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## HAVING A SIBLING WITH AN INTELLECTUAL DISABILITY

### Introduction

The birth of an intellectually disabled child is a real shock for the family, whose plans and habits must now be reorganized and adjusted to a new situation. Also, a lot of questions and fears regarding the child's health and future as well as the future of the whole family arise. It is not only parents who experience difficult emotions. The siblings of a child with an intellectual disability also need to deal with the whole range of emotions associated with the functioning of their disabled brother or sister, and hence – with the condition of the whole family. The presence of a disabled child in the family changes conditions for the development of their healthy siblings<sup>1</sup>. The key factor here is the attitude of the parents. In this article, the behavior of parents towards the healthy siblings of a child with an intellectual disability as well as the behavior and emotions of the healthy siblings will be discussed.

### 1. Parents' behavior toward the healthy siblings of an intellectually disabled child

The discovery that a child has got some sort of disability may cause various reactions and attitudes among parents towards their disabled child. Similarly, parents may exhibit a number of different behavior

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<sup>1</sup> Cf. M. Duda, K. Kutek-Sładek, *Zaburzenia relacji wewnątrzrodzinnych w kontekście pojawienia się dziecka z niepełnosprawnością*, "Osoby niepełnosprawne a życie rodzinne" 2011, No. 1/4, p. 92.

patterns towards their healthy children, of which the most common are the following: excessive focus on a child with a disability, imposing too many duties on a healthy child, having too high expectations of a healthy child, using a healthy child as an excuse to justify the rejection of a child with a disability, as well as integrating a disabled child with the family while caring for the needs of a non-disabled child. In this part of the article, each of these behaviors will be discussed.

### 1.1. Excessive attention focused on the child with a disability

Parents are sometimes so much involved in the care for their disabled child that they start to marginalize their healthy children. They believe that showing love to the child with a disability should be a priority and all their paternal love should focus on them, to the detriment of other family members, including healthy children who feel neglected by their parents<sup>2</sup>. A disabled brother or sister absorbs so much attention that parents become less sensitive to the needs of their healthy children, or quite the opposite – trying to compensate them for the scarcity of attention, they allow them everything. Excessive focus on a child with a disability can cause jealousy and anger in the healthy siblings, who may, as a result, reject their disabled brother or sister and express negative emotions toward their parents<sup>3</sup>. In fact, they feel rejected and less loved by their parents. These feelings intensify when they compare their situation with the situation of their peers who do not have a disabled sibling. Healthy children begin to think of their disabled brother or sister as the cause of their failures. However, being aware of the situation and the expectations of their parents, they do not speak openly about their negative emotions and blame themselves for feeling this way. According to a study conducted by A. Kosecka<sup>4</sup>,

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<sup>2</sup> Cf. Ibid.

<sup>3</sup> Cf. M. Ochniowska, *Problemy rodziny wychowującej dziecko o zaburzonym rozwoju*, [www.ppp2zamosc.pl/dat/attach/51\\_problemy\\_rodziny\\_wychowujacej\\_dziecko\\_o\\_zaburzonym\\_rozwoju.pdf](http://www.ppp2zamosc.pl/dat/attach/51_problemy_rodziny_wychowujacej_dziecko_o_zaburzonym_rozwoju.pdf) (14.04.2016).

<sup>4</sup> Cf. A. Kosecka, *Stosunki wewnątrzrodzinne w percepcji rodzeństwa dzieci autystycznych*, "Psychologia Wychowawcza" 1991, No. 42(1), pp. 41-50.

the healthy siblings of autistic children feel neglected by their parents, because they spend more time with their disabled children. Nevertheless, they understand the situation; they know that due to disability, their sibling requires more care and attention. This does not mean, however, that they do not experience negative emotions, such as jealousy, resentment or rejection. Kosecka notes, though, that parents realize that their healthy children may feel neglected. Having this awareness, they can try to organize their care and time devoted to their children in such a way as to try to avoid negative consequences for their healthy children. The feeling of neglect affects particularly younger siblings, who may start to fight their disabled brother or sister for attention and affection of their parents, treating them as rivals.

Parents often give their disabled child more attention not only because the disability of their son or daughter objectively requires it, but because they feel sorry for him or her. Such an attitude is always detrimental to healthy children who consider it unfair, as they notice that parents are uncritical and overprotective toward their sibling, while taking little interest in their needs and limiting their rights<sup>5</sup>. Healthy children experience negative emotions that may be targeted at both their parents as well as their disabled sibling.

## 1.2. Imposing too many duties on the healthy child

The care for an intellectually disabled child often absorbs so much time that parents burden their healthy children with excessive household chores or responsibilities associated with the care for their disabled sibling. Younger children may be particularly affected by the loss of the privileges reserved to the youngest members of the family and, therefore, experience the feelings of anger, resentment and guilt<sup>6</sup>. Healthy siblings may feel overburdened and face more adaptation problems<sup>7</sup>. The responsibilities that fall on the healthy siblings of an

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<sup>5</sup> Cf. K. Białek, *Dziecko niepełnosprawne umysłowo i autystyczne w rodzinie a potrzeby zdrowego rodzeństwa*, "Dziecko Autystyczne" 2001, No. 2, pp. 94–101.

<sup>6</sup> Cf. P. Randall, J. Parker, *Autyzm. Jak pomóc rodzinie*, Gdańsk 2001.

<sup>7</sup> Cf. *ibid.*

intellectually disabled child vary and may include: performing small household chores, preparing meals by themselves, watching a brother or a sister, feeding them, helping them in learning or taking them to school<sup>8</sup>. The excess of obligations deprives healthy children of the free time and carefree their peers enjoy. According to a study carried out by Stomma<sup>9</sup> et al., as many as 63% of children felt overburdened with too many responsibilities toward their disabled sibling.

Performing duties connected with the care for a brother or sister with a disability often interferes with learning and happens at the expense of healthy children's social life and hobbies. This is also emphasized by T. Gałkowski<sup>10</sup>, who notes that the older siblings of an intellectually disabled child are often burdened with too big responsibilities. It is often the case that an older sister has to take the role of the mother, carer and teacher. According to Gałkowski, the care for a disabled sibling does not always contribute to the development of a positive social attitude in healthy children. On the contrary, it often adversely affects their education and functioning in the peer group.

On the other hand, adults who participated in the care for their disabled sibling in childhood admit that they gained valuable experience by learning patience, empathy and resourcefulness<sup>11</sup>. What is important, though, is that the care for a disabled brother or sister should not become healthy children's main activity, pushing other elements of their life into the background. "If a child devotes almost all of their free time to help their siblings and do household chores, it is a sign that they are overburdened, even though such an attitude may seem very positive at first glance. Their whole world revolves around their brother or sister; they do not have time to pursue their own interests. Also, they may simply feel tired and have no energy

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<sup>8</sup> Cf. *Rodzeństwo osób z niepełnosprawnościami*, ed. J. Koral, Warszawa 2013, p. 38.

<sup>9</sup> Cf. K. Białek, *Dziecko niepełnosprawne umysłowo i autystyczne w rodzinie a potrzeby zdrowego rodzeństwa*, op. cit., pp. 94–101.

<sup>10</sup> Cf. T. Gałkowski, *Problemy rodzin dzieci upośledzonych umysłowo*, "Zagadnienia wychowawcze a zdrowie psychiczne" 1978, No. 6, pp. 69–75.

<sup>11</sup> Cf. *Rodzeństwo osób z niepełnosprawnościami*, op. cit., p. 38.



to do other things”<sup>12</sup>. Overloading a child with too many duties may also result in the feeling of burnout.

### 1.3. Having too high expectations of the healthy child.

It happens that a healthy child with a disabled sibling is idealized by parents who transfer their unfulfilled ambitions and hopes on him or her, all those expectations that cannot be met by their disabled offspring<sup>13</sup>. It is a huge pressure for the healthy child. Believing in their special talents and above-average development capabilities, parents put too high demands on their healthy children. Gałkowski states that in a family with a disabled child a healthy son or daughter can be viewed as compensation for the shortcomings associated with their disabled child<sup>14</sup>. In such a situation, healthy children feel that they cannot make any mistakes, and, holding this belief, they develop severe anxiety<sup>15</sup>.

### 1.4. Using the healthy child as an excuse to justify the rejection of the disabled child

The healthy child sometimes becomes an excuse for parents to distance themselves from their disabled child<sup>16</sup>. This concerns situations in which parents choose to place their intellectually disabled child in institutional care, justifying their decision with the necessity to provide care for their healthy children. However, if a disabled child does not objectively require staying in a special care center, and parents seek to find justification for their decision in the good of their healthy

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<sup>12</sup> Ibid.

<sup>13</sup> Cf. M. Ochniowska, *Problemy rodziny wychowującej dziecko o zaburzonym rozwoju*, op. cit.

<sup>14</sup> Cf. T. Gałkowski, *Problemy rodzin dzieci upośledzonych umysłowo*, op. cit., pp. 69–75.

<sup>15</sup> Cf. A. Hamerlińska, *Kształtowanie osobowości dziecka zdrowego w obliczu niepełnosprawnego rodzeństwa*, [http://kpsw.edu.pl/pobierz/wydawnictwo/noe3/113\\_Agnieszka%20Hamerlinska.pdf](http://kpsw.edu.pl/pobierz/wydawnictwo/noe3/113_Agnieszka%20Hamerlinska.pdf) (12.07.2016)

<sup>16</sup> Cf. M. Duda, K. Kutek-Sładek, *Zaburzenia relacji wewnątrzrodziny w kontekście pojawienia się dziecka z niepełnosprawnością*, op. cit., p. 92.

children, the healthy siblings may experience a sense of guilt towards their brother or sister. What's more, they may perceive this situation in terms of parental rejection of the disabled sibling, and thus may feel insecure and have concerns about their own relationship with their parents<sup>17</sup>. Numerous studies have shown that despite placing an intellectually disabled sibling in a center, the healthy children did not experience any relief or satisfaction<sup>18</sup>. Some studies have even demonstrated escalation of a conflict between parents and healthy children. According to researchers, this may be due to the fact that parents' all attention focused on their healthy children after putting the disabled son or daughter in institutional care. Placing a child in a center for children with special needs is a separate and very important topic, which will be elaborated further in the paper. It is worth noting, though, that the decision to refer a disabled child to a care facility should always be driven by necessity, not convenience, which seeks justification in the good of healthy children.

#### 1.5. Integrating the disabled child with the family and caring for the needs of the healthy child

This is the healthiest and most appropriate approach that parents can take. What is comforting is that, according to research, such an attitude is adopted by the majority of parents<sup>19</sup>. It allows to keep the balance between the needs of an intellectually disabled child, and the rest of the family, including his or her healthy siblings. It is a model that should be implemented in all families where a disabled child is raised, regardless of the type or degree of disability. The rest of the paper will discuss various emotions experienced by the healthy siblings of children with intellectual disabilities. It is crucial to show

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<sup>17</sup> Cf. M. Ochniowska, *Problemy rodziny wychowującej dziecko o zaburzonym rozwoju*, op. cit.

<sup>18</sup> Cf. T. Gałkowski, *Dzieci specjalnej troski*, Warszawa 1972, p. 246.

<sup>19</sup> Cf. M. Duda, K. Kutek-Sładek, *Zaburzenia relacji wewnątrzrodziny w kontekście pojawienia się dziecka z niepełnosprawnością*, op. cit., p. 93; M. Ochniowska, *Problemy rodziny wychowującej dziecko o zaburzonym rozwoju*, op. cit.

how much a disabled sibling changes in their lives and how important it is that parents be able to keep this healthy balance, dividing their time, attention and care among all of their children.

## **2. Emotions felt by the siblings of an intellectually disabled child**

The presence of an intellectually disabled child in the family can be a source of huge stress and burden for his or her healthy siblings<sup>20</sup>. However, it can also be a positive and enriching experience. “Research shows that children who have a brother or sister with a disability are more socialized and tolerant, become independent and self-reliant more quickly, behave altruistically more often, and are also more mature and trustworthy. Thanks to such experiences, they are able to interpret the situation of other people more deeply”<sup>21</sup>.

It depends on the parents how the relationship of a healthy child with his or her disabled sibling will be shaped, and what kind of experience this relationship will bring. The subsequent part of the article will present various emotions that accompany the healthy siblings of an intellectually disabled child. These include: love, happiness and pride; anger; shame and embarrassment; jealousy; anxiety; feeling guilty; loneliness and inadequacy; fatigue as well as being overloaded with duties and responsibilities<sup>22</sup>.

### **2.1. Love, happiness and pride**

To begin with, it is worth noting that the majority of healthy siblings of children with intellectual disabilities have a strong emotional bond with their brother or sister<sup>23</sup>. They are involved in taking care of their siblings and try to protect them in threatening situations. They are also proud of their siblings’ successes and happy when their brother or sister acquires new skills. Shared moments of fun and jokes are a source of joy and strengthen their mutual bond. The healthy siblings

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<sup>20</sup> Cf. *Zespół Downa w XXI wieku*, ed. J. Koral, Warszawa 2013, p. 98.

<sup>21</sup> Ibid.

<sup>22</sup> Cf. *Rodzeństwo osób z niepełnosprawnością*, op. cit., pp. 18–41.

<sup>23</sup> Cf. *ibid.*

are not indifferent to their disabled brother or sister's mood; they share joy with them, but are also affected by their sadness and frustration. The healthy children and their disabled brother or sister often build a very close relationship.

## 2.2. Anger

Anger appears in various relations and is a permanent element of our lives<sup>24</sup>. Siblings often get angry at each other, also in the families where none of the children is struggling with a disability. Feeling anger is natural; it is crucial, though, how to express it. Parents should teach their children to call emotions building up inside them and release tension in a way that would not hurt anyone. The siblings of an intellectually disabled child may experience anger in the following situations:

- when they feel underestimated or ignored at home; when they get insufficient attention from their parents and have the impression that parents do not appreciate their efforts and that they are treated unfairly because parents devote more attention to their disabled brother or sister;
- when they experience aggression from their intellectually disabled siblings or when they witness the siblings' aggressive behavior toward their parents, or when a disabled brother or sister destroys their property;
- when they realize that their disabled siblings are mistreated, ridiculed, isolated, or excluded;
- if they experience mistreatment themselves for having an intellectually disabled sibling (e.g. someone ridicules them or calls them names);
- when they are asked to do things they do not want to do, e.g. take care for the disabled siblings;
- when they cannot do what they want, e.g. having parents exclusively for themselves for a while;

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<sup>24</sup> Cf. *Ibid.*, pp. 19–22.

- when they experience rejection or feel being ignored by their disabled sibling.

Children have different ways of expressing anger, from bottling it up inside to bursting with it and being aggressive. The more parents will help their children understand and call emotions stirring up inside them, the better way of dealing with them the children will work out. This is crucial as uncontrolled anger can be a source of intense stress for a child.

### 2.3. Shame and embarrassment

The feelings of shame and embarrassment are often experienced, usually in public places, by the siblings of a disabled child. Intellectually disabled children may behave in a way that attracts people's attention. They may scream, make incomprehensible sounds, have fits of aggression, throw objects, and even if their behavior does not significantly deviate from the accepted standards, they still very often become an object of interest of people passing by. In such situations, the healthy siblings may be ashamed of their mentally disabled brother or sister. However, these feelings need not be limited to public places only but can appear whenever non-family members are present, e.g. when friends pay a visit and witness incomprehensible behavior or lack of resourcefulness of the disabled siblings.

This is how Beata, who has got an intellectually disabled sister, describes it: "I love my sister, but when I see that others laugh or poke jokes at her, I feel terribly sorry. I am ashamed that I have such a sister, I am ashamed that these people are so cruel and I am ashamed that I can't pass over it"<sup>25</sup>.

### 2.4. Jealousy

There may be various reasons behind jealousy experienced by the healthy siblings of a disabled child. Jealousy may stem from the sometimes justified belief that parents spend more time with their disabled

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<sup>25</sup> Ibid., p. 23.

son or daughter, that the whole family is focused primarily on him or her, while the healthy child's needs are of secondary importance.

The feeling of jealousy may also occur when a healthy child compares his or her situation to the life of their friends who do not have a disabled sibling. They can see that those families find time for family entertainment and trips, while their family has to give up a number of things because of the disability of one of its members. Sometimes a healthy child feels ignored or even less loved by their parents, who, in their eyes, become interested in their life only when they start to cause problems. Indeed, such a feeling may directly result from the parents' wrong attitude toward their healthy children, as has already been indicated. Although healthy children do not require special care and are able to take care of themselves, parents must realize that their healthy children still need their interest, time devoted only to them and simply love.

## 2.5. Anxiety

Anxiety is another emotion often experienced by children having a disabled sibling. Disability is difficult to understand. It remains a mystery and as such generates fear. Uncertainty about further diagnosis and future development prospects only intensify not only parents' concerns, but also the concerns of the healthy siblings. This is normal; however, the intensity of anxiety depends on a number of factors, including the age of the healthy siblings, parents' attitude towards the disabled child, the degree of disability, as well as the scope of the healthy siblings' knowledge about their brother or sister's disability. Lack of knowledge is always a driving force behind all fears. Healthy children may be afraid that they will get infected with their brother or sister's disability. Anxiety may also be caused by concerns for the future of the disabled siblings, whether they will become more self-reliant, and if not, what it will mean for the whole family. Healthy children may also be afraid that their family is loaded genetically and perhaps their own children will also suffer from some kind of intellectual disability. Parents should not underestimate any of these fears, even if they seem completely irrational. They

should talk with their children and explain them the nature of their sibling's disability. Meetings with experts, professional literature, as well as books specially dedicated to children may also prove helpful here. The conversation and the degree of knowledge passed to a child must always be adjusted individually to the age of a given child. Even the youngest child has the right to know what is happening to their brother or sister. Lack of knowledge and unawareness will, in fact, only increase fear and anxiety.

## 2.6. Guilt

It sometimes happens that the siblings of a disabled child experience guilt. The healthy child may feel guilty for having negative feelings or behaving badly toward their disabled brother or sister. Feeling guilty could also be caused by the awareness that they are more capable, successful, and resourceful than their sibling. Guilt is a very destructive emotion, especially when it is unfounded. Children having a disabled sibling may feel guilty because they actually acted wrongly toward their brother or sister. But they can also blame themselves for the disability of their siblings, or, as has already been mentioned, for being more successful than their brother or sister. Parents should help their children understand what kind of guilt they are experiencing and work it through together. According to Spock and Lerriga<sup>26</sup>, the feeling of guilt experienced by the healthy siblings related to the fact that their brother or sister is disabled while they are not, can reduce their involvement in taking care of their disabled siblings.

## 2.7. Loneliness and the feeling of inadequacy

When a family has no contact with other families raising a child with an intellectual disability, the healthy siblings may have the impression that they are the only persons in the world that are confronted with such a situation<sup>27</sup>. Today, however, this is rarely the case as

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<sup>26</sup> Cf. K. Białek, *Dziecko niepełnosprawne umysłowo i autystyczne w rodzinie a potrzeby zdrowego rodzeństwa*, op. cit., pp. 94–101.

<sup>27</sup> Zob. *Rodzeństwo osób z niepełnosprawnością*, op. cit., pp. 36–37.

most families raising disabled children gather in organizations and associations founded precisely with the purpose of helping children with intellectual disabilities and their families, as well as integrating them with each other and the rest of society. There are also many websites and forums where families can meet and exchange experiences. Children with intellectual disabilities are no longer isolated from the society; they go to school and have social relationships, while their healthy siblings have the opportunity to meet peers who are in a similar situation.

The feeling of inadequacy and isolation can also result from the fact that a child spends too little time with their peers, because, for example, he or she is overburdened with excessive duties or ashamed to invite friends to the house. Healthy children can also isolate themselves from others if they are victims of bullying. The reason for peer harassment may, but need not be, the disability of their siblings.

The feeling of loneliness may intensify when the family does not talk about a brother or sister's intellectual disability, when it is treated as a taboo topic. Anyone who is struggling with a disability of their loved one should have someone who will listen to and understand them.

## 2.8. Fatigue and being overloaded with too many duties and responsibilities

The siblings of a disabled child must learn a lot and be able to do things that their peers need not to. The relationship between a healthy brother or sister and their disabled sibling is not a typical siblings relationship, as it is determined by an intellectual disability of one of the children. The healthy brother or sister is not just a playmate, a rival, a friend or a confidant. They often become a tutor and a therapist too. In this work there have been discussed various behaviors of the parents of a disabled child; imposing too many duties and responsibilities on a healthy child was one such kind of behavior.

Due to the specific behavior of an intellectually disabled child, and the need to adjust the rhythm of the family life to his or her needs, having an intellectually disabled sibling can be tiring. When



non-disabled siblings are burdened with too large responsibilities, they may start to experience fatigue, but also the state of burnout with very serious consequences. Parents must remember that their children are still children, even if they may exhibit exceptional maturity and sense of responsibility. They need to have time to rest and play, have the right to their own space and be allowed to have a bad day from time to time. They have the right to live their own lives. And they have the right to choose to what extent they want to be involved in the care for their disabled sibling. It often happens that healthy siblings undertake various duties in spite of themselves and their own needs, but do not talk about it, because they do not want to hurt anyone or cause trouble. This may give rise to some various negative emotions building up inside them. Therefore, parents should discuss with their children how the care for their disabled sibling will look like and make some decisions together so that the needs and capabilities of all family members are taken into account. Children who have siblings with disabilities are often mature beyond their years. “Many adults who grew up with a brother or sister with special needs say that this experience made them stronger and more resourceful. Generally, their life looked different from the life of their peers – from an early age they had more responsibilities (...). This meant that they lacked the leisure and carefree their peers could enjoy, but on the other hand, they became more patient, resourceful, able to empathize with the needs of the other person”<sup>28</sup>. However, if a child has too many responsibilities while feeling pressure to fulfill them, instead of learning a useful lesson for the future, they will be frustrated and exhausted. Therefore, it is important that their needs be respected and met.

### **Conclusion**

The emergence of an intellectually disabled child in the family is a huge blow not only for the parents but also for the healthy siblings. It is parents who are responsible for how they themselves, and each of their children, will find themselves in a new situation. Parents of

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<sup>28</sup> Ibid., pp. 37–38.

a mentally disabled child often take the wrong attitude towards their healthy son or daughter, giving them too much responsibility, having too high expectations of them and not devoting enough attention to them. The healthy children who have got a disabled sibling are struggling with a lot of new tough emotions. They experience jealousy, fear, guilt, shame, loneliness, burden of too much responsibility, but also love and pride. Parents' attitude should offer support instead of giving rise to further frustration or anxiety. Parents should help their children name and understand all these feelings that their children are experiencing due to having an intellectually disabled sibling. It is necessary to talk openly and honestly about the negative and positive things of a given situation. Parents should encourage their children to express different emotions, speak about their fears and anxieties, and accept the feelings they are experiencing, while teaching them how to deal with these emotions.

### **Summary**

The birth of an intellectually disabled child is a shock not only for the parents but also for the non-disabled siblings. How a healthy child will adapt to a new situation depends largely on the parents themselves. The article describes the attitudes of parents towards their non-disabled children as well as the emotions experienced by the healthy siblings of an intellectually disabled child.

### **Streszczenie**

Pojawienie się w rodzinie dziecka niepełnosprawnego intelektualnie to wstrząs nie tylko dla rodziców, ale także dla jego pełnosprawnego rodzeństwa. To, w jaki sposób zdrowe dziecko odnajdzie się w nowej sytuacji, zależy przede wszystkim od samych rodziców. W artykule zostały opisane postawy, jakie rodzice przyjmują wobec zdrowego dziecka, a także przeżycia zdrowego rodzeństwa dziecka niepełnosprawnego intelektualnie.

**Keywords:** intellectual disability, family, sibling with an intellectual disability, parent's behavior, excessive attention, high expectations, disabled child, integration

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