

# Social Communication Difficulties and Autism in Previously Institutionalized Children

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**Objective:** To determine the risk of difficulties with social communication and restricted/repetitive behaviors as well as the rate of autism in children institutionalized in early infancy and to assess the impact of a foster care intervention on ameliorating this risk.

**Method:** Children abandoned at birth and raised in institutions in Bucharest, Romania were randomly assigned to a care-as-usual group (institutional care, CAUG), or placed in family-centered foster care (FCG) as part of the Bucharest Early Intervention Project (BEIP). At approximately 10 years of age, the Social Communication Questionnaire (SCQ) was administered to caregivers of children in both groups as well as to parents of a typically developing community sample (Never-Institutionalized group [NIG]) residing in Bucharest, Romania. Children scoring  $\geq 12$  on the SCQ underwent clinical evaluation for autism spectrum disorder (ASD).

**Results:** Caregivers of children with a history of institutionalization reported that these children had significantly

more deviant behavior than never-institutionalized children on all subdomains of the SCQ (all  $p < 0.001$ ). Children in the FCG had significantly lower scores on the SCQ than children in the CAUG ( $p < .001$ ), particularly in the reciprocal social interaction domain, indicating that the intervention reduced problems in social communication. Three of 60 CAUG children, 2 of 57 FCG children, and none of the NIG children received a formal ASD diagnosis.

**Conclusion:** Early institutional rearing was associated with an increased risk of social communication difficulties and ASD. A family-centered foster care intervention improved social communication skills.

**Key Words:** institutional care, foster care, development, social communication, autism

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Children raised in institutions are at increased risk for a variety of adverse outcomes,<sup>1</sup> including risk for “quasi-autistic” patterns of behavior.<sup>2,3</sup> In the English and Romanian Adoptees Study, quasi-autism was found in 11.1% of previously institutionalized children at 11 to 12 years of age.<sup>4</sup> A similar disorder described as post-institutional autistic syndrome (PIAS) was found in 16% of previously institutionalized children adopted from Romania to the Netherlands at an average age of 8 years.<sup>5</sup> Although children with these disorders have features overlapping with autism spectrum disorder (ASD), including social communication difficulties and repetitive behaviors,<sup>6,7</sup> the authors of those studies used the terms “quasi-autism” or PIAS to highlight several features seen in previously institutionalized children that differ from those often seen in “ordinary” ASD. These features include a general trend for decreasing severity of ASD features over time and an equal male:female ratio (compared to the 4:1 male:female ratio seen on average in other studies of ASD).<sup>8</sup>

Other studies, while not looking specifically at ASD, suggest that post-institutionalized children demonstrate behaviors often seen in ASD, including abnormalities in social approach, difficulties adjusting behavior to suit social context, and difficulties with peer relationships.<sup>4,9–16</sup> Children with a history of institutionalization also have an increased likelihood of demonstrating repetitive movements such as stereotypies.<sup>17</sup>

The Bucharest Early Intervention Project (BEIP), a randomized controlled trial of foster care versus institutional rearing, provides the opportunity to examine social communication abilities, restricted/repetitive behaviors, and presence of a diagnosis of ASD in institutionalized Romanian children randomly assigned to a continued institutional care-as-usual group (CAUG) or to a foster care intervention group (FCG). Similar to the studies by Rutter et al<sup>2,3</sup> and Hoksbergen et al,<sup>5</sup> children in this study were placed in institutions early in life, most at birth. Because ASD cannot be reliably diagnosed in the newborn period or in the first year of life even in countries where there is considerable awareness of the disorder,<sup>18,19</sup> it is unlikely that ASD was a reason for abandonment; instead, political pronatalist policies in the context of frequently insufficient financial and social support for child rearing led many children to be abandoned for social reasons.<sup>20,21</sup> Within institutions, medical determination of whether a child was “typically developing” or “handicapped” generally did not occur until the age of 3 years.<sup>22</sup>



This article is discussed in an editorial by Dr. Dante Cicchetti on page 83.



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Supplemental material cited in this article is available online.

Because of the random assignment to CAUG or FCG, the BEIP offers the unique opportunity to assess the extent to which foster care placement improved behaviors associated with autism, including social communication and restricted/repetitive behaviors. Although prior studies in the BEIP have specifically examined attachment,<sup>15,23,24</sup> teacher-rated social skills,<sup>16</sup> and stereotypies,<sup>17</sup> these findings are not always specific to ASD. No study has previously addressed the broad range of difficulties with social communication and restricted/repetitive behaviors specifically seen in ASD or the specific diagnosis of ASD in a randomized sample.

The objectives of the current study are as follows: to describe the distribution of social communication difficulties and restricted/repetitive behaviors in children with a history of early institutional care; to evaluate the efficacy of a foster care intervention compared with continued institutional care in improving social communication and restricted/repetitive behaviors; and to investigate the prevalence of ASD in children with a history of early institutional care.

### METHOD

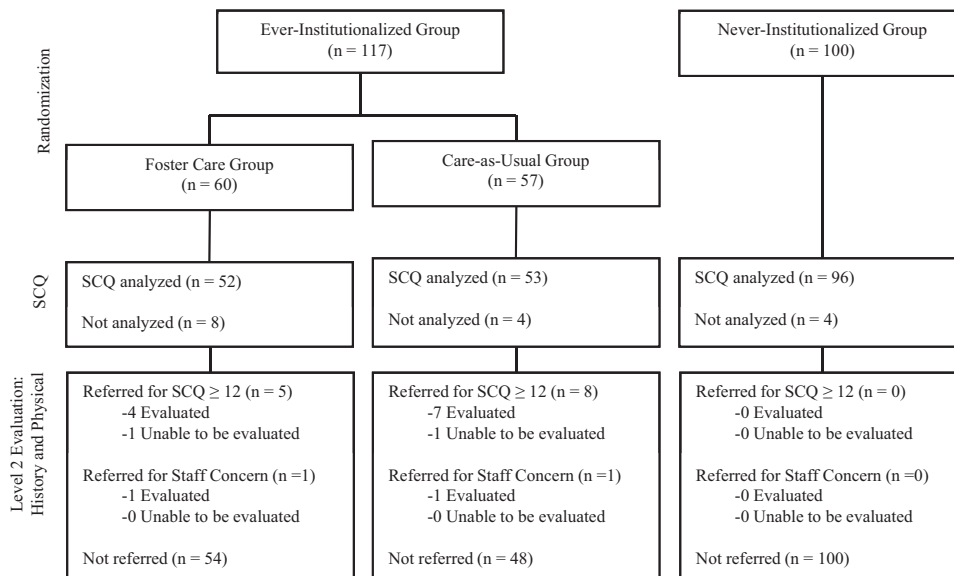
Complete historical background, design, and ethical considerations of the BEIP have been previously described in detail.<sup>25-27</sup> During the initial stages of the project, 187 children living in institutions in Bucharest, Romania were initially evaluated by physical examination; those with obvious genetic syndromes, fetal alcohol syndrome, or microcephaly were excluded from the study. The remaining 136 children constituted the ever-institutionalized group (EIG). Half of these children were randomly assigned to continued care-as-usual in the institution group (CAUG), and the other half were randomized to a foster care group (FCG). Age at foster care placement in the FCG ranged from 7 to 33 months (mean = 22.6 months). Foster care was designed to replicate the home experience and caregiving

quality that a never-institutionalized child received.<sup>27</sup> A never-institutionalized community comparison group (NIG) was matched to the other groups by child age and gender.<sup>25</sup>

Institutional review boards at Boston Children's Hospital, the University of Maryland, and Tulane University, as well as the Institute for Maternal and Child Health and the local Commissions for Child Protection in Romania approved the study protocols. Informed consent was obtained from children's legal guardians, comprising biological parents, the local commissions for child protection, sector mayors, or adoptive parents. BEIP had a policy of noninterference, which meant that after randomization, child protection authorities could make decisions to alter placement; the most common result of this policy was that children in the CAUG were moved to family-centered care later in the study.<sup>28</sup> All initial analyses in the current article follow an intent-to-treat model, with children considered within their original assigned group. We performed follow-up analyses based on each child's living situation, number of transitions between placements, and percentage of life spent in an institution at the time of SCQ administration.

The Social Communication Questionnaire (SCQ) is a validated, parent-report screening measure that assesses for symptomatology associated with ASD.<sup>29</sup> When each child was approximately 10 years of age (mean = 10 years, range = 8–11 years), the caregiver who knew the child best (biological parent, foster parent, adoptive parent, or institutional caregiver) filled out the lifetime SCQ, which had been translated into Romanian and back-translated into English. With the SCQ, higher scores indicate more concerning behaviors, and a cutoff score of  $\geq 15$  is generally recommended as an indication of possible ASD. The manual also recommends using a slightly lower threshold in populations with other risk features. In this study, any child with an SCQ score  $\geq 12$  underwent a second level of evaluation. In addition, BEIP psychologists who were familiar with the children in the study referred 2 children for whom they had clinical concern about possible ASD. The numbers of children from each group evaluated by the SCQ, referred because of clinical concern, and clinically evaluated for ASD, are presented in Figure 1.<sup>30</sup>

**FIGURE 1** Research and control participants evaluated at 8 years of age. Note: Children are shown undergoing Social Communication Questionnaire (SCQ) and subsequent autism spectrum disorder evaluation, by group. Only those children still participating in the study at age 8 years are included here; the reasons for which some children discontinued participation are described elsewhere.<sup>30</sup>



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