INSTITUTIONAL AUTISM IN CHILDREN ADOPTED INTERNATIONALLY: MYTH OR REALITY?

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Institutional autism *is understood as a* learned behavior *produced by an institutional environment such as an orphanage. Some autistic-like behaviors may be adaptive in an institution, but become mal-adaptive after the child's adoption into a family. A differential diagnosis between autism as a medical condition and learned autistic-like post-institutional behaviors is to be made. A conclusion is drawn that* institutional autism *is merely a description of certain patterns of post-institutionalized behavior that may appear similar to what is observed in children with autism. Abrupt native language attrition, typical for the majority of international adoptees, could contribute to* autistic-like *behavior.*

The term *institutional autism* has emerged with the influx of children born overseas, raised in orphanages, and adopted by American families within the last 20 years. Several terms have been used interchangeably: *institutionally induced autism* (Federici, 1998), *quasi-autism* (Rutter, 1999, 2001, 2007), *acquired institutional autism* (Miller, 2004), *post-institutional autistic syndrome* (Hoksbergen, 2005), etc. The common meaning behind all these modifiers of the term autism is that children may acquire autistic symptoms due to their early life in orphanages, hospitals, and other similar institutions.

For the sake of clarity, only one term is used in this article, namely *institutional autism.* It must be stressed that *institutional autism* has nothing in common with the phenomenon of *acquired* or *regressive* autism, a concept that is currently debated in the medical community (see Vaccines and Autism, 2004, Immunization Safety Review Committee, Washington DC). *Acquired or regressive autism* is a condition in which children develop normally for the first 12 to 18 months of life and then regress into an increasingly wide spectrum of autistic disorders due to damage done to their immune system, whether by virus, genetic disposition, intrauterine, prenatal, or neonatal stress, or other traumata (Baskin, 2004, Presentation to the Immunization Safety Review Committee, Washington, DC).

Historically, the notion of *institutional autism* can be traced to an article by British/American psychiatrist Rene Spitz (1945). Spitz described several patterns of behavior he observed in young children who had been placed in the London Children's Hospital after their parents perished during the Nazi bombardment of London in 1940-1942. In reaction to emotional traumata, loss of primary caregiver, isolation in hospital cribs, and lack of stimulation, these children developed symptoms that were at least similar to those often found in children with autism. The notion of *hospitalism* was not used much over the next 40 years, until the massive adoption from Romanian orphanages by American, Canadian, and British families began in the late 1980s and early 1990s. Almost simultaneously researchers in Canada, the US, and Western Europe began using the notion of *institutional autism* in describing young children adopted from Romanian orphanages.

Following in the footsteps of Spitz, the researchers depicted autistic-like behavior in children, seen as a result of the ultimate deprivation and isolation associated with living in an institution. In essence, these authors conveyed that orphans learned autistic patterns of behavior due to their experiences in orphanages: such self-stimulating behavior as rocking, picking at themselves, head banging, withdrawal, limited verbal expression, rituals, and emotional outbursts in response to changes in routine were the ways in which institutionalized children learned to fill the gaps in their lonely and desperate lives. Thus, according to

Federici, *Over time they practiced these behaviors as a defense mechanism to block out pain and misery and had ultimately become self-absorbed and withdrawn in a way similar to children with autistic conditions* (Federici, 1998, p.74).

The prevalence of autism and other developmental disabilities in internationally adopted children is unknown at the moment, although there is a widespread belief that orphanage residents are more prone to developmental disabilities than their peers at large (Miller, 2004; Welsh, Andres, Viana, Petrill, Mathias, 2007). It is understood that in addition to general risk factors that predispose institutionalized children to any developmental disability (heredity and the neurological make-up of the child) there are secondary factors, social in nature (such as the lack of post-natal care and negative conditions of development in institutions), that facilitate the formation of developmental delays and disabilities in this population. The proportion of *organic* (genuine, biologically-based) autism and institutionally-induced autistic-like behavior in institutional residents is also unknown. The only statistical research data at this point are provided by Rutter and his colleagues in their publications dated 1999, 2001, 2007 and Hoksbergen, Laak, Rijk, Dijkum, & Stoutjesdijk (2005), based on relatively small samples.

Rutter (2001) and his colleagues examined 165 children adopted from Romania before the age of 4. The children were examined at 4 years and 6 years, and compared with 52 children of the same age and gender adopted in infancy in the United Kingdom. The researchers found 12% of Romanian adoptees had *quasi-autistic features* (versus none in the UK sample) that included rocking, self-injury, unusual and exaggerated sensory responses, and problems chewing and swallowing. (The study was mostly based on adoptive parents' interviews. The Autism Screening Questionnaire was completed by all participants and the Autism Diagnostic Interview – Revised was administered to those parents who reported autistic symptoms.) The investigators found that, with the exception of unusual sensory responses, the rate of autistic-like behaviors in most cases steadily declined after the child entered the adoptive family. In a number of cases, however, the difficulties remained, despite good-quality care in the new home.

In the most recent study (Rutter, 2007), in which the sample consisted of 144 children adopted from Romania by UK families, Rutter and his colleagues assessed twenty-eight children for whom the possibility of autistic behavior had been raised, using the Autism Diagnostic Interview-Revised (ADI-R) and the Autism Diagnostic Observation Schedule (ADOS). All the examinees joined their adoptive families before the age of 4 and were examined every two years, the last time at the age of 12. It was found that sixteen children had clearly shown autistic symptoms, a rate of 9.2% in the Romanian institution-reared adoptees as compared with 0% in the domestic adoptees. There were, in addition, 12 children with some autistic-like features, but for whom the *quasi-autism* designation was not confirmed. The longitudinal study of this sample (started at the age of 4) indicated that a quarter of the children who had previously shown autistic-like features were free of these symptoms at the age of 12. The article concluded that initially the quasi-autistic patterns were found in over 10 percent of the sample but the significance of these features was diminished with years of living in adoptive families. The authors stressed that *…although there were important similarities with 'ordinary' autism, the dissimilarities suggest a different meaning* (p. 1200). Unfortunately, no further analysis was provided and the reader remains with the impression that while some children in the studied group show definite signs of autism, others have something else of an unknown nature that may resemble autism.

Hoksbergen (2005) and his group basically repeated the research design of Rutter's 1999 and 2001 studies and applied it to 80 Romanian children adopted by families in The Netherlands. (Adoptive parents were interviewed using Autism Diagnostic Interview – Revised.) In about 1/3 of the group the parents reported (in retrospect, because the children had already lived in the families for four to five years at the time of the interview – BG) stereotypic behaviors and communication and language disorders. Six out of 80 were diagnosed with full-fledged autism, while seven showed some autistic behaviors (in a relatively mild degree) even five years after adoption. As in Rutter's study, there was no statistical difference between the genders (in organic-based autism males have a higher incidence – BG). Like Rutter, Hoksbergen found that those who had been in their adoptive families for five years or longer showed fewer autistic-like behavior problems than children who had been in their adoptive families less than five years.

One may conclude from the Rutter, *et al.* and Hoksbergen, *et al.* studies described above that:

1. On arrival, a significant number (from 10% to 30% in their samples) of former orphanage residents present patterns of behavior similar to those observed in children diagnosed with different degrees of autism. These patterns include:
    (a) Self-stimulating behaviors (rocking, head banging, shaking of hands, face shielding, etc.).

(b) Self-mutilating behaviors such as hair pulling and picking at the body.
(c) Abnormal responses to sensory stimulation (e.g.: seeking unusual tactile sensations, attraction to bright visual stimulation).
(d) Temper tantrums in response to change in routine and seemingly unmotivated uncontrollable outbursts of rage and aggression.
(e) Some behaviors that are normally not associated with autism (e.g.: problems chewing and swallowing).

2. In contrast to organic-based autism, in which boys are more affected, the listed behaviors were equally present in both genders.
3. These patterns are mostly evident on arrival and in the majority of symptoms diminish in intensity and usually disappear along with the children's time in their families.
4. A substantial minority of children continue to exhibit these difficult behavior patterns for many years. Thus, in Hoksbergen's study 7.5% of the children in his sample were diagnosed with autism. (The usual prevalence in the population at large is less than 1%, according to DSM-lV-TR.)

Based on a review of the short list of existing publications on *institutional autism*, a question can be raised: Does this notion indeed reflect clinical reality? In the samples studied by Rutter and Hoksbergen there were two categories of children: those who had genuine autism and those who demonstrated a rather heterogeneous cluster of behaviors, with some patterns similar to those observed in truly autistic children. Both the nature and the psychological mechanism of these *autistic-like* behaviors remain unexplained. In addition, none of the reviewed publications discussed a crucial element in producing autistic-like behavior, namely, abrupt native language attrition (Gindis, 1999, 2005). Indeed, what is common to practically all international adoptees is the process of speedy native language loss and the relatively slow process of new language learning, which may heavily contribute to autistic-like behavior during the initial adjustment period when *institutional autism* is mostly observed.

A clinical study focusing on differential diagnosis of autism in international adoptees was completed at the Center of Cognitive-Developmental Assessment and Remediation, located in Nanuet, NY (www.bgcenter.com). This is a private clinic specializing in the assessment and remediation of internationally adopted post-institutionalized children. In our clinical database we have the results of 389 cases of *screening-on-arrival*. These evaluations were performed within the first 2 to 10 weeks of the children's arrivals in the USA. All assessments were done in the children's native language (the children were adopted mostly from the countries of Eastern Europe, republics of the former Soviet Union, and China). The age range of cases in our sample was from 3 years 6 months to 9 years 6 months. The purpose of the screening-on-arrival was to check for possible mental health issues, to facilitate appropriate school placement, and to determine the need for mental health or school-based remedial services. Screening consisted of cognitive, language, adaptive behavior, and academic readiness components. A thorough parent interview included inventory of autistic behavior in their children - *Children Autism Rating Scale* (CARS). The screening was done during the acute phase of initial adjustment of a child to the family and new social/cultural environment. Indeed, many parents reported behaviors (see below) that were similar to those listed in Rutter's publications. These patterns of behavior, varying in intensity, were often transitory, but in some cases the children persisted in displaying typical orphanage survival skills that resembled autistic symptoms. In fact, these were patterns of institutional behavior.

Institutional behavior – what is it?

Learned orphanage behavior is a set of survival skills that are functional and adaptive in the specific milieu of an orphanage. Through direct observation and clinical interviews with almost four hundred adoptive families during *screening-on-arrival* procedures in our clinic, the following major clusters of institutional behavior were detected in international adoptees in the age group of 3 years 6 months to 9 years 6 months:

1. *Self-soothing behavior:* withdrawal (aloofness) with finger sucking or clothes sucking, hair twisting, full-body spinning and rocking, head spinning and banging, covering ears to block out even ordinary sounds.

2. *Self-stimulating behavior:* excessive reaction to even ordinary stimuli, extreme restlessness, obsessive touching of self and objects, unusual reaction to some sensory stimuli (taste, smell, touch), making weird and animal-like sounds.

3. *Self-defending behavior:* active resistance to any changes in routine and environment, hyper-vigilance to physical gestures and tone of voice, *proactive* aggressiveness, extreme fear or its opposite - extreme fearlessness, lying, stealing, hoarding (food or objects).

4. *Attention seeking and over-friendliness with strangers:* for many months after arrival, former orphanage residents continue to pursue adults' attention, negative or positive (any adult, not only their parents). A variation of this extreme attention seeking is *learned helplessness*: children in orphanages had been conditioned to get more attention from caregivers when they seemed helpless.

5. *Controlling or avoiding behavior* resulting in abrupt refusal/noncompliance with family and school rules and routines.

6. *Immature self-regulation of behavior* and emotions resulting in impulsivity, difficulty following rule-governed behavior, emotional volatility, difficulty with delaying gratification.

The above behaviors are typically presented in a wide range of intensity. Also, quite opposite characteristics could be found in the same child. There is no gender difference in these behaviors, except withdrawal being more typical for girls and aggressiveness being more typical for boys. Some of these behaviors are similar to those observed in a range of psychiatric conditions, such as ADHD, PTSD, and RAD. It is important to note that the first three (most autistic-like) patterns of institutional behavior are more typical for a younger cohort (3 to 5 years old) and are much less often found in children older than 5.

As reported by our respondents, typically the dynamic of observed autistic-like behaviors goes from a rather intense degree on arrival to a relatively rapid loss of intensity and at least partial disappearance within several weeks and months after entering the family.

One common denominator for all these behaviors among international adoptees is rapid native language attrition. It significantly limits verbal communication during the first several weeks of the child's life in the family, when institutional behavior is at its peak. A lack of or severe limitation in verbal communication typically leads to significant regression in the child's behavior and the emergence of the immature self-stimulating conduct described previously (for more discussion please refer to Gindis, 2004). To the best of this writer's knowledge, no research has been done on the links between the transient autistic symptoms and the language transition experienced by international adoptees within the first several months in an adoptive family. So far this is a hypothesis that has been evoked by often empirical observations. It is supported, although indirectly, by the finding that children who are adopted within their native countries (that is, do not experience language disruption) have fewer autistic symptoms than international adoptees (Groark, C, Muhamedrahimov, R., Palmov, O., Nikiforova, N., McCall, R. (2005).

Differential diagnosis

To make a differential diagnosis between autism, institutional behavior, and temporary patterns of behavior related to the adjustment period and abrupt language attrition is one of the most daunting tasks in the field of mental health and rehabilitation. Experience with internationally adopted children is an essential qualification for involved mental health professionals. In addition to testing, the correct diagnosis requires skillful observation, a thorough parent interview, and study of the child's adoption documentation. A careful review of the developmental history after adoption is crucial because such features of institutional behavior as repetitive self-stimulating and self-soothing behaviors, as well as a lack of appropriate spontaneous social interactions, do show dramatic improvement with time, in contrast to symptoms associated with the autistic spectrum disorders.

Another problem with differential diagnosis is that temporary autistic-like behaviors, caused by institutionalization and/or by an abrupt language loss at adoption, may go hand-in-hand with a wide variety of different psychiatric disorders, such as RAD, PTSD, childhood depression, etc. In addition, verbal communication deficiency during the initial adjustment period, followed by abrupt first

language attrition, provokes patterns of behavior that fit a description of genuine autism very well, including withdrawal, angry outbursts related to an inability to communicate effectively, and self-soothing and self-stimulating behaviors. In many ways these *abnormal* behaviors are a typical human reaction to a new and unmanageable situation. It is known that typically developing children may demonstrate some autistic-like behaviors either as passing patterns of normal development (Leekam, 2007) or as a temporary trauma-induced pattern (Gomberoff, 2000).

The factors facilitating a differential diagnosis, are the dynamic and severity of each symptom. A major distinguisher between organic-based autism and temporary autistic-like institutional behavior is the presence of positive dynamic in the child's development in the family. While most behaviors originating in organic-based autism persist, showing only small and slow, if any, changes, the same identifiable behaviors associated with institutional behavior and loss of language should diminish progressively until they completely disappear, although they may re-surface in response to stress and environmental challenges. The timetable depends on a child's age and a host of individual differences, but if after two to six months in the family autistic-like behavior patterns do not diminish in intensity, it is likely that we are dealing with organic-based autism or another variation of developmental disability. In children younger than 5, during the first several weeks in a family some withdrawal, lack of interactive communication, poor eye contact, and self-stimulating behavior is a relatively common occurrence and should be considered normal and expected for the adjustment period.

Another distinguisher is the severity of a problem within a constellation of symptoms. In organic-based autism the symptoms are usually more clearly defined and presented in well-known clusters described in the professional literature. Institutional behavior reflects only separate patterns of autistic behavior that are not consistent and can often be explained by environmental circumstances.

Based on the information presented, it is likely that in the samples studied by Rutter and by Hoksbergen both groups (children with organic-based autism and learned orphanage behavior) were present. Those children whose behavior improved with the time spent in the family demonstrated temporary orphanage behavior patterns whereas those with stubborn autistic symptoms most likely had organic-based autism. Some children may present an undifferentiated cluster of symtoms and so qualify for the designation of PDD-NOS.

Practical implications

A differential diagnosis between institutional behavior and autism has significant practical implications. The term *institutional autism* (and its synonyms), which has gained some popularity, has led to confusion among professionals, false hope among adoptive parents, and ill-suited remedial efforts from educational and rehabilitative facilities.

The notion of *institutional autism* is confusing for personnel involved in remedial work with post-institutionalized children because if a child has autism, a range of proper educational (remedial methodology) and administrative (placement and services) actions should take place. If a child demonstrates institutional behavior, a completely different set of actions should take place. The notion of *institutional autism* gives false hope to adoptive parents, leading them to believe that their children will *outgrow* the condition known as autism: it diverts their efforts and de-mobilizes them in their search for an appropriate remedial program for their children.

In contrast to autism, institutional behavior is to be recognized as learned maladaptive behavior and addressed with behavior modification methodologies commonly used for non-autistic children. One time-tested recommendation is that children with institutional behavior should not be placed in the same programs as children with organic-based autistic in order to prevent their mimicking and reinforcing inappropriate behaviors. Parental consultation and counseling, modification of parenting techniques, changing parental expectations and attitudes, using short-term behavior programs and addressing specific behavior have proven to be effective in addressing issues of institutional behavior.

Summary

We must clearly differentiate between *autism* (an organically-based and behaviorally-defined developmental disability with a range of conditions and degrees) and *institutional behavior* (as learned in orphanages, adaptive/survival skills that are temporarily reinforced by an abrupt loss of language and an acute adjustment period to a new social/cultural environment and new family). The former is a medical condition depicted in the current DSM-lV-TR (2005, pp. 70 – 75); the latter is the product of

specific social conditions. Although the notion of *institutional behavior* as related to post-institutionalized children is much more diverse than a behavior pattern associated with autism, certain autistic-like manners/actions are a part (albeit temporarily) of *institutional behavior* (Gunnar, M., & VanDulmen, M. (2007). Both may have similar overt behavior patterns, and both may be present in internationally adopted children, but these conditions require entirely different remedial approaches.

Now that the biological nature of autism is well documented (Trottier, Srivastava, Walker, 1999; Freitag, 2007), suggesting that social factors (e.g.: *deep institutional privation* Rutter, 1999) without known neurological aberration (or other biological and genetic causes) can result in autism (even with modifiers such as *institutional*) seems a relic of psychogenic theories of the causes and origins of autism. It is a scientific fact that no known psychological factors in a child's development have been shown to cause autism, and autism spectrum disorders are certainly not caused by bad parenting or rearing in an institution. *Institutional autism* is merely a confusing metaphor; instead of using this misleading term, a differential diagnosis is the first step in crafting a solution.

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