INSTITUTIONALIZED AUTISM AND THE ADOPTED CHILD

By

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Table of Contents

1. Abstract 3
2. Introduction 4
3. Table 1: DSM Criteria for Autism 4
4. Justification of Interdisciplinary Approach 5
5. Relevant Disciplines 6
6. Table 2: Comparison of Literature Reviewed 6
7. What is an institution? 9
8. Early Deprivation 9
9. Theoretical Concept of Institutional Autism 11
10. Language Delays 13
11. Behavioural Issues 14
12. Comparison of Institution versus Non-Institution 16
13. Conclusion 18
14. References 21
ABSTRACT

Children adopted from institutional settings often come into their new homes displaying characteristics, such as language delays, social delays and repetitive behaviours, which are similar to characteristics of autism. Institutionalized autism is a new theoretical concept to give an understanding to the characteristics these children display. Understanding the connection between autism and children who are will allow for the families adopting these children to better prepare for their arrival. Further, understanding the impact of institutional life on children will help to make changes within the organized institutionalized care of children to reduce the symptoms of institutionalized autism. This project will focus on the autistic characteristics of children who have been adopted from an institution and test the reality of the theoretical concept of institutionalized autism. An integrated approach will be taken to review the literature about surrounding delays in adopted children. Disciplines including psychology, mental health, language development, child development and special education will be evaluated and integrated to understand kinds of the delays experienced by adopted children.
Introduction

Many children who have been adopted internationally have spent time in an orphanage. For some children this time is limited to only a few months, and for others this time can last for years. The time spent in an orphanage is often filled with deprivation and isolation. Children in orphanages are regularly often neglected; whether left in a crib alone or put in a group of children without continuous care.

Autism is a neurological disease characterized by deficits in communication, social and play skills, often accompanied by repetitive behaviours. A new concept termed “institutionalized autism” has arisen in the field of international adoption. This concept developed in the late 1990’s during the time of a large influx of children into the United States and Canada from Romania (Gindis, 2008). Many children who were adopted internationally have had arrived home to their new families displaying many characteristics of autism. Gindis corroborates a link between the two when he states “Children may acquire autism symptoms due to their early life in orphanages, hospitals, and other similar institutions.” (Gindis, 2008, p.120). The brain development of children may be adversely affected by the lack of attention in a deprived setting. (Federici, 1998). While Gindis found a link between deprivation and delays due to institutionalization, I will introduce evidence from multiple perspectives to confirm his findings, and test the concept of institutionalized autism.

Table 1: DSM Criteria for Autism

The DSM is the Diagnostic and Statistical Manual of Mental Disorders created by the American Psychiatric Association. The guide claims that a person must show at least six characteristics, including:

> Qualitative impairment in social interaction, with at least two of the following:
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<th>Marked impairment of nonverbal communication behaviours, such as facial expression, eye contact, gestures and posture</th>
<th>Does not develop peer relationships appropriate to their developmental level</th>
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<td>Does not seek to share enjoyment, accomplishments, or interests</td>
<td>Lacks emotional and social reciprocity</td>
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**Qualitative communication impairments, and has at least one of the following:**

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<th>Lack of or delay of spoken language, with no attempt to use compensatory communication systems</th>
<th>Impairment in initiating and sustaining reciprocal conversation</th>
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<td>Repetitive, idiosyncratic, or stereotypical use of language</td>
<td>Lack of spontaneous social play, including lack of make believe play and do not play at their developmental level</td>
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**At least one of the following characteristics of restricted and stereotypical patterns of behaviour:**

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<th>Preoccupation with a restricted and stereotypical pattern of interest that is abnormal in intensity or focus</th>
<th>Inflexible towards change, tends to have inflexible and nonfunctional routines or rituals</th>
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<td>Preoccupation with parts of objects</td>
<td>Stereotypical and repetitive motor patterns</td>
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Must also have delays or abnormal functioning (with an onset prior to 3 years of age) in social interaction, communicative language, and symbolic or imaginary play.

*Note:* Adapted from the Diagnostic and Statistical Manual, Fourth Edition (APA, 1994).

**Justification of Interdisciplinary Approach**

This study will be interdisciplinary in nature. In interdisciplinary studies the concept of problem solving can be looked at as the opportunity to examine and study while researching the question. This is opposed to a research question focusing on a specific
discipline within definite limitations. The concept of problem solving allows observation and consideration from an array of disciplines rather than staying within the parameters of a specific discipline. In looking at institutionalized autism and internationally adopted adoption children it is not an examination of a particular topic, but an occasion to explore and investigate the incidents of internationally adopted children showing autistic tendencies. Interdisciplinary studies encourage collaboration and exchange which promotes the exploration of a concept which could impact two very different areas, such as medicine and psychology. (Turner, 2000)

**Relevant Disciplines**

In this research project interdisciplinary studies impact fields such as psychology, language disorders, mental health, child development and special education.

**Table 2: Comparison of Literature Reviewed**

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<th>Source</th>
<th>Discipline</th>
<th>Methodology</th>
<th>Conclusions</th>
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<tr>
<td>Improvements in Early Care in Russian Orphanages and Their Relationship to Observed Behaviours (C. Groark et al.)</td>
<td>Mental Health</td>
<td>Both caregivers in a Russian orphanage and the children living in the orphanage were studied. Pre and post intervention observations were made of both groups. Training was given to the caregivers to teach them to be more socially responsive in their interactions with the children.</td>
<td>Caregivers – showed more flexibility in interactions; also showed decline in anxiety and depression. Children – increase in physical growth, general development, and personal-social development.</td>
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<td>Prolonged Institutional Rearing is Associated With Atypically Large Amygdale Volume and Difficulties in Emotion Regulation (N. Tottenham et al.)</td>
<td>Child Development</td>
<td>Two sample groups – one children who has been previously institutionalized, other not. Assessments done with parents and children including parent interview, IQ test, anxiety questionnaire, behavioural tasks and a MRI</td>
<td>Longer institutional stays associated with atypical limbic development and associated emotional regulation difficulties</td>
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<td>Communication Development in Infants and Toddlers Adopted from Abroad (D. Hwa-Froelich)</td>
<td>Language Development</td>
<td>Literature review of children adopted from China and Eastern Europe, as well as a case study. Describe current developmental evidence on the speech, social language and symbolic behaviour</td>
<td>Most children within two years language delays gone; children receiving better care resulted in better language skills; transdisciplinary approach to treatment was</td>
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<td>Study Title</td>
<td>Field</td>
<td>Description</td>
<td>Findings</td>
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<td>Do Theory of Mind and Executive Function Deficits Underlie the Adverse Outcomes Associated with Profound Early Deprivation?: Findings from the English and Romanian Adoptees Study (E. Colvert et al.)</td>
<td>Child Psychology</td>
<td>Comparison between two groups of adoptees; one group from Romania who were institutionalized and U.K. adoptees who were not institutionalized. Standardized tests were used to assess theory of mind, executive functioning, as well as quasi-autism, inattention/over activity and disinhibited attachment</td>
<td>Institutionalized children found to have decreased scores in theory of mind and executive functioning</td>
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<td>CBCL Behaviour Problems of Post-Institutionalized International Adoptees (B. Hawk and R. McCall)</td>
<td>Child Psychology</td>
<td>Literature review of 18 studies of adopted children and institutionalization. The Child Behavior Checklist was used to assess behaviours, including consistency of behaviour rates across studies and behaviour rates in post-institutionalized children.</td>
<td>The results showed that children adopted younger showed more internalized behaviours, while older adoptees showed more externalizing behaviours. Overall, children who were previously institutionalized showed more behaviours.</td>
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<td>Psychological Adjustment of Adoptees: A Meta-Analysis (M. Wierzbicki)</td>
<td>Child Psychology</td>
<td>A meta-analysis of 66 published studies that compared the psychological adjustment of non-adoptees and adoptees.</td>
<td>Adoptees showed higher rates of maladjustment including externalizing disorders, academic problems and general severity.</td>
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<td>Early Adolescent Outcomes of Institutionally Deprived and Non-Deprived Adoptees. (M. Rutter et al.)</td>
<td>Child Psychology</td>
<td>Researchers compared two groups of adoptees: one from Romania where they were institutionalized, the other from the United Kingdom whom had not been institutionalized. The researchers evaluated both the social and emotional functioning of the children.</td>
<td>Quasi-autistic patterns were seen in over 1 in 10 children from institutional settings versus 0% of the UK children who suffered no deprivation. This study confirms that children from institutional settings in Romania have exhibited behaviours of institutionalized autism.</td>
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<td>Analysis of Environmental Deprivation: Cognitive and Social Development in Romanian Orphans (S. Kaler and B. Freeman)</td>
<td>Child Psychology</td>
<td>Two groups of Romanian children were compared. The first group were orphans living in an institution, the second Romanian children attending kindergarten (living with their families) Researchers administered standardized assessments to assess development, behaviour and social interactions.</td>
<td>The orphan children were found to have deficits in both cognitive and social functioning; however there was no one variable or combination of variables that was predictive of these deficits.</td>
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<td>Cognitive, Language and Educational Issues of Children Adopted from Overseas</td>
<td>Child Psychology</td>
<td>Research on post institutionalized adopted children was studied to look at their language, cognitive and academic difficulties.</td>
<td>Adoptees have shown issues with language, as well as cognitive deficits. These issues can lead to emotional/behavioural issues.</td>
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<tr>
<td>Study</td>
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<td>Orphanages (B. Gindis)</td>
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<td>This leads to using a more complex examination of internationally adopted children and whether to address language delays or behaviour issues.</td>
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<td>The Impact of Institutionalization on Child Development (K. Maclean)</td>
<td>Child Development</td>
<td>A study on the effects of institutionalization on adopted Romanian orphans, including examining cognitive and physical development, behaviour and attachment.</td>
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<td>Behavior Problems in Post institutionalized Internationally Adopted Children (M. Gunnar et al.)</td>
<td>Child Development</td>
<td>The families of children adopted into Minnesota from foreign countries completed mailed out surveys. The surveys included The Child Behaviour Checklist, information about pre adoption and post adoption history. Two groups were established: a control group whom has spent less than 4 months in an institution, the other group of children spent more than 4 months in an institution.</td>
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<td>Do the Effects of Early Severe Deprivation on Cognition Persist Into Early Adolescence? Findings from the English and Romanian Adoptees Study (C. Beckett et al.)</td>
<td>Child Development</td>
<td>A study comparing adoptees from Romania and adoptees from the United Kingdom. The objective of their study was to measure if the effects of early deprivation (particularly cognitive delay) lasted into adolescence. The effects of early deprivation lasted into adolescence; however children who were adopted did show improvements in deficits initially found.</td>
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<td>Post-Institutional Autistic Syndrome in Romanian Adoptees (R. Hoksbergen et al.)</td>
<td>Special Education</td>
<td>A semi-structured questionnaire and the Auti-R scale (determines presence of autistic behaviours) were used in a study of post-institutionalized adopted children from Romania into the Netherlands. The results showed that 13 of the 80 children were found to display symptoms of autism. Children adopted from institutional setting in Romania into different countries in Western Europe have shown symptoms of autism, which can be described as institutional</td>
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What is an institution?

Children who are orphaned in foreign countries often live in a variety of institutional settings. The most common of these setting for orphans is an orphanage. While orphanages differ greatly between and within countries, the basic concept of an orphanage is the same. Children being raised in an orphanage are children who are no longer living with their parents and instead are being cared for by a rotating staff. Often there are many children in the orphanage of varying ages living together in tight quarters. Children are often left on their own or within a group with little adult stimulation.

While orphanages are one type of institution, other types of institutions house children. Hospitals are one example of an institution. Children who are medically fragile or have special needs may be in the care of a hospital. Further, care homes created to care for special needs children are another type of institution. Again these children are living without their parents and within a large group setting, with very little one to one stimulation.

Early Deprivation

Children who are living in an institutionalized setting are often deprived of many basic necessities. Food may be in limited quantities, health care may be limited and one to one care and stimulation from an adult may be missing. The development of the brain has been studies to examine if children who have been maltreated, malnourished, or lived in deprived conditions have any physical differences in their brain. Tootenham et al.
(2010) conducted a study to explore if there was a relationship between early life adversary and amygdala volumes in the brain. A sample of 78 children participated in the study, 38 of the children were post institutionalized and the other 40 were a never institutionalized. Various measures were used to conduct the study; structured interviews with the parent (Schedule for Affective Disorders and Schizophrenia for School Age Children), IQ testing using WASI, internalizing and anxiety questionnaires (CBCL and Screen for Child Anxiety Related Emotional Disorders), behavioural task (emotional go-nogo paradigm) and an MRI. The researchers concluded that longer stays in an orphanage were associated with atypical limbic development and associated emotional regulation difficulties. The impact of deprivation on young children can physically alter a child.

Many studies have been conducted which compare adopted children (particularly Romanian children) with other adoptees and non-adoptees. Kaler and Freeman (1994) studied a group of Romanian orphans living in an institution. They compared this group with a sample of Romanian children attending kindergarten. There were 25 Romanian orphans in the study between the ages of 23 to 50 months. All resided in the same institution in Romania, however in three different rooms. The researchers administered the Bayley scales of infant development, a modified five-point scale of the Bayley’s infant behaviour record, the Vineland adaptive behaviour scales, assessment of non-verbal communication skills, a modified mirror and rouge test, a social referencing measure, symbolic maturity of play and an observation in a group situation in which behaviour was coded based on interaction with others. These results were then compared to 11 Romanian kindergarten students. The orphan children were found to have deficits
in both cognitive and social functioning; however there was no one variable or combination of variables that was predictive of these deficits.

Early deprivation of children in institutional setting has shown to cause many deficits in developing children. Wierzbicki (1993) completed a meta-analysis of 66 published studies that compared the psychological adjustment of non-adoptees and adoptees. Through his meta-analysis, the results showed that in the area of maladjustment, adoptees were significantly higher than non-adoptees when comparing representation in clinic samples, externalizing disorders, academic problems and general anxiety. Children reared in their early years in such deprived conditions are likely to show deficits in many areas of functioning.

Early deprivation is shown to cause biological differences in children. The brain of a young child who suffers early deprivation, such as isolation, malnutrition and maltreatment, can be altered. Children often emerge from a deprived state with issues, which could include behaviour, cognitive or mental health.

**Theoretical Concept of Institutional Autism**

Children raised in institutions during their early years, often show signs of impairment. Communication, social skills and behaviour have all been shown to delay due to being institutionalized. Many children who are adopted into Canada from foreign countries spent their formative years in an institution, where they are often one child out of many being raised by nannies and caretakers without much stimulation; young children being left in cribs several hours a day, large groups of children left without much supervision, too few caregivers left to care for the children, resulting in not enough
attention for the children. Institutional autism has emerged as a concept to describe the characteristics displayed by children who were institutionalized in deprived conditions.

Children left in orphanages or institutional settings are often left to suffer in deprived conditions. These children are neglected by caregiver, lacking stimulus and basic necessities of life (enough food). Such desperate conditions can lead to developmental changes within the children. (Maclean, 2003) Ronald Federici (1998) describes the concept of institutional autism as exhibiting some or all of following characteristics:

- actual loss of physical height, weight and growth
- inability to physically decide on the actual age of a child
- language regression significantly below their age
- deteriorated children's behaviour to where primitive acting out occurs
- profound nutritional and medical neglect, affecting the brain and body
- primitive and regressive behaviours
- complete regression to self-stimulating behaviours

Research grew and explored the concept of institutional autism. Gindis (2008) reviews literature and studies that have looked at this concept. He notes studies of Romanian orphans and the incidents of characteristics of institutionalized autism (or other related terms). Gindis continues to evaluate the differences between institutionalized autism and autism as a medical condition. A variety of institutionalized behaviours by children in institutions are defined, including, self-soothing behaviour, self-stimulating behaviour, self-defending behaviour, attention seeking and over-friendliness with strangers, controlling or avoiding behaviours and immature self-
regulation behaviour. Assessing a diagnosis of institutional autism in the post institutionalized child is complicated. Diagnoses such as reactive attachment disorder, post traumatic stress disorder and childhood depression, must first be ruled out. While it has been shown that autistic-like behaviours have been exhibited by post institutionalized children, other disorders must be considered before a diagnosis can be given.

**Language Delays**

Language development has also been shown to be impacted by early deprivation. Language develops early in life and one key factor of language development is being spoken to. Children in institutions often lack in interaction with others and therefore speech is not modeled for them.

Haw-Froelich (2009) describes research results in language development of both institutionalized and adopted children. Haw-Froelich studied children from China and Eastern Europe, as well as conducting a case study. Haw-Froelich describes a multidisciplinary approach to address the often interrelated developmental issues of institutionalized children. While the researchers noted that language delays can be found in children adopted internationally, most results show that two years later most children are no longer showing those prior deficits.

While Haw-Froelich studied the deficits in children’s language and the interventions necessary to correct those deficits, Gindis also examined language in internationally adopted children. Gindis (2005) explored the research and clinical experience on language, cognitive and academic issues on post institutionalized adopted children. He discussed the cultural aspect of international adoptees and finding their
personal identity, while ignoring other aspects of culture. He links the works of L. Vygotsky and R. Feuerstein as the best theoretical conceptualization for culture and the international adoptee. International adoptees are not typical language learners in that they are not bilingual, but learn English through a subtractive application and have a loss of language of their first language. International adoptees are also shown to have cognitive deficits affecting their school academic performance, which can cause emotional/behaviour issues. Thus we are faced with a more complex issue of examining internationally adopted children and whether to address language delays or behaviour issues. We must try to find the main cause of the issues, and that is, which deficits are affecting the others deficits.

**Behavioural Issues**

While many studies have focused on the deficits of post institutionalized children, such as cognitive and language deficits, researchers have also started to look at behaviour. Researchers are studying if there is a link between being institutionalized and problem behaviours in later years.

Internalizing behaviours, such as depression, withdrawing and shutting down, and externalizing behaviours, such as aggression and acting out, have been thought to increase in children who were institutionalized. Hawk and McCall (2010) reviewed 18 studies of adopted children and institutionalization that used the Child Behavior Checklist as an assessment tool. The purpose for the review was to evaluate various studies that have shown an increase in these behaviours in post institutionalized adoptees and to assess any different outcome measures. The researchers focused on three main areas: whether post institutionalized children have higher rates or levels of behaviour problems,
are the rates consistent across studies and are the results more consistent when certain parameters are evaluated. The researchers examined internalized behaviours versus externalized behaviours and found that younger (under 5 years of age at time of adoption) adopted children showed more internalized behaviours, while externalized behaviours were more present in older adopted children. Other parameters that were examined included age at adoption and length of time in the institution. Thus internalized and externalized behaviours increased in children who were previously institutionalized.

Other studies have looked at behaviours of post institutionalized children and found differing results. Gunnar, Van Dulmen and the International Adoption Project Team (2007) assessed children who were adopted into Minnesota from foreign countries between January 1, 1990 and December 31, 1998. Mail out surveys were used, with 1,948 (65.6%) completed surveys being returned. The survey included The Child Behaviour Checklist, information about preadoption history and postadoption history and demographics. The respondents were divided into two groups; one group consisted of children who had spent more than 4 months in an institution (post institution group), the other group was children who had spent less than 4 months in an institution (control group). The results showed that using the CBCL most of the children in both groups were mainly free of behaviour problems; however there were a few children from the post institution group that were exhibiting pervasive problems. With internalizing and externalizing behaviours, post institutionalization was shown not to predict an increase.
Comparisons between Post Institutionalized Children and Non-Institutionalized Children

After the emergence of the term institutional autism and the characteristics associated with it, researchers began to study this new concept. Much of the research has been centered on Romanian adoptees. Rutter conducted two studies examining what he termed “quasi-autism” in Romanian adoptees. Rutter’s first study in 1999 randomly selected a sample of 165 Romanian adoptees adopted by English families who came to England before the age of 42 months. They were assessed based on their social, behavioural and emotional functioning to explore any features of autistic symptoms. The autism screening questionnaire based on the Autism Diagnostic Interview was used to assess the children. The results show that most of the autistic symptoms were more pronounced at 4 years of age versus the reassessment at 6 years of age. Eleven of the children (or approximately 6%) in the original sample showed autistic symptoms.

In 2007 Rutter continued his study measuring the effects of “quasi-autism” using the same population at early adolescence. Of this group 54 were assessed at 6 years of age, while the other 111 children were assessed at 4 years of age and again at 6 years of age. The group was compared with a sample of United Kingdom born adopted children from non-deprived backgrounds. The social and emotional functioning of the children was evaluated by the researchers. Quasi-autistic patterns were seen in over 1 in 10 children from institutional settings versus 0% of the UK children who suffered no deprivation. This comparative study confirms the assumption that children from institutional settings in Romania are have exhibiting behaviours of institutionalized autism.
Continuing with the evaluation of Romanian adoptees, Hoksbergen et al. (2005) completed a study which examined post-institutionalized adopted children from Romania into the Netherlands and the incidence of post-institutional autistic syndrome. The sample consisted of 80 Romanian adopted children who were previously institutionalized. The families of the children were required to fill out a semi-structured questionnaire, and then complete the Auti-R scale used to determine the presence of autistic behaviours. The results showed that 13 of the 80 children were found to display symptoms of autism. Children adopted from institutional setting in Romania into different countries in Western Europe have shown symptoms of autism, which can be described as institutional autism.

While many studies have examined the results of institutionalization by studying adoptees, one must consider how changes in an institution may impact the child. If children adopted into homes where they are nurtured and stimulated begin to thrive and regain deficits previously lost, then changing the situation within the institution where children are stimulated and nurtured within that institution the children living in institutions should change those children begin to thrive.

Groark, et al. (2005) designed a study using Russian orphanages with the objective of implementing changes both structurally and in the training of the caregivers that would continue to be maintained after the research project was done. The hypothesis being that these changes would decrease the maladaptive behaviour in children in the orphanage. The caregivers were given training to help them to understand how to be “more socially responsive in their interaction with children in every aspect of life in the orphanage” (Groark 2005, p. 102). The structural changes implemented included
forming subgroups with consistent caregivers in order to support the development of relationships between the children and consistent caregivers. Observers from the research team observed at the orphanages both pre-intervention and post-intervention. In regards to the orphanage environment, pre-intervention it was very orderly, but stark and devoid of emotion. It was an impersonal environment. Caregivers were hurried and showed very little social interaction with the children. The children showed limited social interest, stereotypical behaviours, and were often left in cribs on their own. Post-intervention the caregivers were found to be more animated and actively engaging with the children. They were talking and responding to all the children; including those with disabilities. The children were found to be happy and enthused. There were increases in peer social interaction and fewer aggressive incidents. An adoptive home can help a previously institutionalized child regain deficits, however if efforts were placed upstream in the institution itself, these deficits would be non-existent.

Conclusion

Institutional autism has emerged as a concept to describe the characteristics displayed by children who were institutionalized in deprived conditions. Children who were institutionalized suffered from extremely deprived conditions. These deprivations have been shown to cause physical changes in the brain of these young children. A social experiment to examine the effects of institutionalization and deprivation on children was brought about by the influx of Romanian adoptees into Canada, Western Europe and the U.S in the early 1990s. These children were found to have delays in communication, behaviour issues and social delays. While these delays in some cases lasted into
adolescence, in the majority of children these deficits were steadily overcome after entering an adoptive home.

While there have been many studies examining the effects of early deprivation, a large portion of these studies have used Romanian children adopted into Western homes. Further research should explore children from other parts of the world to see if institutionalized autism is a common condition in regards to post institutionalized children or if it only occurs within Romanian adoptees. Further, while the effects of deprivation have been studied, but the only factor causing improvement is being adopted. Research needs to take the next step and look at how we can help these children, even before adoption. Finally, other diagnoses need to occur, especially of behaviour that results from early deprivation including reactive attachment disorder and post traumatic stress disorder. These diagnoses must be ruled out, before the concept of institutionalized autism is explored.

Overall, the research from various disciplines supported the concept of institutional autism in post institutionalized adoptees. Fields of study such as child development, psychology and mental health were able to show from each of their own unique perspectives that children who spent time in institutionalized care had delays as a result. Comparative studies such as Groak et al (2005) and Beckett et al (2006) were the most effective in confirming the pattern of delays in children. These studies confirmed that concept of institutionalized autism occurring in children who were formerly institutionalized.

In conclusion, research has shown that the brain of a young child can physically be altered by early deprivation. The symptoms caused by early deprivation include
language delays, academic issues, social delays and behavioural issues. These symptoms can often correlate with the diagnosis of autism. Children adopted from institutions often display some or all the characteristics of institutional autism; however these symptoms usually fade when the child is placed in a nurturing and supportive home. The concept of Institutional autism is associated with the symptoms that children from adoptive institutions exhibit.
References


