

SENSING THE WORLD: MEANING, SENSORY EXPERIENCE AND CONTESTATION OF FAMILIES WITH AUTISTIC CHILDREN

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ABSTRACT

This study aims at examining meaning, sensory perception of autistic individuals and the striving for normalcy of families with an autistic child. It is a qualitative study of 23 autistic individuals including in-depth interviews with 14 families with autistic members in Lopburi and Singhburi Provinces.

The findings indicate that autism has diverse meanings. The mainstream explanation of autism is based on a bio-medical model, viewing autism as an impairment to be corrected by medical intervention. Families hope that medical treatment will provide normalization processes so as to have their children able to study in an inclusive educational system. Many families have experienced dealing with the abuse of authority, stigmatization and discrimination. Some families have suffered from, and were willing to comply with, the requirements of professional authorities for a while, before refusing further intervention.

The meanings given to autism in local culture are diverse and fluid. Perception of autism as a disease category is relatively recent. Autistic children with severe symptoms are often labeled as “crazy.” The labeling, however, has not been without contest. Families felt miserable and struggled to deny such imposed meaning. To lessen their suffering and enable their normal existence within society, families have had to construct their own more acceptable meanings, drawing on various local beliefs, for example, the belief that their child has been frightened by evil spirits, or the belief that it is a matter of karma. Such explanations help make their misery more acceptable. Treatment and care for an autistic child reflects medical pluralism, combining treatment of various medical systems as well as Buddhist and Brahministic rituals. Some families have chosen to disregard their child’s disability and focus instead on the child’s strong points, such as exceptional language skills; Children with exceptional skills were sometimes perceived as “Thep” (or god).

Autistic children exhibit an ability to understand their normal world through their specific sensory perceptions. The sensual relationship is crucial not only for their capacity for development as an individual person but also critical in how they relate to the world around them. They feel attached to certain places and relate to individuals through their memory of their sensations. The world of familiarity is constructed by and memorized through specific sensory perceptions, i.e. visual, acoustic, touch or tactile. The sensing of the world constitutes a normal lifeworld to which autistic individuals are comfortably related. It is a world of sensitivity seen by others as the cause of their unwanted behaviors.

This study argues for a more humanistic approach by first accepting and understanding the different sensory modalities employed by autistic individuals to relate to the world. It is only by understanding differing sensory experiences and a unique sense of self among autistic individuals that we will be able to restore and restate the dignity of autistic individuals and create an inclusive society.

KEY WORDS: AUTISM/ MEANING / SENSORY EXPERIENCE / CONTESTATION

211 pages