Post-Institutional Autistic Syndrome in Romanian Adoptees

René Hoksbergen, 1,3 Jan ter Laak, Kathinka Rijk, Cor van Dijkum, and Felicia Stoutjesdijk

Romanian adoptees have a background of severe neglect. International research has shown that this can give rise to symptoms of autistic behavior. Rutter *et al.* (1999, *Journal of Child Psychology Psychiatry*, 40(4), 537–549.) refers to "quasi-autistic patterns", and Federici (1998, *Help for the hopelss child: A guide for families*. Alexandria: Federici & Assocoates.) to Post-Institutional Autistic Syndrome (PIAS). Eighty Romanian adoptees, averaging 8 years of age, who had resided in the Netherlands for 5 years were studied. Parent interviews and the Auti-R scale showed the extent to which the children exhibited PIAS. In one third of these children we observed (in addition to other behavioral problems) stereotypic behaviors and communication and language disorders. Our findings resembled the Rutter *et al.* (1999, *Journal of Child Psychology Psychiatry*, 40(4), 537–549). data. Six of the children were classified within the autistic spectrum pursuant to the Auti-R, and seven within the so-called intermediate group. No difference was found between the girls and the boys. Children who had been in their adoptive families for 5 years or more showed fewer behavior problems than children who had been in their adoptive families for four or less years.

tions:

KEY WORDS: Autism; Adoption; Romania; institutionalized; research.

INTRODUCTION

Early Child Deprivation and Post-Institutional Autistic Syndrome

During the first interview with adoptive parents of a Romanian child, in 1998 and 1999, we were confronted with behavioral problems that resemble those of autism (Hoksbergen and the co-workers of the Romania-project, 1999). The so-called "Wing Triad" (Cohen & Volkmar, 1997) guided the diagnosis of autism. Autism contains disorders or major delays in:

interests, imagination, and fantasy play.

In this second part of the study, we intend to investigate the hypothesis that a substantial part of

(a) the development of reciprocal social rela-

(b) verbal and non-verbal communication; and

(c) activities, such as recurrent behavior, strange

In this second part of the study, we intend to investigate the hypothesis that a substantial part of the group of Romanian adoptees show symptoms of a pervasive development disorder (PDD) like autism. This disorder is mainly genetically based. In our group, however, symptoms are caused by environmental factors, including neglect and abuse in a children's home.

Dahl, Cohen and Provence (1986) and Wing and Gould (1979) established for example that autism involved a developmental disorder originating in the child itself. In the classic form, the disorder was estimated to occur in four to six children per 10,000, and in some 20–30 children per 10,000 if the related disturbances are included (Buitelaar, & Willemsen-Swinkels, 2000; Van Berckelaer-Onnes & Van der

¹ Faculty Social Sciences, Adoption Department, Utrecht University, Utrecht, The Netherlands.

² Romanian Children's Home Trandafir din Saron, Utrecht, The Netherlands.

³ Correspondence should be addressed to: Department of Adoption and Non-genetic Parenthood, University of Utrecht, Heidelberglaan 2, 3584 CS, Utrecht, The Netherlands; e-mail: R.Hoksbergen@fss.uu.nl

Gaag, 1999; Wing, 2000). The prevalence of autistic spectrum disturbances is four times higher among boys than among girls. Over three-quarters of the population with autism are also mentally retarded. Furthermore, the disorder may occur with other disorders such as Attention Deficit Hyperactivity Disorder (ADHD), tics and depression (Van Berckelaer-Onnes & Van der Gaag, 1999; Eisenmajer et al., 1996).

As the symptoms of autism were analyzed more, sub-classifications in the spectrum of autism were added. Environmental factors were found to play a major role in the development of behavioral disorders similar to autism. Fraiberg (1977) found that blind children showed some similarity to autistic children. He wondered whether the symptoms he called "autistiform syndrome" were caused by brain damage, or by the severe sensory deprivation, experienced by these blind children (Ladee-Levy, 1990). The connection between the occurrence of autistic behavior and severe neglect was established by Wing (2000, p. 72). She pointed out "what is decisive to the diagnosis is whether any improvement may be observed if better care and a more colorful existence is offered". She did not conceptualize any special classification in the autistic spectrum. Federici (1998) and Rutter et al. (1999) did so using data from research and clinical experience with children adopted from Eastern European countries. Both pointed to the severe psychosocial disturbances of long-term institutionalization. Federici referred to the "post-institutionalized child" who has a significant chance of exhibiting a "Post-Institutional Autistic Syndrome". Federici (1998, p. 73) speaks of 'learning to become autistic as a direct result of being institutionalized', and he reports seven specific criteria of the 'unique and institutionally specific pattern of behaviors which constitute Institutional Autism':

- Actual loss of physical height, weight and growth.
- 2. Does not look to be anywhere near actual age.
- 3. Loss of previously acquired language, or the use of language, which is extremely regressive to the point that it resembles "infant babbling".
- 4. Primitive acting-out behavior.
- Brain syndrome involving language deficits, attention and concentration problems, bizarre behaviors and deficient memory and learning.

- 6. Complete regression to self-stimulating behaviors, such as rocking, head banging, hair pulling etc.
- 7. If left to continually practice these self-stimulating behaviors, the child will develop a repetitive pattern of newly learned movements, mannerisms and speech (Federici, 1998, pp. 73–74).

Rutter et al. (1999), and Kreppner, O'Connor, Rutter, and The English and Romanian Adoptees Study Team (2001) refer to the entirety of the observed behavioral disturbances as "Quasi-autistic patterns". They found that a large number of the Romanian adopted children, relative to the control group consisting of within-UK adoptees, showed a pervasive dysfunctional pattern at the age of six, almost always involving some mixture of attention/hyperactivity (25%) and quasi-autistic problems (12%). Rutter et al. (1999, p. 546) concluded that 'the quasi-autistic pattern seemed to be associated with prolonged perceptual and experiential deprivation, lacking the opportunity to develop attachment relationships, and with cognitive impairment.'

If one examines the concepts Post-Institutional Autistic Syndrome, Quasi-autistic patterns and Autistiform syndrome, it is apparent that they all refer to the same phenomenon. We employ the first term, because the term 'post-institutionalized' is precisely applicable. The Post-Institutional Autistic Syndrome (PIAS) refers to all symptoms of autistic behavior. Each category in the Wing Triad has to be observed for at least 3 months. Per category, various symptoms have to be present, which, contrasting to classical cases of autism, have no neurological basis. Environmental factors, such as having resided in an orphanage and/or having had extremely neglectful parents/caregivers are primarily the cause of the behavior. Improvement of the child's environmental circumstances leads to an improvement in his behavior, and some of the symptoms may disappear.

Both Federici (1998) and Rutter *et al.* (1999) stated that little is known about the long-term consequences of severe early childhood deprivation. Studies of children who had resided in an orphanage for an extended period primarily focused on the negative consequences of such experiences for the child's emotional development, social behavior, and the lack of normal relationships with parents and peers (Bowlby, 1946; Rutter, 1979; Spitz, 1945).

Federici and Rutter studied children adopted from abroad in order to analyze effects of early childhood neglect. Many of these children have a background of neglect and/or abuse. The medical and behavioral problems complicating the rearing of children adopted from foreign countries have been the subject of much research. (Hoksbergen & Walenkamp, 1983; 1991; 2000; Sorgedrager, 1988; Verhulst, Althaus, & Versluis-den Bieman, 1992). In addition, specific behavioral consequences have been studied, such as Reactive Attachment Disorder (Hoksbergen, 1998; O'Connor, Rutter, & The English and Romanian Adoptees Study Team, 1999); Post Traumatic Stress Disorder (Hoksbergen, 1996, 2001; Hoksbergen *et al.*, 2003; Verrier, 1993) and Attention Deficit Hyperactivity Disorder (Hoksbergen, 1999).

The renewed interest in the consequences of severe early childhood deprivation evolved out of recent experiences with Romanian and Russian adoptees (Ames, 1990; Federici, 1998; Hoksbergen, 1999; Human Rights Watch, 1998). Emphasis was on medical problems (Jenista, 1992; Johnson et al., 1992), but also on behavioral disorders, such as indiscriminate friendliness to strangers, absence of attachment, and emotional disorders (Ames, Fraser, & Buraby, 1997; Johnson, 1999). Symptoms of autistic behavior were not reported by the adoption agency, despite the fact that interviews with the parents, and findings from the Child Behavior Check List (Achenbach & Edelbrock, 1983) indicate that these children in fact did exhibit autistic behavior (Rutter et al., 1999).

An example is the story of Hester.

Hester, a 21/2 year-old child adopted from Romania one year before our study, is one example¹. She was in poor health upon arrival in her adoptive family. She had severe sleeping problems, exhibited stereotypic and imitative behavior, did not make eye contact, and was apathetic and withdrawn. The child exhibited a variety of fears. According to her parents her language development, and her ability to relate to her peers and her motor and emotional development were significantly delayed. She was indiscriminately friendly with strangers. Her parents had sought contact with the Association for Autism. When we approached her parents for the second time, approximately 1½ year after the first visit, the child showed some improvement. Other problems had, however, emerged more clearly, such as aggressive, irritable, hysterical behavior and extreme stubbornness.

MAIN QUESTIONS

Our first interview showed that many parents were wrestling with their child's severe behavioral problems

and language problems. We were confronted with behavioral problems that resemble disorders in the autistic spectrum. In the second interview we focused on PIAS. We investigated how many children were perceived to have this problem, and whether there were improvements in their behavior. We compared our results with those of Rutter *et al.* (1999), who conducted research among Romanian children adopted in England prior to the age of 42 months. His group consisted of 111 children, studied at 4, and 6 years of age; 6% exhibited PIAS behavior and 6% showed milder, and in some cases only one or a few, symptoms of this behavioral disorder.

METHOD

Our Sample

The population of adopted children from Romania who came to the Netherlands from 1990 until the first quarter of 1997 was invited in 1998 to take part in the study. A group of 74 families with 83 Romanian adopted children (response 86%) was extensively interviewed. In the first half of 2000, this study was repeated and expanded. Seventy-four and 72 of the former 74 parent-couples (response 83%, 80 adopted children)² were interviewed again. This involved eighty children, who resided in an orphanage virtually from their birth and who were, on average, age 2 years and 10 months upon arrival in their adoptive family, (range: 1 month-6.7 years). The group consists of 44 (55%) boys and 36 (45%) girls. In addition to the extensive interview, standard instruments were administered during the second part of the Romanian study. The extent to which the Romanian children exhibited PIAS was determined with the Auti-R and a general questionnaire.

The co-operation of the parents during the study was excellent.

Instruments

Firstly, a semi-structured questionnaire was filled out. This questionnaire was developed by the first author and contained questions about the demographic situation, the child, the adoptive family, medical problems, psychosocial problems, the development of the child, the use of professional care and (special) education. The duration of the interview was approximately 45 minutes.

Secondly, the Auti-R scale (Van Berckelaer-Onnes & Hoekman, 1991) was employed to determine the presence of autistic behavior. According to the COTAN (Commissie Test Aangelegenheden Nederland: the Dutch Test Evaluation Authority), this questionnaire met criteria of reliability and validity. The parents were requested to complete the Auti-R after having received written instructions. Approximately 40 minutes are required to complete the questionnaire, which consists of 51 questions with six possible replies, ranging from "no, never; only once or twice; sometimes; regularly; often; to very frequently³. The items cover seven areas:

- 1. Relationship disturbance: 12 questions (for example: Does the child seek eye contact? Does the child differentiate between individual people?).
- 2. Language disturbance: 15 questions (Does the child speak? Does the child always talk about the same subject?).
- 3. Striking motor phenomena: 5 questions (Does the child continuously seek to discuss any given object? Does the child imitate other's movements?).
- 4. Striking sensory phenomena: 9 questions (Is the child fascinated by certain noises? Does the child have a high pain threshold?).
- 5. Resistance to change: 6 questions (Does the child become upset in the face of changes in its environment? Does the child want all sorts of things to exhibit a given pattern, to occur in a fixed sequence?).
- 6. Acute, illogical fears: 2 questions (Does the child exhibit sudden, entirely incomprehensible fears or panic reactions).
- 7. And two other questions (Does the child have any understanding of danger? Does the child use toys as they are intended to be used?). The children were classified in the non-autistic and the autistic group, but for a proper diagnosis further study and observations are required.

The Auti-R is similar to the instrument used by Rutter *et al.* (1999). They used the Autism Screening Questionnaire (ASQ) with 40 questions about social relationships, unusual forms of communication, and stereotypic behavior. This test has no Dutch equivalent. Both tests contain all three of Wing's components of autism.

Procedure

In 1998, the parents were extensively interviewed. Using a semi-structured questionnaire, data

about the family situation was collected during two interviews.

During interview 1, data were collected concerning two periods:

Time 1: at the time of arrival in the adoptive family (the average age of the children then was 2.9 years);

Time 2: at the time of the first interview (average age of the adoptive children was 6.8 years). At the time of interview 1, the children had been in the family, on average, 4 years;

Interview 2 (time 3) took place one and a half years later. At this time the children were on average 8 years old and on average over 5 years in the family. In addition to the second interview, standard instruments were administered.

The interviewers were adoption specialists and psychologists (Ph.D. and Masters).

RESULTS

Characteristics of Children

According to the parents, the health at time of arrival is 'bad' for 18 (22%) children, 'mediocre' for 23 (29%) children, and 'good' for 39 (49%) children. Twenty-five children (31%) receive special education. Professional care has been used by 51 (64%) children.

Results of the Auti-R

We asked the parents of all 80 children to complete the Auti-R. However, after having read the instructions, the parents of 33 children stated that the questions asked in the Auti-R did not apply at all to their child. The parents of 47 children completed the Auti-R. The internal consistency is good (Cronbach's $\alpha = .95$).

Thirteen of the 80 children (16%) scored within the autistic range, hence, exhibiting symptoms of PIAS, hereafter referred to as the PIAS-group.

The group consisted of eight boys and five girls, implying that there is no gender-related difference. Of the 13 children, 9 (70%) were in mediocre or poor health upon arrival. Of the remaining 67 Romanian children, 48% were in mediocre or poor health.

Table I contains the average scores per area of the Auti-R. In order to compare our results with Rutter's (1999) we studied the results of the PIASgroup in the various areas. A representative sample of 14 of the remaining 34 children that did not score in the autistic range was used as comparison group. The

Table I. Average Scores of the PIAS-group (13) and "Other" (14), per Auti-R Area

Auti-R area	PIAS-group (13)	Others (14)
Relationship disorder	2.8	1.9
Language disorder	2.8	1.7
Striking motor	3.3	1.7
phenomenon		
Striking sensory	3.1	1.3
phenomenon		
Resistance to change	3.2	1.2
Extreme, seemingly	2.4	1.2
illogical fears		
Other questions (positively		
formulated):		
Uses toys in the intended	3.7	5.4
manner		
Exhibits an understanding of	3.6	4.8
danger		

number of children who scored "never" "only once or twice", "sometimes", "regularly", "often" and "very frequently" (scores from 1 to 6) was ascertained for each of the two groups in each of the seven categories of concern (see Table I).

Table shows that the PIAS-group differs significantly in all areas from the group "Other children" (Mann–Whitney U: p < 0.05). In the three categories of Wing, the parents filled out answers ranging from "sometimes" to "regularly". The two groups scored the lowest on "extreme, seemingly illogical fears". The scores of the "Other children" indicated fewer areas of concern.

Results of the Two Interviews

We also tried to get some insight into behavioral and maturation disorders, resembling autistic symptoms, with two interviews with an interval of $1\frac{1}{2}$ years.

In Table II, the 13 children of the PIAS-group are compared to the 67 other children on behavioral disorders observed by the parents.

- 1. Autistic symptoms like Rocking and Language disorders were perceived in 60% of the total group at arrival.
- 2. Testing for ANOVA curvilinear, resulted in a significant downward trend (p < .10) in items A (< .007), B (0,017), C (< .001), D (< .052), E (< .07), F (.000) and I (< .000). These results indicated a decrease in behavioral disorders in the whole group.
- 3. The PIAS-group scores higher than the Others on all items with the exception of the items A and F. This could be due to the small size of the groups (Mann–Whitney U, Wilcoxon, p < .10).
- 4. The PIAS-group showed, testing with ANO-VA, a significant downward trend in items A (<.04) and C (<.047). The level of improvement between time 1 and time 3 of the PIAS-group is less than of the Others. Those children who still exhibited the behavioral problem at time 2 had been, on average, in their adoptive family just as long as the other children. Rocking and language disorders had become less extreme, but occurred in both groups with the highest frequency at time 2.

PIAS and Cognitive Development

Dutch rules for admission of foreign adoptees force a selection among the children admitted. This is

Table II Behavioral Disorders, PIAS-group (13) Compared to All Other Romanian Children (67), Upon Time 1, 2 and 3, Frequencies and Percentages

	PIAS $(n=13)$		Others (<i>n</i> = 67)			
	Time 1 N (%)	Time 2	Time 3 N (%)	Time 1 N (%)	Time 2	Time 3 N (%)
A. Indifference to the father	7 (54%)	5	3 (23%)	15 (22%)	6	5 (8%)
B. Indifference to the mother	5 (39%)	3	2 (15%)	7 (10%)	1	2 (3%)
C. Apathetic behavior	6 (46%)	3	4 (31%)	8 (12%)	1	1 (2%)
D. Avoidance of contact	7 (54%)	5	4 (31%)	6 (9%)	2	2 (3%)
E. Very withdrawn behavior	5 (39%)	4	4 (31%)	7 (10%)	4	4 (6%)
F. Rocking	11 (85%)	8	6 (46%)	39 (58%)	21	18 (27%)
G. Tics	2 (15%)	3	4 (31%)	1 (2%)	4	3 (5%)
H. Other stereotypic behavior	4 (31%)	5	6 (46%)	13 (19%)	9	6 (9%)
I. Language disorders	10 (77%)	9	10 (77%)	37 (55%)	25	19 (29%)

due to the fact that Dutch law prohibits adoptive placement of any foreign child with any "dangerous or infectious disease or any long-term physical or mental disorder" (Justitie, 2001), regulations promulgated by the Dutch Ministry of Justice.

In studying the academic development of the Romanian children, a few did not meet this requirement for admission. Twenty-five of the 80 children are enrolled in special elementary education programs or special education programs for children of middle school or high school age. The figure of 31% for the Romanian children is considerably higher than for Dutch children: 5.8% (Verschure, 2001). Eleven children of the PIAS-group are enrolled in special education programs. The other two children are in the second and third grade in elementary school. Compared with the 67 Other Romanian children, the PIAS group differs significantly in enrollment in special education (Tables III and IV).

The frequency with which the PIAS-children are enrolled in Special Education programs is significantly higher (χ^2 : 17.71 with a continuity correction, $p \sim .000$).

A girl aged 8.2 years, and a boy aged 6.5 were not enrolled in a Special Education program. The girl needed therapeutic care by a specialized social worker and her functioning at school compared with classmates was inferior according to the parents. However, since her arrival in the family her developmental level had improved. Parents saw hardly any difference between their daughter and her peer group. The boy still showed stereotypic behavior but functioned well at school. According to the parents, his devel-

Table III. PIAS-Group and Other Romanian adoptees with Respect to the Type of Educational Facility (Frequencies and Percentages)

	Special education		
	Yes	No	Total
PIAS	11 85%	2 15%	13
Other Romanian adoptees	14 21%	53 79%	67
Total	25 31%	55 69%	80

Table IV. Use of Professional Care (Percentages)

	PIAS-group (13)	Others (67)
Professional care used	13 (100%)	39 (58%)
Professional care not used	0	28

opment had improved considerably between time 1 and time 3.

Professional care was used by all PIAS-children and by 58% of the "Others". This professional care involved a large variety of caretakers, social workers, child psychiatrists, speech-trainers, and physical therapists.

At both times, we asked the parent's judgment of functioning at school. Among the group of PIASchildren at time 2, and at time 3, three of the 13 parents judged that their child functioned "well" at school. When the parents were asked to compare their child with normal peers, one of the parents judged that their child functioned well at the time of the first interview (time 2). At the time of the second interview (time 3) three parents stated a positive judgment. These results contrasted greatly with the judgment of the parents of the Other Romanian adoptees. Among these 67 children, parents' judgment about how their child "functions at school in general" was stated to be "well" at the time of the first interview by 45% (16%)⁴, and at the time of the second interview 60% (20%). Those that judged their child functioned well "Compared with his/her peers" came to 32% (8%) and 58% (20%), respectively.

In Table V, we provide an overview of the assessment of the parents regarding their child's development upon arrival and at the time of the first and second interview.

The PIAS-group showed improvement in the five areas of development. In the areas of physical development and development of motor skills, the improvement was significant (Wilcoxon, p < .01). There is no clear improvement in the area of general development. Among the other adoptees, significant improvement was seen in all areas (Wilcoxon: p < .001). The longer the children had been in their adoptive family, the more improvement was seen in the post-institutionalized autism behavior. The PIAS-group had been in the family, on average, 4 years and 4 months, and the other children, 5 years and 3 months.

DISCUSSION AND RECOMMENDATIONS

Studies that compared the psychological adjustment of adoptees and non-adoptees indicated that adoptees had significantly higher levels of maladjustment (Miller, Fan, Christensen, Grotevant, & Van Dulmen, 2000; Wierzbicki, 1993) and that children

Aspect of development	PIAS-group (13)			Other adoptees (67)		
	Time 1	Time 2	Time 3	Time 1	Time 2	Time 3
General:						
No difference	0	1	1 (8%)	11 (17%)	32	35 (54%)
Some delay	2 (15%)	3	4 (31%)	16 (25%)	23	23 (35%)
Major delay	11 (85%)	9	8 (62%)	38 (59%)	12	7 (11%)
Physical:						
No difference	0	8	7 (54%)	15 (23%)	51	56 (84%)
Some delay	2 (15%)	3	5 (39%)	18 (28%)	13	9 (13%)
Major delay	11 (85%)	2	1 (8%)	32 (49%)	3	2 (3%)
Motor skills:						
No difference	0	3	3 (23%)	18 (28%)	43	49 (74%)
Some delay	1 (8%)	3	8 (62%)	19 (30%)	17	13 (20%)
Major delay	12 (92%)	7	2 (15%)	27 (42%)	7	4 (6%)
Language development:						
No difference	1 (8%)	2	2 (15%)	20 (32%)	41	46 (70%)
Some delay	1 (8%)	2	5 (39%)	9 (15%)	17	16 (24%)
Major delay	11 (85%)	9	6 (46%)	33 (53%)	9	4 (6%)
Emotional development:						
No difference	1 (8%)	1	2 (15%)	11 (18%)	35	41 (61%)
Some delay	0	4	5 (39%)	19 (31%)	28	22 (33%)
Major delay	12 (92%)	8	6 (46%)	32 (52%)	4	4 (6%)

Table V. Scores by the Parents on the Five Developmental Areas: PIAS Compared with Other Romanian Adoptees (Frequencies and Percentages)

adopted from institutions are at dramatically increased risk for disturbances' (O'Connor et al., 1999; Peters, Atkins & McKernan McKay, 1999; Zeanah, 2000, p. 230). As expected, a part of the Romanian adopted children (13 out of 80) showed symptoms of autism. The frequency of symptoms of autism in the Romanian group was comparable to the percentage that Rutter et al. (1999) reported. We label this a post-institutionalized autistic syndrome because it is probably due to environmental factors instead of genetic factors.

Parents of 13 of the 80 Romanian adoptees reported behavior that corresponded to the three dimensions of the Wing Triad. Especially Federici's aspects 3, 5, 6 and 7 were applicable (Federici, 1998). Eleven of these 13 children are enrolled in special education programs. The PIAS group also differs considerably from the Other Romanian adoptees in their cognitive functioning, as was found by Rutter et al. (1999). Indiscriminate friendliness to strangers appears to be a persistent relationship disorder. This was also found in the research of Rutter et al. (1999).

The 67 Others and the 13 children from the PIAS-group showed progression toward recovery in the course of the (on average) 5 years that they have been in the adoptive family. The improvement in

physical and motor skills development was most clear in the PIAS group. Among the Others, a significant improvement was visible in all six areas of development. This developmental progress of the Romanian adoptees is probably related to the major efforts of their adoptive parents (Hoksbergen, 1999; Hoksbergen et al., 2001). It is related to an improved environment. Although all 80 Romanian adoptees have a background of deprivation, it is apparent that only some of them experience particularly negative consequences from this. This effect cannot be explained on the basis of a difference in age upon arrival in the adoptive family, as this factor was virtually the same in the two groups.

It was not within the scope of our study to execute the extensive, empirical and clinical investigation required for the reliable identification of a subgroup of adopted children of Pervasive Development Disorder (PDD), like PIAS. We were not able to properly diagnose this pervasive development disorder. We could only use the opinion of the parents, who filled out the Auti-R scale. Asking experts to diagnose autism would have been more valid. This diagnosis could give more information about differences with a group of children with the diagnosis of basic autism. Proper measurement with

standardized instruments of the cognitive development of all Romanian adoptees in our group would also give a better view on the special characteristics of our PIAS-group, and their differences from the other Romanian adoptees. Multiple measurements over time will make it possible to test the hypothesis that PIAS is not a permanent disorder like basic autism.

Literature examining behavioral, diagnostic, and demographic characteristics of adopted children has provided five explanatory models for the high rate of behavior problems among adopted children. Our findings explore two of these factors. One of these factors is long-term consequences of impaired preadoption child rearing. Not age of adoption, but the type of caregiving environment into which a child is placed is a determining factor for the severity of maladjustment (Peters et al., 1999). Results of our study illustrate the detrimental effects of either, or both of these factors on long-term behavioral adjustment of some adoptees. Removing a child from a bad institution and placing him into a motivated family does not guarantee a successful adoption and a healthy adaptation and integration.

Due to the fact that the general diagnosis of autism is reported four times more among boys than among girls, our results, finding equal numbers of boys and girls with this constellation of symptoms, suggest that a specific syndrome in the autistic spectrum is involved. If a comparable but much more extensive study shows the same results we might think of inclusion of the Post-Institutional Autistic Syndrome in the DSM, as one of the specific disorders in the autistic spectrum.

Various studies show that there are several factors that pose a risk to the quality of care provided in raising children. Groenendaal and Dekovic (2000, p. 18) found that in those families "in which the child is experienced as being 'difficult' due to a troublesome temperament, raising them is experienced as being aggravating and the quality of the parent-child relationship clearly leaves something to be desired". McGlone, Santos, Kazama, Fong, and Mueller (2002) investigated the psychological stress in adoptive parents of special-needs children. Their study on the nature and extent of parental stress among adoptive parents of 35 special-needs children (children from the protective/foster care system because they were exposed to issues of neglect) indicated higher than average levels of stress. Five stress categories were identified: child characteristics, parent-child interactions, family cohesion, parental adjustment, and adoption services issues. Families with special-needs children form a serious risk group. The higher the number of risk factors involved, the bigger the assault upon the quality of the upbringing the parents can provide. Children with the Post-Institutional Autistic Syndrome will be experienced as "difficult".

We see this syndrome in the autistic spectrum appear in a relatively large number of children adopted from Romania. Their parents need significant levels of services. It is recommended that children with a history of any negative long-term residence in an orphanage only be placed with adoptive parents if professional supervision and support can be offered to the family immediately upon arrival of the child in the family. Special adoption services are also needed. Especially during pre-placement time, adoptive parents should be given all relevant information about the child, and they should never be "rushed" to accept the proposed child. Also information about the time that needs to be invested in a special-needs child should be realistic. Bringing up and educating, for instance, a PIAS-child is like accepting a new job in your home and family; it is a parental task and responsibility with a very high workload.

NOTES

- 1. The names and some aspects of the various cases have been changed to protect the privacy of the individuals involved.
- 2. These adoptions were arranged privately and via two recognised organisations for mediation in adopting foreign children—Wereldkinderen (*World Children*) and FLASH.
- 3. We have combined the results of virtually identical versions for the two age groups (10–83 and 72–155 months).
 - 4. Between brackets: PIAS-group.

REFERENCES

Achenbach, T. M., & Edelbrock, C. S. (1983). *Manual for the child behavior checklist and revised profile*. Burlington, VT: University of Vermont, Department of Psychiatry.

American Psychiatric Association, (1994). *Diagnostic and statistical manual of mental disorders*. Washington D.C: Author.

Ames, E. W., Fraser, S., & Burnaby, B. C. (1997). *The development of romanian orphanage children adopted to canada: Final report*. Canada: Human Resources Development.

Bowlby, J. (1946). Forty-four juvenile thieves: Their characteristics and home life. London: Bailliere, Tindall & Cox.

Bowlby, J. (1971). Attachment and loss. Vol. 1 Attachemnt. Harmondsworth: Penquin Books.

- Buitelaar, J. K., & Willemsen-Swinkels, S. H. N. (2000). Autism current theories regarding its pathogenesis and implications for rational pharmacotherapy. *Peadiatric Drugs*, 2(1), 67–81.
- Cohen, D. J., & Volkmar, F. R. (1997). Handbook of autism and pervasive developmental disorders. New York: Wiley & Sons.
- Dahl, K., Cohen, D. J., & Provence, S. (1986). Clinical and multivariate approaches to nosology of pervasive developmental disorders. *Journal of the American Academy of Child and Adolescent Psychiatry*, 25, 170–180.
- Eisenmajer, R., Prior, M., Leekman, S., Wing, L., Gould, J., Welham, M., & Ong, B. (1996). Comparison of clinical symptoms in autism and Asperger's syndrome. *Journal of the American Academy of child and adolescent Psychiatry*, 35, 1523–1531.
- Federici, F. (1998). Help for the hopeless child: A guide for families. Alexandria: Federici & Associates.
- Fraiberg, S. (1977). *Insights from the blind*. New York: Basic Books.
- Groenendaal, H., & Dekovic, M. (2000). Risicofactoren voor kwaliteit van de opvoeding. Pedagogiek, wetenschappelijk forum voor opvoeding, vorming en onderwijs, 20(1), 3–22.
- Hoksbergen, R. A. C., & Walenkamp, H. (Red., 1983). *Adoptie uit de Kinderschoenen*. Houten: Bohn Stafleu Van Loghum.
- Hoksbergen, R. A. C., & Walenkamp, H. (Red., 1991). Kind van andere ouders. Houten: Bohn Stafleu Van Loghum.
- Hoksbergen, R. A. C. (1996). Traumabeleving door geadopteerden. Tijdschrift voor orthopedagogiek, 35, 279–293.
- Hoksbergen, R. A. C. en de medewerkers van het Roemeniëproject. (1999). Adoptie van Roemeense kinderen: Ervaringen van ouders die tussen 1990 en medio 1997 een kind uit Roemenië adopteerden. Utrecht: Afdeling Adoptie.
- Hoksbergen, R. A. C., & Walenkamp, H. (Red, 2000). *Adoptie: een levenslang dilemma*. Houten: Bohn Stafleu Van Loghum.
- Hoksbergen, R. A. C. (2000). De Nederlandse adoptiepraktijk, 1956–2000. In René Hoksbergen, & Hans Walenkamp (Eds.), *Adoptie: een levenslang dilemma*. Houten: Bohn Stafleu Van Loghum.
- Hoksbergen, R. A. C., Stoutjesdijk, F., Rijk, S., van Dijkum, C., & Rijk, K. (2003). Posttraumatic Stress Disorder in adopted children from Romania. American Journal of Orthopsychiatry, 73(3), 255–265.
- Hoksbergen, R. A. C., & Van Dijkum, C. (2001). Trauma experienced by children adopted from abroad. *Adoption & Fostering*, 25(2), 1–8.
- Human Rights Watch. (1998). Abandoned to the state, cruelty and neglect in Russian orphanages. New York: Human Rights Watch.
- Jenista, J. A. (1992). Disease in adopted children from Romania. Journal of the American Medical Association, 268, 601.
- Johnson, A., Miller, I., Iverson, S., Thomas, W., Franchino, B., Dole, K., Kierman, M., Georgieff, M., & Hostetter, M. (1992). The health of children adopted from Romania. *Journal of the American Medical Association*, 268(24), 3446–3451.
- Johnson, D. (1999). Adopting a Post-Institutionalized Child: What are the Risks? In T. Tepper, L. Hannon, & D. Sanstrom (Eds.), Parent network for the post-institutionalized child. international adoption: Challenges and opportunities. (pp. 8– 12). Meadow Lands: PNPIC.
- Justitie, (2001). *U wilt een kind uit het buitenland adopteren*. Den Haag: Ministerie van Justitie.
- Kreppner, J. M., O'Connor, T. G., Rutter, M., & The English and Romanian Adoptees Study Team (2001). Can inattention/overactivity be an institutional deprivation syndrome? *Journal of Abnormal Child Psychology*, 29(6), 513–528.
- Ladee-Levy, J. D. (1990). Psychische Problemen bij Somatisch Zieke Kinderen. In J. A. R. Sanders-Woudstra, & H. F. J.

- Witte (Eds.), Leerboek Kinder- en Jeugdpsychiatrie. (pp. 246–270). Assen/Maastricht: Van Gorcum.
- McGlone, K., Santos, L., Kazama, L., Fong, R., & Mueller, C. (2002). Psychological Stress in Adoptive Parents of Special-Needs Children. *Child Welfare League of America*, LXXXI(2), 151–171.
- Miller, B. C., Fan, X., Christensen, M., Grotevant, H. D., & Van Dulmen, M. (2000). Comparisons of adopted and nonadopted adolescents in a large, nationally representative sample. *Child Development*, 71(5), 1458–1473.
- O'Connor, T. G., Rutter, M., & The English and Romanian Adoptees Study Team. (1999). Attachment disorder behavior following early severe deprivation: Extension and longitudinal follow-up. *Journal American Academy Child Adolescent Psychiatry*, 39(6), 703–712.
- O'Connor, T. G., Bredenkamp, D., Rutter, M., & The English and Romanian Adoptees Study Team. (1999). Attachment disturbances and disorders in children exposed to early severe deprivation. *Infant Mental Health Journal*, 20(1), 10–29.
- Peters, B. R., Atkins, M. S., & McKernan McKay, M. (1999). Adopted children's behavior problems: A review of five explanatory models. *Clinical Psychological Review*, 19(3), 297– 328.
- Rutter, M. (1979). Verwaarlozing van jonge kinderen. Utrecht: Het Spectrum.
- Rutter, M., Andersen-Wood, L., Beckett, C., Bredenkamp, D., Castle, J., Groothues, C., Kreppner, J., Keaveney, L., Lord, C., O'Connor, T. G., & The English and Romanian Adoptees (ERA) Study Team. (1999). Quasi-autistic patterns following severe early global privation. *Journal Child Psychology Psychiatry*, 40(4), 537–549.
- Rutter, M. (1991). Autism as a genetic disorder. In P. McGuffin, & R. Murray (Eds.), *The new genetics of mental illness.* (pp. 225–244). Oxford: Butterworth-Heineman.
- Sorgedrager, N. (1988). Oriënterend medisch onderzoek en groeistudie van buitenlandse adoptiekinderen. Haren: Cicero.
- Spitz, R. A. (1945). Hospitalism: An inquiry into the genesis of psychiatric conditions in early childhood. *The psychoanalytic* study of the child, 1, 53–74.
- Van Berckelaer-Onnes, I. A., & van der Gaag R. J. (1999). Pervasieve ontwikkelingsstoornissen: een spectrum van autistische stoornissen. In *Handboek kinderen & Adolescenten*, December 1999, B 030–1 tot B 030–16.
- Van Berckelaer-Onnes, I. A., & Hoekman, J. (1991). Handleiding en verantwoording van de Auti-R schaal ten behoeve van de onderkenning van vroegkinderlijk autisme. Lisse: Swets & Zeitlinger.
- Verhulst, F. C., Althaus, M., & Versluis-den Bieman, H. J. M. (1992). Damaging backgrounds: Later adjustment of international adoptees. *Journal of the American academy of child and* adolescent psychiatry, 31(3), 518–524.
- Verschure, J. (2001). Roemeense adoptiekinderen binnen het speciaal onderwijs. Utrecht: Afd. Adoptie, Thesis.
- Verrier, N. N. (1993). The Primal Wound, understanding the adopted child. Baltimore: Gateway Press, inc.
- Wierzbicki, M. (1993). Psychological adjustment of adoptees: A meta-analysis. *Journal of Clinical Child Psychology*, 22(4), 447–454.
- Wing, L., & Gould, J. (1979). Severe impairments of social interaction and associated abnormalities in children. *Journal of Autism and Developmental Disorders*, 9, 11–29.
- Wing, J. (2000). Leven met Uw autistische kind. Een gids voor ouders en begeleiders. Lisse-Swets & Zeitlinger.
- Zeanah, C. H. (2000). Disturbances of attachment in young children adopted from Institutions. *Developmental and Behavioral Pediatrics*, 21, 230–236.