



Home-Based, Parent-Implemented Intervention for Underserved Families in Taiwan

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Abstract

The prognosis and outcomes of autism spectrum disorder (ASD) are highly influenced by social and family contexts, cultural history, public policies, available programs, environment, and opportunities. Families who live in under-resourced environments face more than

their share of stress and obstacles. Social determinants that prevent families affected by ASD from accessing needed interventions may have a detrimental impact on child and family outcomes. Addressing these issues is particularly critical for vulnerable families who are SES disadvantaged. In this chapter, we describe general understanding and cultural interpretation of ASD in disadvantaged families in Taiwan. We also summarize ASD-related services in the Taiwanese health-care and education systems available to families of children with ASD, as well as common barriers to ASD diagnosis and ASD services. Furthermore, we discuss the challenges and opportunities for adapting individualized parent-implemented intervention for the underserved and SES-disadvantaged families who are affected by ASD. Lastly, we suggest feasible strategies for successful adaptation and adoption of parent-implemented intervention for these families.

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Understanding of ASD in Disadvantaged Families in Taiwan

Although health-care providers and child development researchers in Taiwan have gradually become more aware of autism spectrum disorder

(ASD) and are catching up with updated research findings and knowledge about ASD, many families continue to have a limited understanding about the signs of ASD and potential interventions. While public awareness of ASD has been increasing recently, disparity of ASD awareness between high-SES (social economic status) and SES-disadvantaged families remains (Lai, Tseng, Hou, & Guo, 2012; Lung, Chiang, Lin, & Shu, 2016). The percentage of low-income households in Taiwan is 1.68% as of 2016 (definition of low-income varies by district; the threshold ranged from US\$300 to 450 per person/month) (Ministry of Health and Welfare Republic of China (Taiwan), 2016). We recognize that great variation exists across SES groups in experience of health-care access. In this chapter, we focus our discussion on families living in Taiwan who have lower SES and access to fewer resources.

Cultural differences in understanding and interpreting child behavior may relate to challenges recognizing early signs of ASD. Often families misunderstand the disorder due to cultural influence and societal desirability (Wong, Yang, Steward, Chiang, & Wu, 2017). For example, a study conducted in Japan reported that Japanese caregivers may interpret a lack of interest in other children as modesty or shyness rather than a problem behavior (Inada, Koyama, Inokuchi, Kuroda & Kamio, 2011). Such observation is also common in Taiwan. Although lack of shared affect or enjoyment is considered a hallmark sign of autism in Western developed countries, in Taiwanese society, this is often seen as emotional suppression. Another ASD early sign, not responding to name, can be attributed by a caregiver as a child being appropriately focused on an activity – a positive trait that is thought of as being appropriate in Taiwan. Unusual preoccupations or circumscribed interests with numbers, blocks, books, or other academic-related objects are considered signs of great potential for high academic achievement rather than a developmental concern.

Another challenge in recognizing ASD is limited experience with typical development. Taiwan bears one of the lowest birth rates in the world, with a fertility rate of 1.18 per woman of child-bearing age in 2015 (Department of Human

Resources Development, 2016) and an estimated 2015 annual crude birth rate of 18.47 births per 1000 persons, ranked as the 216th of 224 countries (Central Intelligence Agency, 2016). With such a low birth rate, it is not surprising that most families only have one child. Thus, a child has fewer opportunities to interact with other children, and parents have less experience comparing their child's behaviors to other same-age children or siblings. Even if caregivers notice something is not quite right about their child, denial of ASD symptoms is not uncommon for parents in Taiwan as they wish to "save face" for the family. Denial of the diagnosis and refusal of follow-up services or treatments are often seen in Taiwanese families when ASD is suspected (Wong et al., 2017).

ASD-Related Services in Taiwan

In the health-care system. The National Health Insurance (NHI) Program was launched in 1995 to provide all civilian residents with mandatory comprehensive medical care coverage with modest cost sharing. As a result, an estimated 99% of all resident citizens are covered by NHI (Wu, Majeed, & Kuo, 2010). However, early detection and early intervention processes for children were not well established until 1997 when the Child Welfare Bureau of the Ministry of the Interior announced the Children with Developmental Disabilities Early Intervention Service Act. The act requires an integration of resources from social welfare, health-care, education, and police agencies to provide early detection and screening, referral, comprehensive evaluation, treatment and services, follow-up, and support to families of children with a developmental delay. Since then, early detection and early intervention methods have become well known by health-care providers. Currently, more than 100 health-care settings are eligible to provide evaluations for children with developmental concerns (Health Promotion Administration, 2016). The assessments and evaluations are covered by the NHI. With the coverage, developmental evaluations have become more affordable for many families, especially those of lower SES.

In the education system. Children with ASD were not eligible to receive special education services until 1997 (C.-F. Chang 2014a). As of March 2016, a special education classification of ASD makes up 6.2% (900/14423) of children who receive special education services in pre-schools, 13.9% (5569/40086) in elementary schools (grades 1–6), 12.3% (3230/26273) in middle schools (grades 7–9), and 11.2% (2252/20185) in high schools (grades 10–12) (Special Education Transmit Net, 2016). However, the special education programs often do not have enough resource to provide adequate individualized program for children with ASD (Chu et al., 2017); rather, the classrooms consist of students with a variety of disabilities – this is particularly the case in the regions that have fewer education resources.

In Taiwan, ASD-related treatments are mainly clinic- or center-based; that is, a treatment team delivers the intervention at a hospital or private practice. The treatment can be 1:1 or in group. The team members who deliver the intervention may include a rehabilitation physician, child psychiatrist, or pediatrician as a lead person, with occupational therapists, physical therapists, clinical psychologists, language pathologists, or social workers as part of the multidisciplinary team. Parent or family member involvement often is not a focus of such treatment/intervention. Although parent-delivered intervention has been known for quite some time in the field of child psychiatry and psychology in Taiwan, it has not yet been widely implemented as a part of early intervention service. One of the reasons is that professionals and parents both feel that health-related treatments should be delivered by professional care providers and that parents should not serve, or may not be qualified to serve, as a therapist and that treatments should be a responsibility of health-care professionals (T.-T. Chen, 2009).

Quality ASD-related education and health services are typically only available in the metropolitan areas of Taiwan. Given the limited resources in nonmetropolitan and rural areas, children in these regions are diagnosed at an older ages than children residing in metropolitan areas (Chen, Liu, Su, Huang, & Lin, 2008).

Common barriers that delay ASD screening and detection include the following: First, with the increase of nuclear families (54.3% in 2010), multiple-generation families are no longer the mainstream (National Statistics Republic Of China (Taiwan), 2010). However, the society traditionally practices vertical collectivism where a hierarchical structure of power is in place such that senior family members' (often grandparents) ideas and opinions play a key role in decisions on all aspects of all family members' lives, even if members do not live in the same household. Senior family members of the older generation consider a delay of development in young children as a sign that the child will later accomplish greatness (an old saying: a great rooster crows late) and, therefore, often advise parents not to rush to have the child evaluated by health-care professionals (Chao, Chang, Chin, Li, & Chen, 2017). Second, typically, developmental evaluations are carried out in a pediatric or psychiatric clinic, and an ASD diagnosis is made by a psychiatrist. Having a family member being diagnosed with ASD (or any mental disorders) continues to be considered punishment for what family ancestors have done wrong (H.-H. Chang, 2014b; Chung and Wong, 2004; Fung, Tsang, Corrigan, Lam, & Cheng, 2007). Such fatalism is not uncommon in the society, particularly in older generations, and in families in lower SES populations or living in nonmetropolitan areas. To reduce this resistance to seeing a psychiatric health-care provider, clinics that provide services for developmental concerns have been renamed as "physical and psychological medicine clinics" in Taiwan. Third, stigma remains a major issue for having an ASD diagnosis. Parental concern over having the label of such diagnosis can trigger bullying, and they are therefore reluctant to have their child evaluated. Fourth, the most common first concern parents of children with ASD have is delay in verbal communication. Often, an ear, nose, and throat clinic is the first clinic visit a family makes to have their child evaluated. Because no organic injuries or damage is found, families often either wait and see or do not think there is a problem and feel the child is just too shy to talk. Conventionally, as long as the child does not have an obvious physical disability, lack

of social interaction/communication may not be a major concern a parent has. Fifth, families may be concerned that life insurance companies may refuse to insure the family if the child has the pre-existing condition (i.e., ASD diagnosis).

Some of the common barriers to ASD-related services underserved families are facing in Taiwan are similar to those found in low-resource families throughout the world, whereas some are more specific to the families in Taiwan. The following are the most common barriers: (1) Families may not have enough knowledge about child development (Chao et al., 2017), or may not be aware of existing services because most information is available online. Many low-SES families either cannot afford or are not familiar with the Internet and computer usage. This is particularly the case for residents outside of major cities (Ministry of Education Republic of China (Taiwan), 2015). Even if they know ASD services exist, they may lack information and understanding on how to access them or they may not recognize the importance of needed services. (2) Families may consider the diagnosis to be fate and feel that there is nothing they can do about it. (3) Low-resource families often lack transportation or child care and have few resources to pay for these related expenses. (4) Although the NHI provides mandatory comprehensive medical care coverage, the number of visits allowed and reimbursement for behavioral intervention are limited. Even though such costs may not be substantial, they can be significant for families who are struggling to make ends meet. (5) There is a shortage of trained professionals delivering ASD-related services outside of major cities. Because communication and language delay is the major concern for most families who have a child with ASD, language therapy is the most requested treatment by the families. Due to the high demand and limited number of speech and language pathologists available, wait times for treatment are prolonged, with a majority of children receiving language therapy after age 3 (Wang and Lin, 2008). (6) In multiple-generation households, grandparents may have more influence on decision-making about whether or what types of treatment a child with a developmental concern should receive. In many cases, grandparents care

greatly about losing family “face” by having a child in the family labeled with ASD. (7) Taking time off from work to take care of their child’s health-care need can have significant impact on their family income; this is particularly true for families with limited resources or with lower SES. (8) Over the past two decades, there has been a steady and significant increase of children born to new immigrants in Taiwan. Specifically, in 2015, 10.6% of children in 1st to 9th grades were born to immigrant families (Ministry of Education Republic of China (Taiwan), 2016). The vast majority of these are international marriages between a Taiwanese man and his wife from nearby Asian countries. Because these families also tend to be SES disadvantaged and the mother is the primary caregiver of their children, speaking a foreign language becomes a major barrier to a child being evaluated and treated for possible developmental concerns. Additionally, the immigrant mothers often live socially isolated lives and are not able to have much social connection outside of the husband’s family. Such isolation and language barriers not only delay early diagnosis but also make parent-mediated intervention more challenging.

Challenges and Opportunities for Adapting Individualized Parent-Implemented Intervention

Parent-implemented interventions could be a very feasible way for increasing access to treatment for children with ASD in rural and low-resource areas. However, the popular perception is that treatments for ASD and other medical conditions should be provided by specialized and highly trained clinicians rather than family members. Furthermore, it can be highly stressful and anxiety provoking for parents to receive the training to be a “therapist” for their own child, and therefore many refuse to be trained as they think they should not and are not eligible nor can learn to be a therapist for their child (T.-T. Chen, 2009; Yen and Chang, 2014). It is worth noting that there are parents who reported they feel “empowered” to be able to serve as a therapist for their

child (Tsai et al., 2015). Some of the aforementioned barriers to services also are true when it comes to training parents in implementing evidence-based intervention at home. For example, lower literacy levels can make it challenging for parents to read and understand treatment materials. Many of these families also bear excess stress from other demands in life, for example, financial demands to meet basic living needs of the family (Yen and Chang, 2014). Other challenges include different views among family members on how to raise and discipline the child, predeterminism belief (fatalism), significant physical health issues and mental health concerns of the primary caregivers, and immigrant mothers' language barrier and their isolated social network. A combination of these barriers makes the implementation of parent-mediated evidence-based intervention a great challenge.

This has resulted in children of SES-disadvantaged families having limited access to appropriate interventions. Addressing the aforementioned barriers requires the delivery of evidence-based intervention adapted for contextual acceptability (Dingfelder and Mandell, 2011) in family-friendly settings, without losing their model fidelity and effectiveness. Parent-implemented interventions for ASD that were developed and evaluated in Western countries need to be adapted in several aspects in order to enhance acceptability and feasibility in Taiwan (Drmic, Aljunied, & Reaven, 2017).

Family members need to be involved as a unit, including extended family rather than just parents. This is particularly critical for a multiple-generation family homes where grandparents, siblings, and other relatives live in the same household and therefore should be involved as a part of the treatment team. If there are barriers to involving all these family members in the parent training sessions, providers need to at least have their "approval" to allow caregivers receiving such training to implement the strategies at home. The procedures put in place need to work for the whole family. For example, if a parent is working on waiting until a child is calm before responding, but the grandparents believe this is damaging

to the child and do respond, the behavior is not likely to change, and there may be conflict within the family.

Working with parent groups. Parent groups not only provide support to families but also allow parents to share their experiences with other parent members of the group (Rodrigo, Almeida, Spiel, & Koops, 2012). Such support systems empower parents to learn and therefore can serve as a platform for the parent training to happen. Knowing that SES-disadvantaged families may not actively participate in social groups of this kind, such groups should consider including a broader scope (e.g., child development rather than specific focus on ASD) to reduce the resistance due to the stigma of ASD and to increase the acceptance level of other family members (specifically the grandparents). Needless to say, ASD-focused activities and trainings surely should be included. A well-trained parent member of the group can later serve as a consultant or trainer for other parent members. One of the main advantages of this approach is that the trained parent members can share the obstacles and experiences their family is facing and can provide a more culturally relevant and sensitive training for the new parents.

Families living in disadvantaged SES status in Taiwan are likely minorities, new immigrants, or residents outside of major cities. These families often are more comfortable in speaking dialects or other languages (e.g., new immigrant mothers) rather than Mandarin Chinese. Therefore, it is crucial that the support groups or intervention training have the capacity to be implemented in dialects and native languages of immigrant mothers in order to make the training accessible to the families who are in great need.

Expanding the workforce Taiwan is forecasted to become an aged society in 2018 and super-aged society by 2026 (Department of Human Resources Development, 2016). This means that those 65 years and older will account for 14.5% of the population by 2018 and 20.5% by 2026. However, between 2010 and 2015, men and women left their full-time workforce at age 63.3 and 60.6, respectively

(Ministry of Labor Republic of China (Taiwan), 2015). With the increased life expectancy, this presents as an opportunity for retirees to spend their golden years making a difference by volunteering. Retired health-care professionals or educators who have worked in the fields related to child development or working with children with developmental disabilities could be a great resource to provide behavioral intervention after appropriate training. If such training is set up systematically and ongoing, these retirees can either implement the intervention at the child's home or train the families/caregivers in groups at low or no cost. If this increasing number of retirees receives appropriate training, this may increase the likelihood that families residing in rural areas could be reached. Health-care professionals and teachers are often highly respected in the society; having them working with the families would make such training more accepting and convincing to the family.

Conclusion

The prognosis and outcomes of ASD are highly influenced by social and family contexts, poverty, cultural history, public policies, available programs, environment, and opportunities. Implementation of a parent-mediated evidence-based intervention presents a great potential in addressing major obstacles to intervention access for affected children and their families who are underserved in Taiwan (Tsai et al., 2015), although such intervention is still in the developing and adapting stages for many low-resource settings in the world (Blake et al., 2017) and in some communities in Taiwan.

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