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Brief report: Parental descriptions of sleep problems in children with autism, Down syndrome, and Prader–Willi syndrome

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Abstract

Children with an intellectual disability (ID) are at high risk of developing sleep problems. The extent to which the prevalence and nature of sleep problems in these children is dependent on the disorder underlying their intellectual impairments remains unclear. This study examined and compared parental descriptions of sleep problems in children with autism ($n = 37$), Down syndrome (DS; $n = 15$), Prader–Willi syndrome (PWS; $n = 29$), presumed familial intellectual disability (FID; $n = 29$), and typically developing children (TD; $n = 55$) in order to determine any influences of disorder on sleep patterns. The prevalence of sleep problems in the disability groups was at least four times higher than for TD children. Sleep problems were more prevalent in autism than the other disorders. Settling difficulties and co-sleeping were more common in the children with autism, whereas sleep maintenance problems were common in autism, DS, and FID, and daytime napping and excessive daytime sleepiness differentiated the children with PWS. These findings are discussed in light of the specific disorders, and with respect to the impact that sleep problems can have on the child and his/her family.

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Estimates of the prevalence of sleep problems in children with an intellectual disability (ID) are often high (Johnson, 1996). For example, Bartlett, Rooney, and Spedding (1985) examined nocturnal sleep difficulties in 214 children with severe ID between the ages of 6 and 16 years. Eighty-six percent of the children had one or more types of nocturnal sleep anomalies including difficulties maintaining bedtime routines (53%), excessive crying and distress (32%), yelling out to parents (22%), disturbing other family members (62%), frequent night-time awakenings (56.5%), co-sleeping (17.3%) in the parents' bed, and co-sleeping in the child's bed (7.5%).

Similarly, Clements, Wing, and Dunn (1986) reported that 34.2% of 163 children with severe ID had sleep problems, including frequent night waking (12.9%) and limited night sleep (13.5%), and 7% of the children experienced both of these problems. Night-time waking adversely affected family functioning, and in young children was associated with self-injurious behaviour. Limited hours sleep disrupted the child's daily behaviour routines. In a longitudinal study, Quine (1991) collected information on 200 children with an ID, covering including health, academic ability, sleep, behavioural problems, and family issues. Three years later this information was recollected for 178 of these children. In the first phase of data collection, 50% of the children had difficulties settling at night, 67% had problems with frequent night-time waking, and 32% of parents reported that their sleep was inadequate. At follow-up, the prevalence of settling difficulties and night awakenings decreased, but 61% of children continued to experience sleep difficulties. Thus, sleep problems were also chronic in the majority of cases.

These studies describe sleep problems in heterogeneous samples of children with an ID, who have a range of associated diagnoses including autism, Down syndrome (DS), and cerebral palsy, as well as children for whom the aetiology of the intellectual impairment is unknown, but is presumed to be familial (FID). This ignores the possibility that the prevalence, nature, and extent of sleep problems in these children maybe dependent on aetiology (Stores, 1992). If two developmental disorders with unique sleep patterns are combined, then the distinct features of their sleep profiles can be lost.

The prevalence of sleep problems fluctuates between disorders. Estimates of the prevalence of sleep problems in children with autism have ranged from 56% (Clements et al., 1986) to a high of 100% (Patzold, Richdale, & Tonge, 1998), and is higher than in IQ matched control groups (Richdale & Prior, 1995). For children with DS and Prader–Willi syndrome (PWS), the percentage of children with sleep problems is generally lower, averaging between 35 and 45% (Quine, 1991; Richdale, Cotton, & Hibbit, 1999). Thus, depending on the group composition, differences in rates of sleep problems across disorder groups may lead to variation in the frequency of sleep problems in heterogeneous populations of children with an ID.

Disturbances with bedtime settling, sleep onset, sleep maintenance, and early morning waking have commonly been reported in PWS (Cassidy, McKillop, & Morgan, 1990; Richdale et al., 1999), DS (Stores, Stores, Fellows, & Buckley, 1998), and autism (Cassidy et al., 1990; Cunningham et al., 1986; Hoshino, Watanabe, Yashima, Kaneko, & Kumashiro, 1984; Patzold et al., 1998; Richdale et al., 1999; Richdale & Prior, 1995; Schreck & Mulick, 2000; Stores et al., 1998; Taira, Takase, & Sasaki, 1998). It is unclear, however, whether or not children with these disorders experience these problems to the

same degree, or whether the same causative factors operate. Behaviours associated with obstructive sleep apnoea syndrome (OSAS) are commonly observed in children with DS (Levanon, Tarasiuk, & Tal, 1999; Stebbens, Dennis, Samuels, Croft, & Southall, 1991; Stores, Stores, & Buckley, 1996), whereas, excessive daytime sleepiness is often a major concern with PWS (Cassidy et al., 1990; Clarke, Waters, & Corbett, 1989; Helbing-Zwanenburg, Kamphusien, & Mourtazaev, 1993; Richdale et al., 1999). Conversely, long sleep latencies and extended periods of night-time waking often lead to marked reductions in total night-time sleep for children with autism (Hering, Epstein, Elroy, Iancu, & Zelnik, 1999; Hoshino et al., 1984; Patzold et al., 1998; Richdale & Prior, 1995; Taira et al., 1998).

The extent to which the disorder underlying a child's intellectual impairments predisposes him/her to particular sleep problems has not been determined. Typically it is the parents who draw their child's sleep problem to the attention of the clinician. Thus, parent descriptions of the presenting problem may be a valuable source of information concerning the differences and similarities, as well as the severity of the sleep problems suffered by children with an ID. Therefore, the aim of this study was to examine parent's descriptions of sleep problems in children with an ID, including those with autism, DS, and PWS, and how these sleep problems impacted on the child and his/her family. Consistent with previous literature, the prevalence of sleep problems in children with an ID was expected to be significantly higher than in typically developing (TD) children. It was also expected that the prevalence and nature of sleep problems would differ among children with autism, DS, PWS, and FID.

1. Method

1.1. Participants

The sample included children and adolescents aged between 2 and 18 years who had participated in three previous studies (Patzold et al., 1998; Richdale et al., 1999; Richdale, Francis, Gavidia-Payne, & Cotton, 2000). It comprised 153 children, of whom 98 had an ID and 55 were TD children. Of the children with an ID, 37 had autism, 15 had DS, 17 had PWS, and 29 children had FID. The age and gender distributions of the children are displayed in Table 1.

Table 1
Age and gender distributions of children with and without an ID

Group	N	Gender				Age			
		Males		Females		M	S.D.	Minimum	Maximum
		Percentage	n	Percentage	n				
Autism	37	75.7	28	24.3	9	7.09	2.49	3.50	14.00
Down syndrome	15	53.3	8	46.7	7	9.03	3.19	3.00	16.00
Prader-Willi syndrome	17	76.5	13	23.5	4	11.59	4.47	3.00	18.00
Non-specific ID	29	72.4	21	27.6	8	7.02	2.87	4.00	14.00
Controls	55	58.2	32	41.8	23	8.88	3.95	2.00	18.00

There was a higher proportion of males than females in each of the group. For some disorders, such as PWS and FID a gender bias is unexpected, however a 3:1 ratio for autism is consistent with literature reports (Batslaw & Shapiro, 1997).

The mean ages of the children in each of the groups varied. A one-way analysis of variance (ANOVA) indicated that the groups differed significantly with respect to age, $F(4, 148) = 6.50, p < .05$. The Games Howell post hoc test showed that children with PWS were significantly older than those with autism ($p < .05$) or FID ($p < .05$).

Children varied in terms of severity of intellectual impairment, ranging from mild to profound disabilities. For the children with autism 62.2% ($n = 23, N = 37$) had moderate to profound intellectual impairment. This can be compared with 66.7% ($n = 10, N = 15$) of those with DS, 35.3% ($n = 6, N = 17$) of those with PWS, and 64.3% ($n = 18, N = 28$) of those in the FID group with moderate to profound impairments. Chi-square analysis indicated that there was no relationship between the groups and severity of intellectual impairments.

1.2. Materials

In the original studies from which the current data are drawn, both a demographic questionnaire and a sleep questionnaire were used to collect child and family information (see Patzold et al., 1998; Richdale et al., 1999, 2000 for descriptions). Information was obtained on the child's gender, date of birth, birth order, the presence of a medical condition, medication history, and presence and severity of ID. The sleep questionnaire contained questions about the presence and severity of sleep problems, past and present sleep behaviour, daytime napping, excessive daytime sleepiness (EDS), settling habits, bedtime routines, and night-waking. A yes/no response indicated the presence or absence of sleep behaviours. Questions on severity of sleep and behaviour problems were rated on 100-mm visual analogue scales, which have been demonstrated to be both reliable and valid measures of sleep behaviours (Ott et al., 1985). Comments and written descriptions of sleep problems and behaviours were also requested.

1.3. Procedures

Families of children with an ID were recruited from a variety of services and organizations within the state of Victoria and details can be found in the three studies from which these data are drawn. Children in the control group were recruited either through local state schools or through staff in Psychology and Disability Studies, RMIT University.

On verbal agreement to participate in each study, primary caregivers or parents were sent an introductory letter, instruction sheet, consent form, the demographic questionnaire, and the sleep questionnaire. On completion of these questionnaires parents forwarded them to the researchers in a self-addressed, postage-paid envelope.

2. Results

Frequencies and percentages are the main descriptive statistics reported. Chi-square analyses were employed to determine the relationship between disorder and the presence or

absence of sleep problems. The Kruskal–Wallis one-way analysis of variance was used to examine VAS data. As data were missing for some children, and the number of valid data varies, sample size and group totals are reported for each analysis.

2.1. Prevalence and severity of current sleep problems

Parents reported whether or not their child had a sleep problem. Across the disorder groups, 54.2% ($n = 52, N = 96$) of children had a sleep problem. The highest percentage of sleep problems was found in the autism group (73.0%, $n = 27, N = 37$), followed by the children with FID (46.4%, $n = 13, N = 28$), DS (40.0%, $n = 6, N = 15$), and PWS (43.8%, $n = 7, N = 16$). Only 10.9% ($n = 6, N = 55$) of the control group had a sleep problem. There was a significant relationship between group membership and having a sleep problem, $\chi^2(4) = 37.05, p < .05$. Analysis of standardised residuals showed that children with autism were significantly more likely ($p < .01$) to have a sleep problem, whereas typically developing children were significantly less likely ($p < .01$) to have a sleep problem.

2.2. Severity of sleep problems

Severity of the current sleep problem was measured on a 100-mm VAS with zero representing *no problem* and 100 indicating *a severe problem*. The mean severity scores are displayed in Table 2 for the 58 children with sleep problems. Severity ratings were did not differ significantly across groups.

2.3. Types of current sleep problems

Parents were asked to qualify the nature of the sleep problem(s) experienced by their child. On the basis of parents' responses to this open-ended question sleep problems types were identified: settling problems, sleep maintenance, co-sleeping, nocturnal incontinence, early morning waking, and daytime sleepiness and/or excessive tiredness. The frequencies and percentages of the problems in each of the groups are highlighted in Table 3.

The most frequently described sleep problems were sleep maintenance and difficulties settling at bedtime; nocturnal incontinence occurred least frequently. Children with DS and FID were more likely to have sleep maintenance problems, whereas, children with autism were more likely to have settling difficulties or co-sleep. Daytime sleeping and/or EDS were common for children with PWS, but rare in the other groups.

Table 2
Mean severity of current sleep problems

	<i>n</i>	<i>M</i>	Mdn	S.D.	Minimum	Maximum
Autism	27	57.2	60.0	24.1	21.0	100.0
Down syndrome	6	47.8	46.5	23.9	19.0	74.50
Prader–Willi syndrome	6	49.2	50.5	34.4	0.0	100.0
Non-specific ID	13	54.9	53.0	29.9	7.0	100.0
Controls	6	53.3	55.0	16.2	25.0	71.0

Table 3
The various types of sleep problems identified by primary caregivers

Group	<i>n</i> ^a	Types of sleep problems					
		Settling	Sleep maintenance	Co-sleeping	Nocturnal incontinence	Early morning waking	Daytime sleeping/EDS
		<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>	<i>n</i>
Autism	27	18	15	6	1	1	1
Down syndrome	6	1	4	0	0	1	1
Prader–Willi syndrome	7	0	1	1	0	2	5
Non-specific ID	13	4	10	1	0	2	0
Controls ^b	5	3	2	0	0	0	0
Total	58	26	32	8	1	6	7
Total percentage	100	44.8	55.2	13.8	1.7	10.3	12.1

^a Number of children with a sleep problem.

^b For one child in the control group the parent had not described his sleep problem.

Chi-square analyses were conducted to determine the relationship between group membership, and settling and sleep maintenance difficulties, but not for the other types of sleep problems because of the small number of observed cases. Settling problems were related to group membership, $\chi^2(4) = 14.32$, $p < .05$. Children with autism had a significantly higher frequency of settling problems than the other groups, as determined by the standardized residual, $p < .05$ (Table 3). No relationship between group and the occurrence of sleep maintenance difficulties was found.

Often children presented with more than one type of sleep problem. Overall 41.4% ($n = 24$, $N = 58$) of the children had two or more sleep problems. Of the children with a sleep problem, 13 (48%) children with autism, 2 (33.3%) children with DS, 2 children with PWS (28.6%), 5 children with FID (38.5%), and 2 TD (33.3%) children had more than one type of sleep problem. Children with autism presented more frequently with two or more sleep problems, but low numbers in the other groups precluded any analysis of this trend.

2.4. Impact of sleep problems on the child and their family

When asked why their child's sleep patterns were problematic, parents gave two types of responses. The first was that the sleep disturbances were detrimental to the child (87.0%, $n = 47$, $N = 54$), while the second was that the child's sleep patterns adversely affected other family members (44.4%, $n = 24$, $N = 54$). Parents were more significantly more concerned about the child's welfare being affected by the sleep problem(s) than the sleep of other family members, $\chi^2(1) = 9.62$, $p < .01$. As well, 32.7% ($n = 18$, $N = 55$) of parents commented that both the child and family's well-being were being adversely affected by the child's sleep problems. However, there were no significant relationships between group membership and the reporting of whether the child and/or family members were being affected by the sleep problems.

For those families that focused on the welfare of the child, 52.1% ($n = 25$, $N = 48$) of the children had settling difficulties whereas 47.9% ($n = 23$, $N = 48$) had sleep maintenance problems. Focusing on the child's welfare was unrelated to settling problems or sleep

maintenance problems. Where parents focused on the impact of the sleep problems on family members, 40.0% ($n = 10, N = 25$) had settling problems and 72.0% ($n = 18, N = 25$) had sleep maintenance problems. Focusing on the family's welfare was associated with sleep maintenance difficulties, $\chi^2(1) = 6.83, p < 0.05$, but not settling problems.

3. Discussion

As hypothesized, and consistent with previous reports (Bartlett et al., 1985; Clements et al., 1986; Quine, 1991), the prevalence of sleep problems in this study was significantly higher in the disability groups as compared to the TD children. With respect to parental reports of sleep problems, similarities and differences between children with autism, DS, PWS and FID and TD children were also highlighted, and partially supported our second hypothesis that the groups would differ. Group differences observed included a higher frequency of a reported sleep problem, and settling and co-sleeping problems being associated with autism, and EDS being associated with PWS. This partially supports Stores (1992) claim that the prevalence and nature of sleep problems in children with an ID may depend on the aetiology of their developmental disorder. The frequency of sleep problems found for each of the disability groups was consistent with previous research (Cassidy et al., 1990; Hoshino et al., 1984; Quine, 1991; Richdale & Prior, 1995; Stores et al., 1996). However, the reported sleep problem severity did not differ between groups, which is consistent with the findings of Richdale and Prior (1995) for children with autism and an IQ matched control group.

There is limited information on sleep problem severity in children with disabilities, with some speculating that they may be more severe (Bartlett et al., 1985). In the present study, the severity of sleep problems was assessed on a VAS: Parents generally responded conservatively, with responses tending towards the middle. The maximum rating or *severe problem* was reported in the autism, PWS, and FID groups, but not the DS or TD group. The lack of difference between the groups with respect to sleep problem severity may relate to parents' perceptions. Parents of children with an ID often have to cope with many stressful situations, particularly as their children may have marked behavioural and emotional disturbances. Furthermore, in the three studies from which the current sample was drawn (Patzold et al., 1998; Richdale et al., 1999, 2000) sleep problems were significantly associated with increased behaviour disturbance. Significant daytime behaviour difficulties may be as, or more demanding of parents' attention than the sleep problems. Hence, parents of children with an ID may underestimate the severity of any sleep problems in light of other challenging and difficult behaviours with which they must contend. However, causality between behaviour disturbance and sleep difficulties has yet to be determined (Brylewski & Wiggs, 1998).

In the present study, six underlying themes were identified in parents' description of their child's sleep problems: difficulties settling at bedtime or initiating sleep, frequent night-time waking and/or lengthy night-time waking, co-sleeping, nocturnal incontinence, early-morning waking, and daytime sleeping and/or excessive daytime tiredness. That is dyssomnias rather than parasomnias are of greater concern to parents, and primarily involved those associated with the onset and maintenance of sleep. Many children (40%)

often had more than one type of sleep problem, highlighting the complex nature of the sleep disturbances. The most frequently occurring problem was sleep maintenance difficulties, occurring in 55% of the sample. Settling problems were also common, and occurred in 45% of our sample. Both settling and maintenance difficulties can adversely affect the quality (Stores, 1996), quantity (Piazza, Fisher, & Kahng, 1996) and/or timing (Stores, 1996) of the child's sleep.

It has been argued that 20% of children less than 2-years and 14% of children 3-years and older experienced night-time waking; only two of our typically developing children (age 3–18 years) had sleep maintenance problems (Hunter, 1983). Conversely, problems of sleep maintenance have been reported to occur in 50–60% of children with an ID (Bartlett et al., 1985; Quine, 1991), which is consistent with the figure found here for children with an ID. Sleep maintenance difficulties or frequent night-time waking has been reported in children with autism (Hoshino et al., 1984; Richdale & Prior, 1995; Taira et al., 1998), DS (Cunningham et al., 1986; Stores & Stores, 1996), PWS (Cassidy et al., 1990; Richdale et al., 1999; Sarimski, 1994), and FID (Quine, 1991). In the present study, children with DS and FID were more likely to have sleep maintenance difficulties as compared to settling problems. Previous research has linked sleep maintenance problems in children with DS to OSAS (Levanon et al., 1999). However, sleep maintenance problems were unrelated to group membership, indicating that frequent night-time waking may be a common occurrence in children with a developmental disability, though its origin may vary.

Previous research has indicated that 13% of typically developing children (Armstrong, Quinn, & Dadds, 1994; Cluydts & DeRoeck, 1988) and approximately, 50–56% of children with an ID (Bartlett et al., 1985; Quine, 1991) have problems with initiating sleep or settling at bedtime. Only three of our typically developing children had settling problems while 43% of the children with an ID did so. Difficulties settling have been reported previously in children with autism (Patzold et al., 1998; Richdale & Prior, 1995) and DS (Cunningham et al., 1986; Stores & Stores, 1996; Stores et al., 1996). In the present study, settling difficulties were significantly related to having a diagnosis of autism; two thirds of the children with autism had a settling problem. Previous studies have estimated the prevalence of settling problems to be between 26 and 82% in autistic children (Hoshino et al., 1984; Richdale & Prior, 1995; Taira et al., 1998).

Poor sleeping habits may contribute to settling difficulties in autism, including not being able to sleep in a dark room, lengthy and inappropriate bedtime rituals, and being unable to sleep without the mother's presence (Hoshino et al., 1984; Patzold et al., 1998). Such habits are likely to increase the time taken to settle into bed and to fall asleep at night. Indeed, lengthened sleep latencies may be a hallmark feature of settling difficulties in autistic children (Patzold et al., 1998; Richdale & Prior, 1995). Social difficulties leading to an inability to pick up appropriate cues related to bedtime may also be a factor in their aetiology (Richdale, 2001).

Co-sleeping can also be problematic in the sense that it may lead to settling difficulties and conditional night-time wakings (Ferber, 1995; Richman, 1981). Eight parents viewed co-sleeping as characteristic of their child's sleep problems and six of these children had autism. No control children co-slept with their parents. To compensate for their child's resistance, or reluctance, to go to sleep parents of children with autism may be forced to encourage co-sleeping. In children with autism, co-sleeping may also be promoted by their poor settling sleep habits (Hoshino et al., 1984) and night-time fears may also be a factor. A

parent of an 8.5-year-old girl with autism commented “*She wakes very frightened and won’t go back to her bedroom*” and “*... because she is afraid to go to sleep by herself ... since she was born and she has never slept in the room by herself.*”

Early morning waking was not common and it did not differentiate the groups. However past studies have suggested that early waking is more common in young children with autism (Hering et al., 1999; Richdale & Prior, 1995). Herring et al. in particular reported that early waking was the one objective measure (using actigraphy) that differentiated children with autism from a control group.

Daytime sleep and/or EDS was a problem for seven children and five of them had PWS. This suggests that daytime sleepiness is symptomatically specific to PWS and adds further support to the argument that EDS and daytime napping are qualitatively different in children with PWS and DS (Helbing-Zwanenburg et al., 1993). Parents of children with PWS are more likely to perceive these behaviours as problematic. For example, a parent of an 11-year-old male with PWS reported that “*Sleeps usually once or twice a week during school ... causes amusement to classmates*”. Indeed, a combination of the EDS, an increased occurrence of napping, and poor daytime behaviour, are likely to be disruptive to the daily routines of children with PWS and their families. EDS and daytime napping in children with PWS may be centrally mediated (Helbing-Zwanenburg et al., 1993; Hertz, Cataletto, Feinsilver, & Angulo, 1993; Sforza, Krieger, Geisert, & Kurtz, 1991) or due to a variety of causes including OSAS (Sforza et al., 1991), obesity (Harris & Allen, 1996), and narcolepsy (Cassidy et al., 1990; Clarke et al., 1989; Harris & Allen, 1996; Helbing-Zwanenburg et al., 1993; Vgontzas et al., 1996).

Across the groups, parents gave three types of response as to why their child’s sleep patterns were problematic: child-focussed, family-focussed, or child and family focussed and there were no group differences. That is, the frequency of the response categories did not differ across groups. This is an interesting outcome given that children with disabilities and typically developing children differed with respect to susceptibility to, and nature of sleep problems.

The most frequent type of response was child focussed, as parents expressed concern about the child’s welfare being adversely affected by the sleep problems. An example is a comment from a parent of a 9.83-year-old boy with DS was “*He gets tired during the day and is extremely grumbly and teary. He also yawns a lot*”. Over 40% of parents reported concern about how their child’s sleep problems affected other family members. Examples of these responses included: “*He needs supervision until he is asleep, no time for my husband and I to spend time together uninterrupted*” (parent of a 8-year-old boy with autism), and “*He wakes not only those sleeping in the room but needs two of us to put him back to bed*” (parent of a 6-year-old boy with FID). Some parents focussed on the effect of sleep disturbances on the child as well as the family. For example, “*Neither of us get a lot of good sleep and I work full-time as a sole parent. Fatigue and frustration are real problems*” (parent of a 5-year-old girl with autism).

Family-focussed responses were more common in children with sleep maintenance problems. This finding is not unexpected. A child’s broken sleep often disrupts parents’ sleep. A sleepless child may be excessively noisy through playing with toys, turning on the TV, or video game machine (Bartlett et al., 1985; Clements et al., 1986). Children may also wake up other family members for either comfort or attention. Such behaviour is also likely to increase the probability of co-sleeping. Hence, night-time waking is likely to have detrimental consequences across the family.

In summary, sleep maintenance problems, problem severity, and family concerns were similar across the developmental disorders in this study, but other group differences were found. The likelihood of a parent-perceived sleep problem, settling problems or co-sleeping was clearly associated with autism, and EDS was common in PWS. Given that group differences were found, it seems inappropriate to consider sleep research on children with an ID without considering the aetiology of their ID. Also, night waking, which was common in most groups, may occur and be maintained for a number of reasons. Aetiology may be biologically based, such as OSAS, or behaviourally based, such as the failure to be able to self-soothe. Sleep disorders like OSAS are associated with developmental disorders such as DS. Biologically and behaviourally based sleep difficulties have different implications for both prevention and intervention. Thus, the premise on which the current study was conducted, that it is important to consider the nature of the child's developmental disorder when studying children's sleep problems (Stores, 1992), appears to us to be supported. Further research with larger samples is necessary to delineate the scope of sleep disturbances across the different developmental disorders and implications for prevention and treatment.

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