



## Early screening for autism spectrum disorders: A primer for social work practice

Sarah Dababnah<sup>a</sup>, Susan L. Parish<sup>b,\*</sup>, Lauren Turner Brown<sup>c</sup>, Stephen R. Hooper<sup>c,d,e</sup>

<sup>a</sup> School of Social Work, University of North Carolina at Chapel Hill, NC, United States

<sup>b</sup> The Heller School for Social Policy and Management, Brandeis University, MA, United States

<sup>c</sup> Carolina Institute for Developmental Disabilities, University of North Carolina School of Medicine, NC, United States

<sup>d</sup> Department of Psychiatry, University of North Carolina at Chapel Hill, NC, United States

<sup>e</sup> Department of Pediatrics, University of North Carolina at Chapel Hill, NC, United States

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### ABSTRACT

Early identification of autism spectrum disorders has been demonstrated to result in material benefits to children, their families, and society by reducing problem behaviors, improving academic achievement and school outcomes, and increasing social participation. Early intervention also reduces the costs and associated morbidity of autism spectrum disorders across the life span. Despite significant advances in the ability of screening tools to detect autism spectrum disorders in young children, previous research has found that most children are not identified until they are in school, and past the age at which early intervention services are most beneficial. Social workers, given their presence across a wide range of service settings, are uniquely positioned to identify preschool children with autism spectrum disorders and refer them for additional diagnostic services and evidence-based interventions. In this paper, a basic primer on autism spectrum disorders is provided, along with descriptions of the various screening tools appropriate for children ages 3 and younger that social workers can implement in their own practice settings. Policy and practice implications are discussed.

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### 1. Introduction

Autism spectrum disorders are complex neurodevelopmental problems distinguished by deficits in social interaction and communication, as well as the presence of repetitive behaviors (American Psychiatric Association, 2000). Over 1% of US children have a diagnosed autism spectrum disorder (Centers for Disease Control and Prevention, 2009; Kogan et al., 2009). Males are disproportionately affected at a rate of 1 in 70 (Centers for Disease Control and Prevention, 2009; Kogan et al., 2009). The 2006 overall prevalence estimate of approximately one in every 110 children represents a significant increase from previous epidemiological surveys (Centers for Disease Control and Prevention, 2009; Kogan et al., 2009). The precise causes of autism spectrum disorders have not been identified, although scientists believe they have a strong genetic component along with environmental influences (Muhle, Trentacoste, & Rapin, 2004; Pinto et al., 2010).

The increasing prevalence of autism spectrum disorders is clearly a public health and social concern. In general, children with disabilities and their families face high levels of burden, especially when compared to nondisabled children (Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008). Economic burdens are particularly

pervasive in families raising children with autism spectrum disorders, including lower incomes, higher expenses, and more work-related difficulties (Liptak, Stuart, & Auinger, 2006; Montes & Halterman, 2008a,b). Lifetime costs of caring for an individual with autism are estimated to be more than \$1.6 million (Landrigan, Schechter, Lipton, Fahs, & Schwartz, 2002), while societal costs reach \$3.2 million, and include expenditures for lost productivity as well as medical and support service costs (Ganz, 2007). Financial burdens and other factors, including children's behavior, social problems, and elevated needs for specific types of therapies and ancillary services, contribute to parental stress, negative coping strategies, and depression, particularly for parents of young children with autism spectrum disorders (Davis & Carter, 2008). These factors are subsequently associated with a multitude of negative child outcomes (e.g., behavioral) that persist through adolescence and perpetuate parental stress (Lecavalier, Leone, & Wiltz, 2006). However, in addition to the emotional and financial impact on families, it is important to recognize the strengths children with autism spectrum disorders and their families possess (Else, 2001; Welteroth, 2001).

Over the past decade, researchers have made significant strides to improve reliable early detection of children with autism as early as age two (Cox et al., 1999; Lord, 1995; Stone et al., 1999), with screening measures being validated for children as young as 16 months (Dumont-Mathieu & Fein, 2005). Recent research has focused on the development of a tool to reliably identify 12-month old children at-risk of autism (Reznick, Baranek, Reavis, Watson, & Crais,

\* Corresponding author.

E-mail address: [slp@brandeis.edu](mailto:slp@brandeis.edu) (S.L. Parish).

2007). Nonetheless, a recent study found only 10% of children aged nine to 24 months who are eligible for federal Part C early intervention services for developmental delays actually received services before reaching two years of age (Rosenberg, Zhang, & Robinson, 2008). Some children with autism spectrum disorders fail to receive services well into their school years, particularly youth with strong verbal abilities (Yeargin-Allsopp et al., 2003). Key surveillance research reports the median age of diagnosis to be 5.7 years old, well beyond the age where autism spectrum disorders can be reliably diagnosed (Shattuck et al., 2009). Additionally, multiple studies have noted parents often are concerned about their child's development well before the child's second birthday (Coonrod & Stone, 2004; De Giacomo & Fombonne, 1998; Young, Brewer, & Pattison, 2003). Although research has found the mean time between a parent noting concern and seeking professional advice is less than five months (average age of 23 months) (Coonrod & Stone, 2004), the gap between parent concern and actual receipt of diagnosis continues to be wide, at about 34 months (Young et al., 2003).

This trend of late detection is alarming. Diagnosis is often the gateway to educational interventions and other therapeutic services in the United States. If children are not screened earlier, then the diagnosis of autism spectrum disorders will continue to appear at later developmental time periods, missing critical opportunities to promote optimal development. Additionally, access to early intervention can dramatically assist young children with autism spectrum disorders to overcome barriers in learning and transition when they reach school (National Research Council, 2001). Timely treatment is critical for the child's caregivers as well, given that lifelong costs of caring for individuals with autism spectrum disorders are estimated to decrease by two-thirds with appropriate access to services (Jäbrink & Knapp, 2001). Additionally, both mothers and fathers of newly-diagnosed toddlers with autism spectrum disorders have significantly elevated levels of stress (Davis & Carter, 2008). When compared to mothers of children with other intellectual disabilities, mothers with preschool children with autism reported considerably more stress (Eisenhower, Baker, & Blacher, 2005). These findings suggest special attention should be paid to the caregivers of young children with autism spectrum disorders due to their increased risk of negative emotional outcomes.

Social workers are uniquely positioned to respond to the dramatic increase in the prevalence of autism. Social workers encounter children with autism spectrum disorders in a vast range of arenas, including child welfare settings, schools and daycares, social service organizations, governmental benefit offices, hospitals, clinics, mental health treatment centers, and primary care offices. Despite the potential for early and regular exposure to children at-risk for autism spectrum disorders, most social workers are not trained to recognize or intervene on behalf of these children and their families. Furthermore, a limited investigation on social worker beliefs found inaccuracies regarding the understanding of diagnostic methods and characteristics associated with autism spectrum disorders (Preece & Jordan, 2006). The paucity of research on autism spectrum disorders in social work practice journals provides some evidence of this deficiency, and illustrates the critical need for training and professional development in this area.

The current paper has three basic aims. First, it provides a general overview of the national movement to increase awareness of autism spectrum disorders. Key characteristics of autism spectrum disorders are described as a primer for social workers. Second, it describes available screening instruments in detail, with an eye toward guiding future clinical practice and increased involvement of the field of social work in autism screening, detection and intervention. Finally, a brief discussion of policy and practice implications of early screening emphasizes the advocacy potential for social workers outside of the clinical realm, and the potential positive impact that the field of social work can have in the area of autism spectrum disorders.

## 2. Autism awareness: A national agenda

As recognition of autism spectrum disorders and the importance of early detection and intervention have grown, government agencies and professional organizations have responded with awareness campaigns for their constituents. For example, the Centers for Disease Control and Prevention (CDC; National Center on Birth Defects and Developmental Disabilities), which leads national autism spectrum disorders surveillance activities, initiated "Learn the Signs. Act Early." This campaign aims to raise recognition of milestones that are expected for typically-developing children. The campaign also created instructional materials for parents, healthcare providers, policy-makers, and educators, many of which are available at no cost on CDC's website (<http://www.cdc.gov/ncbddd/actearly/>). These efforts have been effective in raising parent and professional awareness of autism spectrum disorders (Daniel, Prue, Taylor, Thomas, & Scales, 2009) and other developmental delays, and furthering a national agenda to address the needs of this population. CDC's efforts are partially funded through the Combating Autism Act of 2006, a key federal legislation that significantly increased expenditures in autism screening, intervention, research, and professional development. President Barack Obama also committed funding through the American Recovery and Reinvestment Act (2009) for autism-related research, with a focused investment in early intervention (The White House Office of the Press Secretary, September 30, 2009).

While the federal government has increased funding for research, some states have initiated their own efforts to mandate universal screening for autism spectrum disorders. For example, California Senate Bill 527 proposed to create the Autism Spectrum Disorders Early Screening, Intervention, and Treatment Pilot Program, a two-year endeavor to test the use of various methods of screening tools in community settings (Autism Spectrum Disorders: screening, 2008). However, the bill was vetoed by Governor Arnold Schwarzenegger. California is also part of a 19-state initiative<sup>1</sup> led by the National Academy of State Health Policy (NASHP; May, 2008) and The Commonwealth Fund to identify best practices and policies for widespread use of standardized developmental screening tools in primary care. NASHP identified four primary mechanisms by which states have promoted standardized screening for young children for developmental delays including: (1) changes to billing and reimbursement policies; (2) public-private and inter-governmental partnerships; (3) quality of care incentives (e.g. integration of screening into well-child visits under Medicaid's Early and Periodic, Screening, Diagnosis, and Treatment program); and (4) changes to provider manuals and updates.

Primary care providers have been the central focus of recent state and federal efforts to promote regular screening of young children for autism spectrum disorders and other developmental delays. The American Academy of Pediatrics provides ongoing guidance to pediatricians on screening and referral for autism spectrum disorders (Johnson, Myers, & American Academy of Pediatrics Council on Children with Disabilities, 2007). As primary care professionals are often the first point of contact for young children and their families, pediatricians play a critical role in early identification efforts and care coordination. Nonetheless, despite improvements in screening, a 2004 survey noted only 8% of pediatricians routinely screen their patients for autism spectrum disorders (Dosreis, Weiner, Johnson, & Newschaffer, 2006). Other research found primary care professionals held inaccurate beliefs regarding the clinical presentation of autism spectrum disorders and their etiology (Heidgerken, Geffken, Modi, & Frakey, 2005). Families with children with developmental disabilities,

<sup>1</sup> The states and territories include: Alaska, Alabama, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Kansas, Maryland, Michigan, Minnesota, Montana, New Jersey, New Mexico, Ohio, Oregon, Virginia, and Wisconsin as of April 2010.

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