

## CULTURAL VALIDITY IN ASSESSMENT INSTRUMENTS FOR CHILDREN WITH AUTISM FROM A CHINESE CULTURAL PERSPECTIVE

Jie Zhang  
John J. Wheeler,  
and  
Dean Richey

*Tennessee Technological University*

*Autism is a chronic developmental disorder characterized by impairments in the areas of social interaction, communication, and repetitive behavior. Early detection followed by early intervention is likely to provide the best chance of long-term beneficial outcome for those children with autism. As demonstrated from research findings, it is important to use developmentally appropriate assessment tools for early detection, diagnosis, and evidence-based interventions. In a diversified society as the United States, it is extremely important to provide cultural competent services to children with autism and their families from diverse cultural backgrounds. The purpose of this paper is to examine from a Chinese cultural perspective the qualities of cultural validity in four assessment instruments designed for young children with autism.*

Autism is a comprehensive developmental disorder caused by a central nervous system abnormality or injury that occurs during the period of brain growth (Edwards & Bristol, 1991). It is chronic, evident in infancy or early childhood and results in lifelong impairments, including impairment of social interaction and communication, and restricted and repetitive patterns of behavior and interest (American Psychiatric Association, 1994). Children with autism always have poor or limited eye contact and facial expressions. They seem uninterested in others. As babies, they are more interested in objects than in faces. Thus, they are more likely to initiate contact to have needs met rather than spontaneous shared enjoyment. Repetitive behaviors include repetitive motor mannerisms, such as finger flicking, hand flapping, or rocking; preoccupation with parts of objects such as spinning wheels; and inflexible adherence to nonfunctional routines and rituals. These repetitive behaviors provide sensory self-stimulation (Koenig & Scahill, 2001; Freeman & Cronin, 2002). Typically, development of speech is delayed in children with autism, with most of them having no single words until after two years old and no phrase speech until after three (Koenig & Scahill, 2001). Besides, fifty percent of all individuals with autism never speak at all, and those who do speak use awkward and often monotone speech (Lord & Paul, 1997). Green, Fein, Joy, and Waterhouse (1995) stated that seventy-five percent of all individuals with autism also have mental retardation.

Once believed to be a low-incidence disorder, autism was estimated to be with the prevalence of 4-5 per 10,000 prior to 1985 (Byrd, Sage, Keyzer, Shefelbine, Gee, & Enders, et al., 2002). However, it is far more common than previously thought, and the number of children receiving services for autism is reportedly on the rise. Current estimates suggest that autism affects 10-12 people per 10,000 (Byrd, et al., 2002). Among children aged 6 through 21 years in the United States and outlying areas (e.g., American Samoa, Guam, United States Virgin Islands), an average of .05% were served under autism in 1995-1996. This percentage increased to .13% in 2000-2001 and .16% in 2001-2002 (United States Department of Education, 2002; United States Census Bureau, 2005). Bryd and his colleague (2002) explained that part of the changes in rates were due to changes in how autism is diagnosed. Autism is now recognized to be more prevalent in childhood than diabetes, cancer, spina bifida, and Down syndrome (Filipek, Accardo, Baranek, Cook, Dawson, Gordon, et al., 1999).

*Early Detection*

While there is no *cure* for autism, early detection followed by early intervention is likely to provide the best chance of long-term beneficial outcome for those children with autism, their families and also, in the long run, the society. First, children who are accurately diagnosed will have immediate access to intervention services (Chakrabarti, Haubus, Dugmore, Orgill, & Devine, 2005). Rogers (1998) reported that children with autism who were treated early exhibited significant improvements in functioning relative to older children with autism undergoing the same interventions. Second, parents will be empowered by the information from early diagnosis, which can help them understand and gain control over their child's situation, avoid confusion, uncertainties, and delays of appropriate services, facilitate intervention planning, and prepare their child for adult life (Chakrabarti, Haubus, Dugmore, Orgill, & Devine, 2005). Therefore, it is important to use appropriate instruments for early detection and diagnosis of autism that are prerequisites for the institution of high-quality, evidence-based interventions.

*Cultural Validity in the Assessment Instruments*

The United States is obvious a diversified society and different cultures add and blend to enrich the America's culture. For example, the Asian American population increased 100% between 1980 and 1990, 40.8% between 1990 and 2000, and 12.6% between 2000 and 2003 (United States Census Bureau, 1990, 2000, 2004). In the year 2000, the Asian American population reached 11.9 million, which accounted for 4.2 percent of the total United States population. Chinese was the largest group and represented 23.8 percent of the Asian population. In 2000, 2.9 million people, or 1.02 percent of the total population, reported them were Chinese (United States Census Bureau, 2004). Accordingly, the number of children from diverse family backgrounds and communities is increasing, thus educating multicultural children is becoming increasingly common in America's schools (Obiakor, 1994, 1999, 2001). In 2001, there were about 3 million Asian American children, comprising 4 percent of the children population on the national level (United States Census Bureau, 2005). 21.4 percent of the Chinese population in the United States was children under age 18 (United States Census Bureau, 2004).

The Autism Society of America, the largest professional organization in the field, states that autism knows no racial, ethnic, or social boundaries (Autism Society of America, 2000). However, the earliest identification of autism occurred with mainly children of Anglo descent, and some researchers have challenged the claim of universality of autism among races, reporting a low incidence of autism in many Latin American countries (e.g., Peru, Argentina, Brazil, and Venezuela) and in some developing countries (such as Kenya, India, and Hungary) (Sanua, 1981a, 1981b, 1984). In the United States, the rate of identification also differs across racial categories. While children aged 6 through 21 are less than half as likely to be served for disabilities than all other groups combined (e.g., American Indian/Alaska Native, non-Hispanic black, Hispanic, and non-Hispanic white), they were 1.2 times more likely to be served for autism than all other groups combined (United States Department of Education, 2003). Comparisons between racial groups of children with autism and children served for disabilities falling into all 13 diagnostic IDEA '97 categories also indicate racial disparities (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). Children aged 6 through 21 who are Asian/Pacific Islanders were being served for autism (4.1%) twice as often as those Asian/Pacific Islanders averaged across all disabilities (1.9%) (United States Census Bureau, 2001). The study by Dyches, Wilder, Sudweeks, Obiakor, and Algozzine (2004) indicated that the percentage of Asian/Pacific (0.13%) children identified with autism is disproportionately high.

Research has highlighted some questions regarding the discrepancies in the number of minority students who are being served for autism. Are there actual differences in the prevalence of autism across races? Are diagnosticians more likely to diagnose autism to children from some minority cultures than others? Are behaviors of some children considered to be problematic by people of other cultures (e.g., avoiding eye contact), resulting in the child being referred (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004)?

Each of the dimensions such as culture, values, beliefs, primary language and so on contributes to a family's attitudes and beliefs about child rearing, disability, and assessments. Take the impacts

of a child's background on communication as an example. It influences when and how a child interacts with adults or strangers and the ways the child views the communication process. Another example is that the types of materials and toys available can influence early cognitive and literacy experiences (Crais & Roberts, 2004). All these dimensions are important considerations for the professionals working to improve the lives of children, including those children with disabilities (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). In sharp contrast, however, assessment instrument developers, special educators, early interventionists, and other service providers in United States remain overwhelmingly White, middle class, European American (Ladson-Billings, 2001). Because the majority of research on special education has been conducted with populations that are predominantly Anglo, and because most research has failed to identify students with autism according to culture, it is especially important for professionals to deliver services with cultural sensitivity, remembering that ethnic diversity may affect the services available for students with autism. In order to know which interventions work most effectively for multicultural students with autism, professionals must first ensure that those children are properly classified (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004). Thus, test results must be interpreted carefully, taken cultural sensitivity into consideration. There is an urgency to deliver assessment and intervention services to young children with autism and their families in a culturally competent way by individuals sensitive to, respectful of, and knowledgeable about the families' sociocultural practices, values, and folkways (Lynch & Hanson, 2004). This paper examines the cultural validity in some assessment instruments of children with autism from a Chinese cultural perspective.

#### *Four Assessment Instruments from a Chinese Cultural Perspective*

Structured observation supported by the use of checklists focusing particularly on the development of social skill and communication is an important means towards early identification of autism (Connor, 1999). According to Connor (1999), diagnostic measures include general developmental screening, screening for autistic symptoms, and rating scales for autistic behavior. The Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984) is one of the scales used for general routine screening. Though not designed as a means of identifying autistic symptoms, it contains sections concerning social relationships and language, and may provide valuable initial 'pointers'. The Checklist for Autism in Toddlers (Baron-Cohen, Allen, & Gillberg, 1992) and the Modified Checklist for Autism in Toddlers (Robins, Fein, Barton, & Green, 2001) are two tools for autistic symptoms screening, and the Childhood Autism Rating Scale (Schopler, Reichler, & Renner, 1988) is one of the autistic behavior rating scales. These four instruments will be discussed in details as follows.

#### *The Checklist for Autism in Toddlers (CHAT) and the Modified Checklist for Autism in Toddlers (M-CHAT)*

The Checklist for Autism in Toddlers (CHAT) was developed by Baron-Cohen, Allen and Gillberg (1992) in the United Kingdom. It is a simple screening tool for identification of children with autism at 18 months of age. It consists of 2 parts, a parent questionnaire with 9 yes/no questions addressing the areas of child development such as rough and tumble play, social interest, motor development, social play, pretend play, protoimperative pointing, protodeclarative pointing, functional play, and showing, and a child practitioner observation with 5 items addressing the child's eye contact, ability of gaze monitoring, pretend play, protodeclarative pointing, and make a tower of blocks. Both components assess parallel functioning in three main areas including protodeclarative pointing, gaze monitoring, and pretend play (Baron-Cohen, Allen, & Gillberg, 1992).

The Modified Checklist for Autism in Toddlers (M-CHAT) was developed by Robins, Fein, Barton, and Green (2001) in the United States. It is a simple screening tool for identification of children with autism up to 24 months of age. It is a parent questionnaire with 23 yes/no questions, with 9 questions from the original CHAT and an additional 14 questions addressing core symptoms present among young children with autism. The six best questions of the M-CHAT addressed areas of social relatedness (interest in other children and imitation), joint attention (protodeclarative pointing and gaze monitoring), bringing objects to show parents, and responsiveness to name responses to calling. Joint attention was addressed in the original CHAT,

whereas the other areas were addressed only in the M-CHAT (Robins, Fein, Barton, & Green, 2001).

Examining the 23 questions and 4 observational items of the CHAT and the M-CHAT from the Chinese cultural perspective, some of these items do not serve well as screening indicators of children with autism. In China, adults are in the authority position, and children are supposed to obey and respect them. So there will be few adults who make a face in front of their children. Therefore, a Chinese parent might have difficulty answering question 13 (does your child imitate you? [e.g., you make a face; will your child imitate it?]). To show the respect to the adults, people used to believe that children should never make eye contact directly with them. Otherwise, the child would be considered rude and arrogant. Although people's opinions are changing as time passes by, an observer will probably still meet that kind of children raised up strictly according to the tradition, and perform traditionally but miss the point in observational item B1 (during the appointment, has the child made eye contact with you?). Index finger is seldom used in China not because it's rude, but because people just don't do that. Instead, Chinese people use forefinger to point at something if it is necessary. So a Chinese parent will seldom encounter the situation mentioned in question 7 (does your child ever use his/her index finger to point, to indicate interest in something?). Neither will an observer see the child point with his/her index finger at the light as what is stated in observational item B4 (does the child point with his/her index finger at the light?).

#### *Vineland Adaptive Behavior Scales (VABS) (Interview Edition)*

The VABS was developed by Sparrow, Balla, and Cicchetti (1984). For children under six years, it assesses four domains of adaptive behavior about day-to-day functioning, including communication, daily living, socialization, and motor skills. The parent is asked to provide examples of day-to-day living with the child by an interview format. It helps establish a basic understanding of whether the child has delays or deviant behavior (Sparrow, Balla, & Cicchetti, 1984).

Examining the items of the VABS from a Chinese cultural perspective, some of these items do not work well as screening indicators of children with autism. Some of the questions cannot be performed because of the way most Chinese children are raised up. For example, to show the authority, Chinese adults used to make decisions for their children, while to show the respect, Chinese children typically follow the decisions the adults made for them. Thus, a typical traditional Chinese child will miss question 18 from the communication domain (indicates preference when offered a choice). To keep the children, especially children under six years old, safe, the Chinese adults usually avoid letting them use scissors, or do some help in the kitchen such as cooking, or touch the breakable items. So Chinese children may fail in performing question 23 (opens and closes scissors with one hand), question 26 (cuts across a piece of paper with scissors), question 30 (cuts paper along a line with scissors), question 34 from motor skills domain (cuts out complex items with scissors), question 41 from the daily living skills domain (assists in food preparation requiring mixing and cooking), and question 38 from the daily living skills domain (clears table of breakable items). In China, people boil the tap water and either wait till it's getting cool or drink warm boiled water instead of drinking tap water directly. So question 24 from the daily living skills domain (gets drink of water from tap unassisted) does not work. And Chinese people use chopsticks instead of fork and knife when eating. So question 12 from the daily living skills domain (feeds self with fork) does not make sense, either. There are not many Chinese kids under 6 years old who have their bicycles. They ride tricycles instead. So question 36 from motor skills domain (rides bicycle without training wheels, without falling) does not serve as a good indicator. Experiences are critical for children to have the access of practices before mastering the skills and having the ability. A child cannot be diagnosed to have something delayed when he/she could not perform a certain task just because he/she has never had the experiences. Besides, different languages have different grammar, which make some performances do not make sense. In the communication domain, question 26 (uses *a* and *the* in phrases or sentences) and question 40 (uses irregular plurals) prove that.

#### *The Childhood Autism Rating Scale (CARS)*

The CARS was developed by Schopler, Reichler, and Renner (1988). It is used to provide a

diagnostic screening in terms of presence or absence of autism, and, if autism is diagnosed, the degree of severity is classified as mild-moderate or severe. It consists of ratings in 15 different areas of functioning significant for autism, which include relating to people; imitation; emotional response; body use; object use; adaptation to change; visual response; listening response; taste, smell, and touch response and use; fear or nervousness; verbal communication; nonverbal communication; activity level; level and consistency of intellectual response; and general impressions. The child is rated on these behaviors during the observation period of the assessment by a 7-point Likert scale ranging from 1.0 to 4.0, with intermediate values between the units (Schopler, Reichler, & Renner, 1988).

Again, because the cultural differences, some appropriate behaviors of Chinese children will be looked on as inappropriate ones from the perspective of the observer from different cultures. The child may avoid looking the adult in the eye to show his/her respect to the adult; or the child may be quiet because he/she is waiting politely for his/her turn. This may also be confounded by the fact that children with autism do not typically make eye contact.

### Summary and Conclusion

Given the severe impacts autism have on the children and their families and the benefits early detection and early intervention bring to them, it is important to use appropriate instruments for early detection and diagnosis of autism that are prerequisites for the institution of high-quality, evidence-based interventions. Considering the diversity of the children and their families' backgrounds, it is extremely important to provide them with cultural competent services. This paper examines the cultural validity in four assessment instruments of young children with autism from a Chinese cultural perspective. With the examination item by item, the authors find out several items from the Checklist for Autism in Toddlers, the Modified Checklist for Autism in Toddlers, the Vineland Adaptive Behavior Scales, and the Childhood Autism Rating Scale are not suitable for the children and families from the traditional Chinese culture, and may need to be adapted before using. However, this examination is based on the authors' Chinese cultural perspective and might vary somewhat from others' point of view.

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