the scales evaluated by the RAADS-R.

Design implications for the

New Autism Nation

Designs need to reflect considerations for ASD

For children with ASD we know that all of the measures of the scales of social, communication and behavior were highly important.

Each of these scales can be directly implicated in the design of spaces, products and information.

In addition, the design considerations must be socially and emotionally appropriate for the age and culture of the child.

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In health care design the following should be considered:

Adults with HFA prefer less face-to-face communication and tend to be technologically savvy.

Information should be kept very clear and concise.

Persons with ASD may have more questions and be very literal in their understanding of information.

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Designs for persons with cognitive and language impairments:

They need consistent designs with flexibility and tailorability.

Low-stimulation levels in the visual and physical environment.

Sound considerations in environments and multi-media designs.

Lighting considerations that can accommodate sensory disintegrative disorders.

Spaces for de-escalation and safety in living and medical spaces.

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In•Site Educational Experience Design Project:

Incorporation of ABA and learning strategies

Differential Reinforcements

Accommodations for ASD and NT peers

Socially appropriate design

Developmentally age appropriate content

Evidence-based design with ethnographic observation

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Ethical Considerations in Design:

User Testing and Evaluation Needs to Consider the User and Measure their Abilities Rather than Disabilities

Any Designs that Collect Data Need to Respect the Rights of the Person Involved and their Ability to Give Consent

Data Life Cycle and Data Ownership Issues Need to be Addressed Adequately

Everyone has the Right to Less than Optimal Health, Civil Liberties, and Privacy