



自闭症儿童 心灵解读

技能干预教程

邵智 张婷◎著

Theory of Mind



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PREFACE

The growing prevalence of children with Autism Spectrum Disorders (ASD) is a concern not only in the United States but across the world. Data from the Centers for Disease Control and Prevention suggest that although initial reports in 2012 indicated a prevalence of 1 in 88 children (CDC, 2012), more recent reports indicate a prevalence of 1 in 68 children with 1 in 42 males and 1 in 189 females affected (CDC, 2014). The prevalence in particular ethnic groups varies and the disparities suggest under identification in some populations. For example, the prevalence of ASD appears to be greater among non-Hispanic white children (12 per 1,000) than non-Hispanic black children (10.2 per 1,000) and Hispanic children (7.9 per 1,000) even though there is no documented difference among these groups that suggest there should be prevalence differences. Further, it appears that insufficient information is available for children of Asian/Pacific Island descent. Time of identification

also appears to be a factor in the prevalence rate as some research suggests girls may be identified later than boys which impacts critical access to early intervention (Giarelli et al., 2010). Most recently, Christensen and colleagues (2015) found differences in the identification of 4 years old vs. 8 years old in the CDC monitoring studies. The 4 years old prevalence in 58,467 children in 5 sites was 13.4/1000 (about 1 in 74 vs. the 1 in 68 for 8 years old). Not surprisingly, prevalence was higher where there was access to education and health records. ASD with cognitive impairment was higher in 4 years old (46%) vs. 8 years old (28%) even though 93% of 4 years old and 87% of 8 years old had reported developmental concerns before 3 years. Data collected suggests 4 years old had their first comprehensive evaluation at about 27 months whereas 8 years old had theirs at about 32 months. Again, health disparities in assessment of children with or at risk for ASD was evident in data suggesting non-Hispanic, white females were most likely to have an evaluation by 36 months as compared to male, non-Hispanic black children. The data clearly indicate there is a need to focus on lowering the age when a child has their first comprehensive evaluation if we hope to initiate impactful early intervention.

The rise in children identified with ASD has a tremendous impact on families and society. Compared to other children with behavioral, developmental and/or

emotional disorders, children with ASD are more likely to have unmet needs for health care and family support services, there are often delays in referrals and care and a family centered approach to care is often lacking (Kogan et al., 2008). We know that children with special health needs are more likely to have families with financial burden and require at least one parent to reduce or stop working to help manage and coordinate their child's intervention and care plan. In addition, caregivers of children with ASD are at risk for psychological morbidity—suggesting providers need to identify stress triggers and address them (Lovell, Elliot, Che Sung Liu, & Wetherell, 2012). For example, the diagnostic process is particularly stressful for parents and when teams are planning a child's program, often parent participation is missing (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). Further, the more severe a child's symptoms are, the greater the stress on the parents (Osborne & Reed, 2009) and in particular for those parents who have children with both ASD and an intellectual disability (Peters-Scheffer, Didden, Korzilius, & Matson, 2012). Notably, there are several strategies that can be used to decrease the stress of parenting a child with ASD, or at least facilitate a parent's ability to cope. Having a sense of control over the events that are happening to their child and family, being able to identify and select the most meaningful resources, receiving peer

support, and having a partner you can count on support a parent' s ability to cope (Siman-Tov &Kaniel, 2011) .

General consensus exists that children with a diagnosis of ASD need access to intensive, evidence-based instruction which actively engages them in developmentally appropriate activities with clear, systematic goals and planned teaching opportunities (National Research Council, 2001) .These teaching opportunities should include families and typical peers to help maintain and generalize a child' s learning. Most importantly, though, families need to be involved in their child' s intervention program which should start as early as possible.

It is the responsibility of professionals and their organizations to help identify and implement the most effective intervention practices to address the individual needs of children and families. For example, the National Standards Project (2009, Phase 1) examined research through 2007, examining 775 studies. They established a model for reviewing all current intervention research in autism and provided a framework for families and professionals to consider in making decisions about evidence-based interventions. Some of the inventions rated as established included joint attention training, naturalistic strategies, pivotal response training, story-based interventions, modeling, comprehensive behaviorally based interventions, etc. (see the National Autism

Center website: www.nationalautismcenter.org for a full description of all established interventions) .Phase 2 of the National Standards Project (2015) examined research from 2007 - 2012 and included all research for those with ASD over 22 years (from 1987 - 2007) . This most recent review supported the findings of the earlier work with even greater support for behaviorally based interventions. Findings also indicated that two additional categories of interventions (e.g., Parent training and Language training) were now in the established intervention category. Notably, however, there was limited available research for supporting interventions with adults over 22.

The Agency for Healthcare Research and Quality (2014) also identified key findings for therapies most often used for children with ASD. The Agency posed some key questions for clinical researchers to think about as program planning for children with ASD is developed. The following selected questions are particularly relevant for healthcare providers and rehabilitation specialists as they are considering treatment selection and implementation for children with ASD:

- What are the short- and long-term effects of available treatment approaches for 2 to 12 years old children with ASD?
- What are the modifiers of outcomes (e.g., frequency, duration or intensity of treatment) for different

behavioral treatments or approaches?

- What is the evidence that effects measured at the end of the treatment phase predict long-term functional outcomes?

- What is the evidence that specific intervention effects measured in the treatment context generalize to other contexts (e.g., people, places, materials) ?

There are, however, two important questions missing. First, how do we determine intervention priorities that address the specific needs of individual children with ASD? Second, are there evidence-based interventions specifically addressing the core deficits in theory of mind (ToM) or social cognition that are at the core of the social impairment in autism?

A number of evidence-based interventions address a variety of behavioral, communication and social skills in children with ASD, but few interventions specifically address the development and enhancement of theory of mind. Considering the varying ToM abilities often characteristic of children with ASD, clinicians need to understand the available interventions, consider the ToM profiles of children with ASD, and recognize those social cognitive skills (e.g., emotion recognition, metarepresentation, empathy) most likely to be positively impacted by intervention (Prelock, 2011). Many of the interventions used for supporting early and basic ToM

in children with ASD are drawn from those treatments identified by the National Standards Project (National Autism Center, 2009, 2015) and the National Professional Development Center (Wong et al., 2015) as having an established or emerging evidence-base. These might include joint attention training, Floor time/DIR, Relationship Development Intervention (RDI) , and More Than Words™, Social Stories™, comic strip conversations, and Talkability™ to name a few. Most interventions described for supporting advanced ToM, however, do not yet have an evidence-base (e.g., Social Thinking™, *Teaching Children to Mind Read*) . At present, the clinical rehabilitation of children lacks a systematic intervention approach to developing and expanding ToM understanding, which is the main neurological and psychological mechanism for children with ASD.

This book, a collaboration between Professor Shao Zhi and Dr. Zhang Ting, fills the gaps that currently exist in ToM intervention approaches. The authors systematically define an intervention approach that builds ToM understanding in children with ASD along a developmental trajectory. Professor Shao Zhi has a long standing commitment to both academic teaching and clinical intervention on ASD. He brings rich experiences from both his clinical practice and academic research to guide the systematic development of the book' s content. Dr.

Zhang Ting is an expert in child developmental psychology and her research interest is focused on the psychological developmental theories of typical children. She uses that knowledge to enhance the reader's understanding of what ToM looks like in neurotypical children and how it develops over time. As Professor Shao Zhi and Dr. Zhang Ting partner to increase our understanding of the development of ToM and the systematic strategies most likely to support ToM learning in children with ASD, the reader begins to understand the complexity and multifaceted nature of ToM and its importance to the developing social cognition of children with ASD.

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中译序

preface

当前儿童自闭症谱系障碍 (Autism Spectrum Disorders, ASD) 日渐升高的患病率引起了美国, 乃至全世界的关注。美国疾控中心 2012 年报道的发病率为 1/88 (CDC, 2012), 而最新数据显示 ASD 患病率现已高达 1/68, 其中男性 1/42、女性 1/189 (CDC, 2014)。ASD 在不同种族间的患病率不尽相同, 这种差异表明某些人群的研究资料还亟待完善。比如, 非西班牙裔白人儿童的患病率 (12/1000) 高于非西班牙裔黑人儿童 (10.2/1000) 和西班牙裔儿童 (7.9/1000), 但并无研究表明上述人群之间的患病率应有不同。此外, 亚太岛国居民儿童患病率资料也并不完善。另外, 诊断年龄也是影响患病率的因素。有报道称, 女孩的诊断年龄多晚于男孩, 这将影响上述患儿及早接受干预治疗 (Giarelli et al., 2010)。近期, Christensen 等 (2015) 在 CDC 开展的监测研究中发现, 4 岁儿童和 8 岁儿童的检出率有明显差别。5 个监测点共 58467 名儿童的 4 岁检出率为 13.4/1000 (1/74, 8 岁为 1/68)。当然, 能够提供儿童教育和健康档案的地区检出率高于其他地区。尽管 93% 的 4 岁 ASD 儿童和 87% 的 8 岁 ASD 儿童在 3 岁前就已

出现发育异常，但4岁年龄组伴发认知障碍的概率（46%）高于8岁年龄组（28%）。调查数据显示，4岁年龄组ASD儿童在27月龄时接受首次综合性评估，而8岁年龄组则为32月龄。此外，为ASD儿童和高危儿童提供评估的医疗服务水平也有明显差异。数据显示，和非西班牙裔黑人男性儿童相比，非西班牙裔白人女性儿童多会在36月龄前接受评估。上述研究结果表明，若要开展有效的早期干预，我们必须围绕降低患儿接受首次综合评估的年龄开展工作。

ASD儿童的日益增加给家庭和社会带来了极大负担。与患有行为、发育或情绪问题的儿童相比，ASD儿童对医疗和家庭支持服务的需求常得不到满足，转诊延迟、治疗延迟、缺乏家庭支持治疗都是常见问题（Kogan et al., 2008）。众所周知，很多有特殊医疗需求的儿童家庭经济都较困难，且需要至少一位家长减少或停止工作以配合和参与孩子的干预和治疗计划。ASD儿童的照顾者是心理疾病的高危人群，他们需要寻找并处理好压力诱因（Lovell, Elliot, Che Sung Liu, & Wetherell, 2012）。患儿的诊断过程对家长来说极其痛苦，当治疗团队在制订干预计划时，家长也并未参与（Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010）。孩子的临床表现越严重，家长的压力也越大（Osborne & Reed, 2009），对伴有智力障碍的ASD儿童家长来说尤其如此（Peters-Scheffer, Didden, Korzilius, & Matson, 2012）。所幸，现在有很多方法可以帮助ASD儿童家长减少或应对压力。能够控制突发事件、有能力识别和选择最有效的治疗资源、获得同龄人的支持、有可依赖的同伴都有助于提高家长应对压力的能力（Siman-Tov & Kaniel, 2011）。

ASD 儿童需要接受密集、有循证基础的训练，参与和自身发育水平相符、精心设计且目标明确、系统的干预活动（National Research Council, 2001），人们对这一观念已达成普遍共识。这些教学活动需要家庭和同龄正常儿童的参与，以帮助儿童维持和泛化所学技能。而最重要的是，家庭成员应尽可能早地参与儿童的干预训练。

专业人员及相关机构对协助患儿及其家庭开展有效干预措施以解其所需责无旁贷。美国国家标准项目（2009，第一版）调查了 2007 年间共 775 项研究，建立了回顾当前自闭症干预研究的模板，并为专业人员和患者家庭提供了合理选择具有循证基础干预措施的框架。具有循证基础的干预措施包括：联合注意干预、自然教学、关键反应训练、以故事为基础的干预、示范、综合行为治疗等（详见美国国家自闭症中心网站：www.nationalautismcenter.org）。美国国家标准项目的第二版（2015）调查了 2007—2012 年间的相关研究，及过去 20 年（1987—2007 年）所有涉及 22 岁以上 ASD 患者的研究。这份最新研究结果提出了对前期以行为训练为主的干预训练的支持，并指出另有两类训练方法（家庭训练和语言表达训练）现已列入有循证基础的干预措施之列。但值得注意的是，目前鲜有关于 22 岁以上自闭症患者支持治疗的报道。

美国医疗卫生保健研究与质量中心（2014）指出了一些关于常用于 ASD 儿童训练治疗的重要发现，并为制订 ASD 儿童治疗计划的医疗工作者提出了一些关键性问题。以下是与医务人员和康复专家考量患儿治疗措施的选择和实施时尤其相关的问题：

- 对 2 ~ 12 岁的 ASD 患儿而言，现有治疗措施的短期

和长期效应是什么？

- 影响不同行为治疗或干预措施疗效的因素是什么？是训练的频率，持续时间，还是强度？

- 治疗后期评价治疗远期功效的依据是什么？

- 从训练中心迁移到另外的环境，评价干预疗效的证据是什么？是人，场景，还是物件？

此外，仍有两个重要问题未被考虑到。第一，如何确定 ASD 患儿个别化治疗的优先次序？第二，心灵解读（Theory of Mind, ToM）或社会认知缺陷是自闭症患儿社会交往的核心问题，是否有针对上述核心问题且有循证基础的干预措施？

目前具有循证基础，且针对 ASD 患儿行为、交流及社交技能缺陷的干预治疗不少，却鲜有针对 ToM 发展和促进的措施。鉴于 ASD 患儿的 ToM 能力会影响其临床表现，临床医师需要了解现有的治疗干预措施，考虑患儿的 ToM 大致情况，并认识到这些社会认知技能（如情绪识别、元表征、共情）可经干预训练得到正强化（Prelock, 2011）。不少用于 ASD 患儿早期和基础 ToM 治疗的干预措施都是从美国国家标准项目（National Autism Center, 2009, 2015）和国家专业发展中心（Wong et al., 2015）认定的有或即将有循证基础的治疗措施中提炼出来的。这些干预措施包括联合注意训练、地板时光/DIR、人际关系发展干预疗法（RDI）、言语之外、社交故事、连环漫画会话、会话能力训练。另有部分干预疗法被认为可提升 ToM 能力，却没有循证基础（如，社会思维、教导孩子解读别人的想法）。ToM 是儿童自闭症重要的神经心理学机制，而目前现有的临床康复训练却没有改善和提升 ToM 的系统化干预措施。

本书由邵智教授和张婷博士合作编写，填补了当前 ToM 干预治疗的空白。作者系统定义了符合 ASD 患儿生长发育轨迹、帮助患儿建立 ToM 能力的干预措施。邵智教授长期致力于 ASD 的学术研究、教学和临床干预治疗，其丰富的临床和研究经验对本书的编写具有重要的指导意义。张婷博士是儿童发展心理学的专家，研究工作主要围绕正常儿童心理发展理论开展。她丰富的知识有助于提高读者对于典型儿童 ToM 的理解及其如何随着时间发展变化。本书将帮助我们更好地理解 ToM 的发展及支持 ASD 患儿 ToM 学习的系统干预措施，读者将从中了解 ToM 的复杂性和多面性，及其对 ASD 患儿社会认知发展的重要性。

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孤独症干预核心是社会交往 ——给邵智主任医师专著的推荐语

首先，我要说这是一部很实用的孤独症干预指导书。能为广大读者推荐它，我感到十分荣幸。

作者邵智主任医师是重庆市第九人民医院重庆市儿童孤独症康复治疗中心的创始人，长期以来一直致力于儿童孤独症的诊断和干预工作。我个人认识邵智主任医师已经有很长时间，经常与他在学术会议上见面，也曾经有幸受邀去他工作的重庆市第九人民医院重庆市儿童孤独症康复治疗中心参观学习，很敬佩他和他的团队坚持以发展心理学为导向，开展孤独症的干预工作，且成绩斐然。印象尤其深刻的是，他长期以来与西南大学心理学部合作，从发展心理学的角度研究孤独症儿童的心灵解读（Theory of Mind）障碍，并与具体临床实践相结合，发展出了独具特色的、基于中国文化基础的儿童孤独症心灵解读干预方法，在帮助孤独症儿童方面起到了很好的效果。

现在他将自己的理论和实践经验编撰成书，欲让更多的专业人员和家长受益，实属幸事。

本书首先指出心灵解读能力缺损是孤独症社交障碍的主要原因，进而提出心灵解读能力干预和自我意识干预