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***Experiences of young people whose sibling has a developmental disability  
– the impact of the type of disability, sex and birth order***

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**Doświadczenia młodzieży związane z posiadaniem rodzeństwa z zaburzeniami rozwoju  
– wpływ rodzaju zaburzeń, płci i kolejności urodzeń**

The problems resulting from the child's developmental disability significantly affect the functioning of their brothers and sisters. Particularly interesting information can be obtained from interviews with children and young people asked about their experience of living in a family with a developmentally disabled sibling. They show that at the age of 2-3 years, children often want to imitate their older brother or sister who has a manifest disability (e.g. physical disability or Down syndrome) (Hames, 1998). At the same time, they begin to notice differences in the appearance of their sibling as compared to other people at a very early stage, usually before their second birthday. Soon, they begin to imitate the behaviour of their parents towards their brother or sister.

The siblings of persons with developmental disabilities recognise the positive changes that occur in their perception of others as a result of their interactions with their disabled brother or sister (Pit-en Cate and Loots, 2000). However, they also notice specific problems related to difficulties in communicating with their brother or sister, fear for their health and future, and the inevitable conflicts. Children who have a typically developing brother or sister experience stress in their everyday interactions as well. The rate of stressful interactions can be equal in the families with developmentally disabled children and in those with typically developing offspring (Roeyers and Mycke, 1995). The major differences concern the type of stressor.

We know very little about the manner in which particular types of disability affect the siblings of the disabled child. It was demonstrated, however, that children whose sibling suffers from autism are more likely to feel embarrassed by their brother's or sister's behavior than those whose sibling suffers from Down syndrome or is developing typically (Roeyers and Mycke, 1995). Knott, Lewis, and Williams (1995) found that the interactions of healthy siblings and children with autism are significantly poorer compared to the interactions of children with Down syndrome and their siblings. An important factor affecting the family process is the sex of the typically developing child (Schreiber, 1984). Girls tend to adapt to the role of their brother's or sister's caregiver more easily, which seems to reflect their typical social roles as women. However, this can sometimes result in the girls being overburdened with care-giving duties. Cuskelly and Gunn (1993) found that mothers of children with Down syndrome tend to notice more emotional difficulties in their typically developing daughters than in their sons. Even though the researchers did not investigate the number of daily chores the boys or the girls were obliged to perform, we can assume that it was a significant differentiating factor.

As was noted by Dyson (1999), the impact of a child's disability for the functioning of his/her sibling can be particularly apparent in the transitional period between childhood and adolescence, due to a number of physiological and psychological changes that occur at that time. Living with a disabled brother or sister generates additional pressure.

The purpose of the study<sup>1</sup> presented in this paper was to determine what are the most important problems experienced by siblings of children with developmental disabilities. We compared the experiences of young people whose sibling had either Down syndrome or cerebral palsy. We also analysed the effect of birth order and sex of the subjects on their problems related to brother's or sister's disability. The purpose of the study was to answer the following questions:

1. Does the type of disability affect the way young people perceive their disabled brother or sister?
2. Is there a relationship between the sex of the subjects and the way they perceive their disabled brother or sister?
3. Is there a relationship between birth order in the family and the perception of a disabled sibling by typically developing young people?

## SUBJECTS

The participants in the study were young people whose brother or sister suffered from cerebral palsy (20 persons), Down syndrome (20 persons) or developed typically (28 persons). The distribution of sex among the subjects and siblings and age of siblings was similar in all study groups. All subjects were aged 12-17 years.

## METHOD

A 21-item questionnaire was devised for the purposes of the study. The items concerned, among others, relationship with brother or sister, time spent together and support from parents. Subjects rated their answers on a 5-point scale (e.g. "Do you ever spend your free time with your brother/sister?" 1-never, 2-rarely, 3-sometimes, 4-often, 5-always).

## RESULTS

The results were analysed using the chi-square test, which revealed differences between groups in terms of:

1. Time spent with brother or sister ( $\chi^2=9,50$ ,  $p<0,01$ ): young people spent the most time with their siblings suffering from cerebral palsy, followed by those with siblings suffering from Down syndrome. The smallest amount of time was spent together by young people and their typically developing siblings.
2. Involvement in providing care for brother or sister ( $\chi^2=28,73$ ,  $p<0,001$ ) – higher for young people whose sibling had a developmental disability than those whose sibling developed typically. No differences were found between young people whose sibling suffered from cerebral palsy and Down syndrome.
3. Including brother or sister in plans for the future ( $\chi^2=17,35$ ,  $p<0,001$ ): significantly more frequent in the case of young people whose siblings had a developmental disability than in the case of those whose siblings developed typically. No differences were found between young people whose siblings suffered from cerebral palsy and Down syndrome.
4. Concerns about the future of brother or sister ( $\chi^2=30,35$ ,  $p<0,001$ ) were significantly more frequent in the case of young people whose siblings had a developmental disability than in the case of those whose siblings developed typically. No differences were found between young people whose siblings suffered from cerebral palsy and Down syndrome.
5. Anger towards brother or sister ( $\chi^2=7,13$ ,  $p<0,05$ ) – most frequent for young people with typically developing siblings; no differences found between the other groups.

Furthermore, young people whose siblings suffered from developmental disability were more likely to claim that their relationship with brother or sister stimulated the development of positive personality traits ( $\chi^2=9,83$ ,  $p<0,01$ ). No differences in that area were found between young people whose siblings suffered from cerebral palsy and Down syndrome.

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<sup>1</sup> Data presented in this article was obtained by Agnieszka Pabisiak-Jerusalimcew in her unpublished MA thesis titled: „Depression in the siblings of children with cerebral palsy and Down syndrome”, prepared under the tutorship of Ewa Pisula at the Warsaw University Faculty of Psychology in 2001.

The relationships between the type of sibling disability and the sex of subjects, and the perception of sibling and subjects' own situation were analysed with the Mann-Whitney U test. The following differences between boys and girls were found:

1. Girls whose sibling has cerebral palsy were meet their friends significantly less often than boys ( $U=21,0$ ,  $p<0,05$ ).
2. Boys whose sibling has cerebral palsy are more likely to blame their sibling for their failures than girls ( $U=27$ ,  $p<0,05$ ).
3. Boys whose sibling has cerebral palsy are more likely to declare that they would prefer to be only children than girls ( $U=7,5$ ,  $p<0,001$ ).
4. Boys whose siblings has cerebral palsy claimed that they had too many chores more often than girls ( $U=12,0$ ,  $p<0,005$ ).
5. Boys whose sibling has cerebral palsy are more likely to feel angry at their siblings than girls ( $U=23,0$ ,  $p<0,05$ ).

The impact of birth order in the family on the perception of siblings was also analysed. We found that:

Young people with younger siblings suffering from cerebral palsy spend more time with them than those whose sibling was older ( $U=24,5$ ,  $p<0,05$ ).

1. For all groups, young people whose sibling is younger take care of them more often ( $U=28,5$ ,  $p<0,05$ ).
2. Parents speak more often with the subjects about the disability of their sibling with cerebral palsy if the sibling is younger ( $U=23,5$ ,  $p<0,05$ ).
3. Young people with younger siblings suffering from Down syndrome are more likely to have support and understanding of their peers than those whose sibling is older ( $U=23,0$ ,  $p<0,05$ ).
4. Young people with older siblings suffering from Down syndrome are more likely to blame them for their failures than those whose sibling is younger ( $U=27,0$ ,  $p<0,05$ ).

## DISCUSSION

The present study confirmed that the experiences of young people whose siblings have developmental disorders differ significantly from the experiences of those whose siblings develop typically. We also found a significant effect of the type of disability (cerebral palsy vs. Down syndrome) on the nature of those experiences, although it is definitely the presence of the disability itself that comes to the foreground. As was predicted, young people with developmentally disabled siblings take care of their brother or sister more frequently than young people whose siblings develop typically. They are also more likely to think about their siblings' future and include them in their own plans for the future. Our subjects, however, did not feel overburdened with care-giving chores. The only exception are boys whose brother or sister has cerebral palsy. This finding confirms the hypothesis that girls tend to adapt more easily to the role of care-giver for their disabled brother or sister (Schreiber, 1984). The boys who participated in our study were more likely to blame their sibling for their failures and to feel anger towards them than girls. Girls were found to go out less often with their friends, which might suggest that the actual load was heavier on them rather than on the boys.

The finding that more young people with typically developing siblings declare feeling angry towards them than young people whose brother or sister has cerebral palsy or Down syndrome is particularly interesting. There is a possibility that children whose brother or sister suffers from developmental problems undergo a special kind of training when it comes to patience and containing negative feelings towards their sibling. We can assume that they are at least equally likely to experience feelings of anger towards their brother or sister – after all, they experience far more frustration in their daily interactions. Perhaps then, the result of the aforementioned training is that young people begin to perceive their anger at their disabled sibling as something unacceptable. This in turn might suggest that young people whose brother or sister has a developmental disability tend to suppress their negative emotions. In consequence, there is no outlet for the mounting tension, which may contribute to the increased level of depressiveness (Pisula, Danielewicz, 2004). Such result would be in line with other data obtained from research. Roeyers and Mycke (1995) demonstrated that siblings of children with autism or Down syndrome expressed more approval for their brother or sister than siblings of typically developing children.

The adjustment of those siblings is influenced to a large extent by their awareness of their brother's or sister's illness or disability. Discussing the sibling's difficulties with the parents is an important factor that determines the young person's adjustment. Siblings of children with attention deficit, motor, and perception disorders, as well as with the Asperger syndrome demonstrate empathetic attitudes towards their brother or sister, as long as the parents provide family members with extensive knowledge about their child's disorder (Dellve et al., 2000). Parental support plays a key role from the point of view of the siblings' adaptive process. With adequate support, even pervasive disorders need not result in adjustment difficulties (e.g. Kaminsky and Dewey, 2002).

## CONCLUSION

1. Young people whose brother or sister has cerebral palsy spend the most time with their sibling, while those whose brother or sister is developing typically – the least.
2. Involvement in caring for their sibling is much greater in the case of young people whose brother or sister has a developmental disability than those with a typically developing sibling.
3. Young people whose sibling is developing typically are more likely to claim that they feel angry at them than young people whose brother or sister has a developmental disability.
4. More boys whose brother or sister has cerebral palsy blame their sibling for their failures than girls. The same result was obtained with regard to anger and the sense of being overburdened with care-giving chores.

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## ABSTRACT

The aim of the present study was to determine what are the most significant difficulties experienced by young people whose sibling has cerebral palsy, Down syndrome, or is developing typically. We analysed the impact of the birth order and sex of subjects on their perception of their situation and their sibling. The participants in the study were three groups of young people aged 12-17 years: siblings of children with cerebral palsy (20 subjects), Down syndrome (20), and developing typically (28). A questionnaire devised specifically for the study was used. Results show that young people whose brother or sister suffers from cerebral palsy spend the most time with their sibling, while those whose brother or sister is developing typically – the least. Involvement in caring for their sibling is much greater in the case of young people whose brother or sister has a developmental disability than those with a typically developing sibling. Young people whose sibling is developing typically are more likely to claim that they feel angry at them than young people whose brother or sister has a developmental disability. More boys who have a brother or sister suffering from cerebral palsy blamed their sibling for their failures than girls. The same result was obtained with regard to anger and the sense of being overburdened with care-giving chores.

## STRESZCZENIE

Celem badania było określenie najważniejszych problemów doświadczanych przez młodzież mającą rodzeństwo z mózgowym porażeniem dziecięcym, zespołem Downa oraz rozwijające się prawidłowo. Analizie poddano wpływ kolejności urodzeń i płci badanych na spostrzeganie przez nich swojej sytuacji oraz swojego rodzeństwa. W badaniu uczestniczyły trzy grupy osób w wieku 12-17 lat: rodzeństwo osób z mózgowym porażeniem dziecięcym (20 osób), z zespołem Downa (20 osób) oraz rozwijających się prawidłowo (28 osób). Wykorzystano ankietę skonstruowaną dla celów badania. Stwierdzono, że osoby mające brata lub siostrę z mpd spędzały z rodzeństwem najwięcej czasu, zaś osoby mające rodzeństwo rozwijające się prawidłowo – najmniej. Zaangażowanie w opiekę nad rodzeństwem było znacznie większe u osób mających rodzeństwo z zaburzeniami rozwoju niż u osób mających rodzeństwo rozwijające się prawidłowo. Młodzież mająca rodzeństwo rozwijające się prawidłowo znacznie częściej deklarowała odczuwanie wobec niego złości niż młodzież mająca rodzeństwo z zaburzeniami rozwoju. Chłopcy mający rodzeństwo z mpd częściej niż dziewczęta obwiniali rodzeństwo o swoje porażki, odczuli wobec niego złość, a także czuli się przeciążeni obowiązkami wiążącymi się z opieką nad nim.