Universal Design 2014: Three Days of Creativity and Diversity
H. Caltenco et al. (Eds.)

doi:10.3233/978-1-61499-403-9-269

Research Tools to Study Vulnerable Populations; A Case of Designing Inclusive Spaces for Autism

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Abstract. 'Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seems to be no clear boundaries, order or meaning to anything. A large part of their life is spent just trying to work out the pattern behind everything'[1]. Educational environments have failed to consider the needs for users with autism, and are unpredictable, fearful and unsafe for children affecting their performance. Regardless of its immense occurrence, it remains unnoticed by the architects and designers in building design guidelines and codes. Most environmental research projects have excluded autistic participants as their involvement is restricted by the code of research ethics involving humans (like Institutional Review Board (IRB) in the United States). Consequently, users with autism and their needs are not considered in the design of built environment. There is an urgent need to develop investigative tools that identify the needs children with autism and conduct environmental research that does not involve them to comply with the research ethics statute. The current study reports the use of newly developed research tools to develop design guidelines for universal access to educational spaces. No children, with autism or able bodied, were involved in the study; only teachers were involved and the environment was examined. First, 'environmental design issues' were identified. Then newly developed evaluating tools were implemented to examine behavioral issues in existing educational settings, and they were tested in inclusive and specialized institutions. The newly developed research tools address the impossibility of involving autistic children in environmental research. The tools have been successfully tested and the results offer important information that have the potential to influence building design, revise building codes, offer new design guidelines and develop inclusive built environments for children with autism and able bodied children.

Keywords. Autism and Design, Environment and Behavior, Research Methods.

Introduction

Autism as a condition was first described by Leo Kanner in 1943. He was a psychiatrist at Johns Hopkins University in the USA and he recognized that a number of children sent to his clinic displayed similar characteristics which he named 'early infantile autism' - deriving from the Greek word for 'self' to mean morbid self-admiration. It was the extensive research work of Lorna Wing and Judith Gould in late 1970s led to the notion of 'autistic spectrum disorders' and to the idea of a 'triad of impairments' [2][3]. The autism is not a rare disorder. The most recent estimates of the prevalence of

Autistic Spectrum Disorders have suggested a figure closer to 1% of the population in UK where it has touched the lives of over 500,000 families. In USA, it is estimated that 1.5 million children and adults have some or the other form of autism, and another 15 million (parents, health care professionals, loved ones, etc.) gets directly impacted by autism. Center of Disease Control's (CDC's) Autism and Developmental Disabilities Monitoring (ADDM) Network at USA released data in 2007 that found about 1in150 8-year-old children in multiple areas of the United States had Autism Spectrum Disorder. Numerous studies have placed the occurrence of autism at a rate of approximately 1 in 500 people. This means there are an estimated 2.0 million autistic persons in India and 2.65 million autistic persons in China, at their current population, assuming that there are no significant variations in this rate worldwide. 'Autism is a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences' (Individuals with Disabilities Education Act-IDEA, USA). Several authors have described autism and have grouped the features and behavior in their own way, but the present research takes widely accepted DSM-IV[4] as defining tool for autism that is based on 'triad' of deficits[3]. Every child with autism is impacted differently, as a result, some people who are highly functioning individuals are taught in classrooms with able-bodied children, whereas others with more unique needs get their education in specialized schools. But for all of them, the environment serves as an important teaching tool; their education is enhanced by well-designed environment and negatively affected by ill-conceived spaces [5] [6].

1. Objectives

Autism is a developmental disorder that leads to a different and characteristic pattern of perceiving, thinking and learning. Because of its complex nature, it has remained under represented in the building standards and design guidelines. Even with its overwhelming prevalence, architects and designers have overlooked it as a condition that influences building design [7]. Most environmental research projects have excluded participants with autism as their involvement is restricted by the Institutional Review Board (IRB). Consequently, users with autism have been not studied and their needs are not considered in the design of built environment. With escalating incidence of autism and emphasis on inclusive education, it has become vital to explore the scope of inclusive environments for everyone, including users with autism. There is an urgent need to develop investigative tools that identify the needs children with autism and conduct environmental research that comply with the IRB statute [7],[8]. The major objectives of the current research are to identify enabling environments for children with autism in educational spaces and to measure the environment's impact on their performance. Though the study employs multiple methods in multiple sequential stages, the current paper only reports the use of newly developed ethically appropriate research tools during the study.

2. Methodology

The process began with identification of environmental issues of importance for children with autism based on an extensive literature survey and study of environmental traces in the classrooms for children with autism. This resulted in identification of 18-design parameters. Then a set of evaluating tools were developed, to validate these 18-design parameters in existing educational settings. The parameters were tested in different type of educational settings those range from inclusive to specialized institutions using developed multiple tools. The overall study is conducted in five sequential phases (1) Establishing relation between environment and the needs of children with autism (2) Developing environmental design considerations to address these needs (3) Deriving Design Parameters to present tangible and testable ideas (4) Conducting evaluations to validate identified Design Parameters (5) Preparing autism friendly Design Guidelines based on these evaluated Design Parameters.

No children, with autism or able bodied, were involved in the study; only teachers who work very closely with children were involved and the environment was examined. Finally, the high performance and high rated design issues laid the foundation to develop design guidelines for autism friendly educational settings. All children with autism have some degree of communication impairment regardless of their functioning level and age. The lack of 'theory of mind' and perception make it difficult for them to learn and implement language for the purpose of communication [6]. With this deficit of autism the most challenging part of the research design was to get informed consent from the subjects and collect data involving them without bias. 'Using multiple research techniques to study a problem, increases reliability and decreases the chances of falsely constant results. Collecting different kinds of data from the same phenomenon with several techniques counterbalances bias inherent in any one technique with the biases of others' [9]. Thus this multi-stage research study employed multiple research tools in orderly way, to achieve the research objectives. The following sections describe the 'Trace Study', 'Environment-Performance Tools' and 'Environment Rating Tool' developed in the current research for collecting and validating data, those comply with statute for ethical practices in research.

2.1. Observing Physical Traces

In the preliminary diagnostic exploration, a field study was taken up together with extensive literature survey, to understand the educational needs of children with autism. Environmental adaptations by teachers and therapists to assist pupils with autism were observed in different types of educational spaces in Germany, United Kingdom, United States of America and India. This helped to spot the similarities and differences in the enabling aspects of environment between those mentioned in literature [5], [6], [10] and those provided by the teachers in existing educational spaces. Case-studies in different countries helped to identify relevant environmental aspects without any socio-cultural prejudices.

The technique adopted for this qualitative field study was 'observing physical traces'[9]; the physical surroundings were observed to find reflections of the activities those were not produced in order to be measured by the researcher. This is an unobtrusive method and did not influence the behavior that caused the valuable traces in the educational setting. Drawings, annotated diagrams and photographs were used to observe the traces in the classrooms with children with autism (on walls, ceilings,

furniture layout, and floor, please refer figure-1). Different type of schools were observed during field visits, like early childhood program, autism school, inclusive school, vocational unit and school with residential facility.

The environmental interventions by the teachers in existing classrooms with children with autism reflected the teaching methods adopted to combat autism conditions. Structured teaching, behavioral modification, one to one teaching, were the most visible amongst all. They were supported by visual cues for improving communication, through visual schedules and visual instructions, for daily and individual activities. Curriculum modifications were done to accommodate the needs of children; varied activities were included in their curriculum like self-help training or vocational training. Other characteristics observed in these educational spaces, atypical to the regular school environment were different sized teaching areas, withdrawal spaces, calm environments and sensory rooms. An extra effort for safety and supervision reflected in almost all setting. These features were observed, irrespective of the type of setting (special education in Germany and India, inclusive education in USA), and the resources for special education in different countries (UK, Germany, India and the USA). When findings of this 'preliminary diagnostic study' were analyzed and summarized, it provided a set of qualitative open ended 'eighteen environmental design parameters', to conceive enabling environment for children with autism.

2.2. Environment-Performance Tools

To make a strong argument, it was necessary to further validate these design parameters quantitatively, for their relevance in improving the quality of physical environment for children with autism. The quantitative data not only contributed precision to the knowledge but also made research convincing to others. The present section discusses the development of the multiple evaluation tools to test these identified environmental design parameters in the preliminary diagnostic study. Since the major concepts to be tested in the present research were well defined, standard questionnaires were developed based on design parameters. These questionnaires helped to discover regularities of opinion amongst different group of people working for children with autism such as teachers, therapists or experts. The research developed two interdependent testing tools to evaluate the design parameters; these tools were the environmental assessment and performance measure for children with autism.

Environmental assessment (EA) and performance measure for children (PMPA), validated the environment and performance inter-relationship for children with autism (Figure 2). Both tools were based on rehabilitation studies [11] and post occupancy evaluation studies in architecture, where existing buildings were evaluated for their functional performance and the resulting body of knowledge is used to design similar buildings in future [9], [12], [13]. The environmental assessment (EA) was a checklist of parameters derived from the 18-environmental design parameters for autism, and their presence was expected to improve educational performance. The performance measure for pupil with autism (PMPA) was derived to test the performance of children, in presence of the parameters. The major factors that guided the development of evaluation tools were:

1) The tools were designed to be tested in the existing educational environment as it was difficult to construct new designs for evaluation.

2) As it was difficult to get accurate responses from low functioning children with autism due to their limitation in communication, the tools were designed to collect data from the people who work very closely with them.

3) Since the research dealt with vulnerable human subjects, the tools and survey procedure were designed keeping the ethical and privacy issues in mind.

2.2.1. Environmental Assessment (EA)

The eighteen design parameters formed the basis of environmental assessment checklist. These eighteen items on the checklist were intended to prompt inspection so that their extent of presence in the environment can be recorded on a five point scale from exceptionally high to unusually low level. The researcher surveying a facility was supposed to check the building features that matched with the checklist of design parameters in the environment, and the assessment criteria depended upon the degree of their presence in the environment. The environment was assessed on a five point scale (points in parentheses), for exceptionally high level 'design parameters' had to be strongly present in all areas (5), for high level they had to be strongly present in the classroom and related spaces (4), for moderate level they had to be moderately present in classroom (3), for low level they had to be present in at least a few activities in the classroom (2) and absence of design parameters in the environment marked unusually low level (1). There was also a possibility to include any other features noticed in the environment as comments.

2.2.2. Performance Measure for Pupils with Autism (PMPA)

Performance Measure for Pupils with Autism was a sequential evaluation by teachers and therapists that measured performance of the pupils in an existing educational environment that had already undergone environmental assessment. This was expected to help in understanding inter-relation between environment and performance of children. The questions to assess the performance were derived from the earlier developed 18-design parameters. Teachers were asked to respond to a questionnaire about the educational performance of children in the existing environment. Their responses were supposed to be based on the broad performance of children with autism in the present environment, and not on any specific child. The answers were pre-coded (points in parentheses) in mutually exclusive categories, if more than two third of the total low functioning pupils with autism perform the activity then the response was 'Yes' (2), if less than one third do, then the response was 'Some'(1) and if no child was able to do the activity, then answer was 'None'(0). Although there were no open ended questions, in all answers there was a possibility for the respondents to write individual opinions, which were not covered in the given categories of answers.

2.3. Environment Rating Scale (DPRS)

Environment serves as an important teaching instrument for all children with and without autism. To address this, teachers were asked to review the eighteen environmental design parameters and rate them for their importance in education and development (Please refer see Design Parameter Rating Scale-DPRS in Table-1) according to their past experiences and future expectations. The rating was done on a five point scale and answers are pre-coded (points in parentheses) as, highly

recommended, when they strongly recommend it for whole school building (5); recommended, when they strongly recommend it for classrooms and related spaces (4); recommended with reservations, when they recommend it for classrooms with certain reservations (3); not sure, when they are not confident about the design parameters (2); and not recommended, when they reject the environmental design parameters (1). Using this scale, the eighteen design parameters were rated for kids with autism by autism experts and for able bodied kids by regular education experts. All experts rating the parameters were thoroughly informed about the formulated 'environmental designed parameters' as conceived by the researcher.

3. Survey Design

After preparation, the evaluation tools were pre-tested with a few autism teachers to understand the un-intended side effects during survey. The comments were received and tools were revised incorporating the feedbacks from the participants. After pretest, the survey was carried out in the existing educational setups in a naturalized environment that was familiar and comfortable for children. The standardized questionnaires were repeated in the same way by the interviewer to avoid difference in understanding. Survey was done in two stages, in the first stage data is collected from educational settings in USA to validate the formulated environmental design parameters and in second stage, data was collected from various educational settings in India to ascertain cross-cultural validity. Data from autism experts in India help to understand cross-cultural dimension of design parameters. The representative samples in the survey comprise of (1) Low functioning children with autism with high autistic features, as the children with autism vary widely in abilities, intelligence and behaviors. This was done with a belief that if the environment is supportive for complex conditions in low functioning children, it will also be supportive for high functioning and mildly effected children. (2) All age pupils between 5-18 years, to understand the usefulness of enabling environment for different age groups in educational spaces. (3) Different type of educational settings based on their restrictiveness, from inclusive to specialized. The samples were although selected randomly, but represent different type of educational settings; public schools with autism class, public schools with special needs class, public schools with fulltime inclusion in inclusive settings and special schools, special schools for autism, specialized therapy centers in specialized settings. Evaluation tool preparation and most of the field survey in the present research was done in the USA, during Fulbright Doctoral and Professional Research Fellowship at College of Architecture in Georgia Institute of Technology, Atlanta, USA. Thus the present research abides by the Federal rules of conducting research in human subjects. All tools and questionnaires in the present research were reviewed by Institutional Review Board (IRB) of Georgia Institute of Technology prior to the field survey.

4. Results

Research results show the new tools were very effective in collecting environmental information. The trace study identified 'Environmental Design Parameters' those were important for children and the environment-performance tools validated the

'Environmental Design Parameters' at several testing levels (primary/middle/high schools and inclusive/special schools), and contexts (US and India). All this was done without involving children, just the environment and people caring for children with autism were involved. To establish relation between environment and autism, the environment (EA) and performances of children with autism (PMPA) were assessed for the same educational environment. The data was then compared and analyzed. The environment was assessed in sixteen educational spaces, at primary, middle and high school level, in which, eight were inclusive and eight were specialized settings. The empirical data that was collected using above two tools show strong correlation between identified enabling environment and educational performance of children with autism (Figure 2). The objective of this analysis was to understand how quality of environment in educational spaces effects performance of children with autism. It attempted to analyze EA and PMPA data for all sixteen schools and compared average data for different age groups. The schools those had high environmental assessment (EA) value also had high performance measure (PMPA) value for identified design parameters. Environment and performance of children with autism were interdependent at all age levels. Some variations in the graph profile, between environment (EA) and performance (PMPA), depicted that the performance was not exclusively dependent on the environment. There were many other factors affecting it, ranging from educational to social. The data was also collected using environment rating scale (DPRS) from eighteen experts working with low functioning children with autism and also from fourteen regular education experts. 95.3% autism experts and 86.3% regular education experts rated the design parameters as highly recommended on a five point scale. This confirms that the identified design parameters were not only favorable for kids with autism but were also beneficial for all school children. Universal consequence of the design parameters to the educational environments was furthermore defined by the mean values of DPRS, Figure-3 illustrates this mean value as universally beneficial, inclusive, autism friendly, recommended value for design for all.

5. Discussion

Autism is a developmental disorder that leads to a different and characteristic pattern of perceiving, thinking and learning in an environment[14]. In rehabilitation practice, the environment provides a prosthetic support for functional performance. Standards and codes establish the importance of the environment and the need for appropriate interventions to match individual capabilities. The prevailing view that one environment for everyone may not provide the needed support that many children with autism require, triggers the idea of individualized learning opportunities that best enhances education and development. To understand the needs of children with autism in the physical environment, it is necessary to develop research tools that help explore interconnection of their behavior and environment. These tools should not only be effective but also comply with the ethical considerations involved in researching vulnerable populations. This paper presents the preliminary diagnostic exploration, supported by literature on autism and trace-study. The trace study was done in Europe, USA and India to observe environmental interventions/ adaptations done by autism teachers and therapists. The paper also attempts to present validation tools to evaluate

identified environmental parameters and their implications in designing educational spaces.

Although school environments can be confusing, over-whelming, and fearful for children with autism, but these common evidence based environmental design parameters may be applied to achieve enabling environments which improve their responses to teaching and therapies. The newly developed research tools address the impossibility of involving children with autism in environmental research. The tools have been successfully tested and the results offer important information that have the potential to influence building design, revise building codes, offer new design guidelines and develop inclusive built environments for children with autism and able bodied children.

	**Classroom layout**	The classroom is well structured. It has individual work areas, group work areas and a withdrawal space partitioned using cabinet. Classroom has wash basin for learning self-help, computer, space for hanging bags and ample storage space, spaces are clearly labeled using pictures. Separate rooms for vocational activities are also provided for children.
	Walls	The light colored walls have a lot picture schedules and visual instructions for students. Pictures are photographs, line drawing or computer generated. Lot of wall shelves are provided in the classroom for storage.
	Floor	Plain dark colored tile flooring, free of patterns and easy to clean is provided in the classroom area. Not many activities are performed on the floor.
	Ceiling	Light colored false ceiling with lighting fixtures
	Furniture	Furniture is provided for small group teaching and individualized teaching. A bean bag is provided in the withdrawal space.
	**Doors and Windows**	The classrooms are air-conditioned and there is ample light through windows. The windows have venation blinds and curtains. Every classroom door has a small window; the children are monitored from outside using these windows.
	Security	The building is fenced with gates. The children are not allowed to leave the building on their own; they are always accompanied by a staff. The building follows fire regulations guidelines and has visual symbols to demarcate evacuation paths.
	Accessibility	Accessible with lifts and ramps
	Toilets	Accessible toilets are provided near classrooms
	Additional services	The other facilities that are available to the children are speech and occupational therapy, sensory room or snoezelum room, dining hall, swimming pool, gymnasium, playground, vocational training center

Figure1. Observation of Physical Traces in an Autism Classroom in Special School

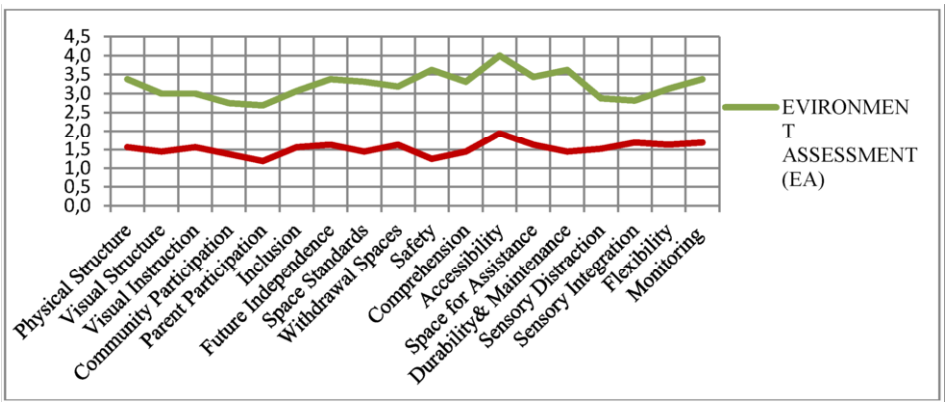

Figure 2. Environment Assessment (EA) and Performance Measure (PMPA) Relationship in Schools

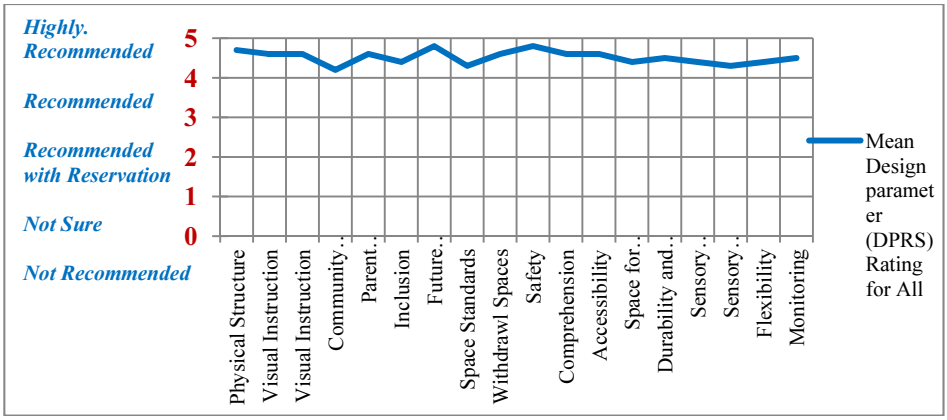

Figure3. Design Parameter Rating Scale (DPRS) Mean Rating

Table1. Tool for Environmental Rating-Design Parameter Rating Scale (DPRS)

Environmental Design Parameters
1. **Provide Physical Structure-** organize physical environment through clear physical and visual boundaries to establish context of activity associated with a physical space.
2. **Maximize Visual Structure-**organize visual environment through concrete visual cues and visual importance by incorporating color coding, numbers, symbols, labeling, illuminated sign boards, highlighters etc.
3. **Provide Visual Instruction-** give sequence of steps to follow an activity (in the spaces where activities are to be performed) in the form of written instructions, pictures, visual schedules etc.
4. **Opportunities for Community Participation-** involve pupils in the community activities in every day works such as shopping or using public transport.
5. **Opportunities for Parent Participation-** involve parent in school activities to address pupil's individual educational needs.
6. **Opportunities for Inclusion -** present an environment to the children with autism to interact with able bodied peers.
7. **Maximize Future Independence-** provide environment for learning life skills and vocational skills that makes them independent in future.

1. **Generous Space Standards-** help pupil with autism to deal with social demands as they are sensitive to loss of personal space and threatened by crowding.
2. **Provide Withdrawal Spaces-** quiet areas that allow pupils with autism to withdraw to avoid unnecessary stress and anxiety in socially demanding spaces.
3. **Maximize Safety-** minimize threats to pupil due to their own condition, unawareness or any disaster.
4. **Maximize Comprehension-** clear layout, direct routes, clear zoning, simple forms, and no visual clutter assist pupil with autism to perceive the school environment easily.
5. **Maximizing Accessibility-** poor coordination and balance, epilepsy, poor attention span in autism may require building to be made physically accessible.
6. **Provide Assistance-** space needed to help pupil doing learning activities in classroom, toilet, dining areas and others
7. **Maximize Durability and Maintenance-** durability and maintenance of equipment, hardware, furnishing, fitting, furniture etc from damage and misuse by pupil.
8. **Minimize Sensory Distractions-** least distracting settings that are away from any visual, auditory, tactile distractions.
9. **Provide Sensory Integration-** include multisensory stimulations in the environment like opportunities for Rolling, jumping, spinning, vibrations, music, different visual experiences etc.
10. **Provide Flexibility-** relating to broad spectrum of functional skills and diverse teaching models.
11. **Provide Monitoring for Assessment and Planning-**monitoring pupil with minimal distraction for assessment, safety and activity planning.

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