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# Time use of parents raising children with severe or profound intellectual and multiple disabilities

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## Summary

**Background** Raising children with severe or profound intellectual and multiple disabilities (PIMD) is expected to put extreme pressure on parental time use patterns. The aim of this study was to examine the total time use of mothers and fathers raising children with PIMD and compare it with the time use of parents of typically developing children.

**Method** Twenty-seven fathers and 30 mothers raising children with PIMD completed a time use diary on a mobile phone or tablet app, as did 66 fathers and 109 mothers of typically developing children. Independent *t*-tests and Mann–Whitney tests were performed to compare mean time use.

**Results** There are no differences in the time use of parents of children with PIMD on contracted time (paid work and educational activities) and necessary time (personal care, eating and drinking and sleeping) when compared with parents of typically developing children. There are significant differences between the parents of children with PIMD and the parents of typically developing children in terms of committed time (time for domestic work and the care and supervision of their children) and free time. The mothers of children with PIMD spend significantly less time on domestic work and more time on care and supervision than mothers of typically developing children.

**Conclusions** This study shows that the parents of children with PIMD have to spend a significant amount of time on care tasks and have on average 1.5 h less free time per day than parents of typically developing children. This is a striking difference, because leisure time can substantially contribute to well-being. Therefore, it is important not only to consider a child with PIMD's support needs but also to identify what parents need to continue their children's daily care and supervision.

## Keywords

care tasks, fathers, mothers, parents, profound intellectual and multiple disabilities, time use

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Most children with disabilities grow up at home, which is in agreement with the Convention on the Rights of Persons with Disabilities (United Nations, 2006). This is, however, not without consequences for parents, as raising a child with a disability requires extra time and care-taking tasks from parents. As McCann *et al.* (2012) showed in their systematic review, parents of children with a disability carry a significant caregiving burden (in terms of time), which often does not reduce as the age of the child increases (McCann *et al.* 2012). The study also showed that the severity of a child's disability is related to higher frequencies of childcare activities in parents

(Crowe 1993; Curran *et al.* 2001; McCann *et al.* 2012). There is however hardly any research on the time use of families of children with the most severe disability: those with profound intellectual and multiple disabilities (PIMD).<sup>1</sup> It is estimated

<sup>1</sup> The group consists of individuals with such profound intellectual disabilities that no existing standardized tests are applicable for a valid estimation of their level of intellectual capacity (Nakken & Vlaskamp 2007). Also motor disabilities are present. Therefore, not only the severity of the intellectual disability (severe or profound intellectual disability) but also the combination and complexity of the disabilities (which leads to dependency on others in all aspects of daily life) is important in describing the target group.

that there are 3000–4000 children with PIMD in the Netherlands (Vlaskamp 2015). Because of their intellectual, motor and sensory impairments, health problems and dependency on others for all aspects of daily life (Nakken & Vlaskamp 2007), raising a child with PIMD can be seen as a highly intensive and lifelong task. Although the study of Tadema and Vlaskamp (2010) showed that providing basic care needs of the child with PIMD has a great impact on the lives of his or her parents, this does not provide insight into parents' time use. This is however important, as time demands have important consequences for quality of life of families (Summers *et al.* 2005). Except for a (dated) study from 1989 (Edebol-Tysk 1989), there are no studies focused specifically on the (total) time use of parents raising children with PIMD. Also, fathers are not included in most studies on time use, even though a family is an interdependent unit and what happens to one member of the unit has an impact on other members (Thomas *et al.* 2011). Finally, the focus in many time use studies is solely on care tasks, whereas collecting information on all daily activities, including leisure time, would provide an indication of which other activities are sacrificed for those concerning the child with PIMD (Thomas *et al.* 2011). Therefore, the main goal in our study is to gather information about the time used for all daily activities for both mothers and fathers raising children with PIMD. As long as these parents' time use remains invisible and unknown, professionals, policy stakeholders and the general public cannot fully understand the parents and their care tasks, or the consequences on their work and leisure time. This knowledge is necessary to understand these family's needs, work in collaboration with them and develop services that are sensitive to the needs of the whole family unit.

## Method

### Participants

Several organizations such as parents' organizations, websites for the parents of 'children with complex needs' and our own research group raised awareness for this study in conventional and social media in the Netherlands. Two organizations offering day care activities for children with PIMD asked parents to participate too. In addition, families with children with PIMD asked other similar families to participate. Parents were included in this study if their child lived at home, had a severe or profound intellectual disability (IQ score < 35 points or a developmental age < 36 months), a motor disability, making them dependent on others for all aspects of daily life.

### Comparison group

A comparison group was used to provide 'normative' data to compare the time use of parents raising children with PIMD with the time use of parents raising typically developing children. The data on the fathers and mothers of typically developing children were selected from a time use study performed by the Netherlands Institute for Social Research (SCP), in which members of the representative Longitudinal Internet Studies for the Social sciences panel participated. The mothers and fathers in this study were not related to each other, resulting in one participating member per family. Fathers and mothers in the comparison group were randomly assigned to keep track of their time use in a week of one of the months of the year previous to the group of parents of children with PIMD. Selection criteria were as follows:

- Raising one or more typically developing children aged between 0 and 12 years;
- A member of a two-parent family;
- A time use diary was correctly completed for 1–3 days.

### Procedure

After signing up for the study, we asked the families to provide us with information about themselves and their child (aetiology and adaptive, motor and communicative behaviours) using a short questionnaire. Given this information, we checked if the participants met the inclusion criteria; in case of doubt, parents were contacted for more information. Families who met the inclusion criteria were explained that participation was voluntary and that the parents' privacy was guaranteed. The aim of the study was again explained during a home visit. Also, the parents received verbal and written instructions on how to keep track of their time use during data collection.

### Data collection

#### *Time use app*

Time use was measured using a time diary app for smartphones and tablets. Respondents could use the app everywhere at any time and complete their diary on their smartphone or tablet, independent from network accessibility. The original time use app [based on the Harmonized European Time Use Surveys (HETUS) guidelines] was developed by

CenterData for a time use study of the Netherlands Institute for Social Research (SCP); the data from this time use study were used as a comparison group (Sonck & Fernee 2013). The app was further adapted by CenterData especially to study the time use of parents raising children with a disability. The adapted version of the time use app was tested in a small pilot study, and the content of the category concerning care and supervision of children with PIMD was checked by parents. Some small inaccuracies were resolved, and the app was made even more user-friendly. Data for the current study were gathered over seven consecutive days in an ordinary week during 1 week in March 2014. The time use app divided hours into 10-min intervals (identical to HETUS), and parents recorded their primary activity for each interval using a pre-coded list, and they could add an additional activity from the pre-coded list to indicate a secondary activity carried out at the same time (secondary activity). Using pre-coded categories deviated from the HETUS guidelines (which prescribe open categories described by the respondents themselves) but is less burdensome for the respondents using a tablet or smartphone. If no pre-coded activity matched their activity, respondents could add a self-defined activity. The pre-coded lists of activities provided to parents with and without children with PIMD consisted of 14

main categories (Table 1) and 37 subcategories. One main category with seven subcategories was added to the app for this particular study: 'care and supervision of children with disabilities' (Table 1). The activities in this subdomain are based on childcare activities described in the review study by McCann *et al.* (2012).

### Analysis

A participant's time use data were included in the analysis if at least 1 day was logged in the time use app for at least 23 h. First, we distinguished four main categories that are fundamentally different at a broader level and were used in earlier studies (Staikov 1982), namely, *contracted time*, *necessary time*, *committed time* and *free time*. The 12 subcategories within these four categories are described in Table 1. Travel time and time to fill in the time use diary were included in these categories and not analysed, as were the secondary activities of parents. Subsequently, independent *t*-tests (if normally distributed) or Mann–Whitney tests (if not normally distributed) were used to compare the mean duration spent by the participant on the 4 main categories and 12 subcategories (expressed in min/day) for fathers and mothers raising children with PIMD and parents raising typically developing children. Because of the large number of significance tests, a Bonferroni multiple-significance-test correction was applied, resulting in an alpha of 0.001.

**Table 1.** Main categories and categories in the time use app

|   |
|---|
| Contracted time   |
| 1. Paid work  |
| 2. Educational activities   |
| Necessary time  |
| 3. Sleeping   |
| 4. Eating and drinking  |
| 5. Personal or medical care   |
| Committed time  |
| 6. Domestic work  |
| 7. Shopping and use of services <sup>†</sup>                                |
| 8a. Care and supervision of child with disability <sup>†</sup> <sup>‡</sup> |
| 8b. Care and supervision of typically developing children/adults            |
| Free time   |
| 9. Social contacts  |
| 10. Television, radio and reading   |
| 11. Computer and Internet   |
| 12. Other leisure time  |
| Other   |
| 13. Travel time   |
| 14. Filling in the time use diary   |

<sup>†</sup> This domain was only available in the time use app for parents of children with profound intellectual and multiple disabilities.

<sup>‡</sup> This domain consists of the following seven subcategories: personal and medical care; (preparing) eating and drinking; travel to appointments and treatments; supervision and vigilance; (para)medical appointments; education, enrichment activities and/or playtime; and administration.

## Results

### Response and characteristics

A convenience sample of 31 families agreed to participate in this study, resulting in a total of 57 participants (30 mothers and 27 fathers). In 83.9% of the families, both parents participated; in the remaining families (four families), one parent participated. Informed written consent was obtained from the participating parents. All families were two-parent families. The characteristics of the children and their families are presented in Tables 2 and 3. The individuals with PIMD ranged in age from 3 to 34 years. All the children had additional impairments (Table 3). Families received on average 41 h (SD = 8.9) of formal support per week, ranging from 18 to 60 h per week. During these hours, parents were relieved of their care tasks and the child with PIMD received formal support in or outside the family home (e.g. day services, child services centre and professional in the family home). Over half

**Table 2.** Participant and family characteristics

| Family characteristics                               | Parents of a child with PIMD ( <i>n</i> = 57) |                          | Parents of a typically developing child ( <i>n</i> = 175) |                           |
|--|---|--------------------------|---|---------------------------|
|  | <i>n</i> (%)                                  |                          | <i>n</i> (%)  |                           |
| Number of children living at home                    |   |                          |   |                           |
| 1  | 6 (19.4)                                      |                          | 43 (24.6)   |                           |
| 2  | 13 (41.9)                                     |                          | 82 (46.9)   |                           |
| 3  | 11 (35.5)                                     |                          | 43 (24.6)   |                           |
| 4  | 1 (3.2)                                       |                          | 4 (2.3)   |                           |
| 5  | 0 (0.0)                                       |                          | 2 (1.1)   |                           |
| 6  | 0 (0.0)                                       |                          | 1 (0.6)   |                           |
| Children under 4 years                               |   |                          |   |                           |
| Yes  | 10 (32.3)                                     |                          | 65 (37.1)   |                           |
| No   | 21 (67.7)                                     |                          | 110 (62.9)  |                           |
| Children 4–12 years                                  |   |                          |   |                           |
| Yes  | 25 (80.6)                                     |                          | 142 (81.1)  |                           |
| No   | 6 (19.8)                                      |                          | 33 (18.9)   |                           |
|  | Fathers ( <i>n</i> = 27)                      | Mothers ( <i>n</i> = 30) | Fathers ( <i>n</i> = 66)                                  | Mothers ( <i>n</i> = 109) |
|  | <i>n</i> (%)                                  | <i>n</i> (%)             | <i>n</i> (%)  | <i>n</i> (%)              |
| Age  |   |                          |   |                           |
| 20–30  | 0 (0.0)                                       | 2 (6.7)                  | 6 (9.1)   | 9 (8.3)                   |
| 31–40  | 9 (33.3)                                      | 14 (46.7)                | 29 (43.9)   | 64 (58.7)                 |
| 41–50  | 12 (44.4)                                     | 13 (43.3)                | 27 (40.9)   | 36 (33.0)                 |
| 51–60  | 5 (18.5)                                      | 1 (0.7)                  | 4 (6.1)   | 0 (0.0)                   |
| Missing  | 1 (3.7)                                       | 0 (0.0)                  | 0 (0.0)   | 0 (0.0)                   |
| Age (mean, SD)                                       | 43.4 (7.2)                                    | 40.1 (6.7)               | 40.0 (6.7)  | 38.0 (5.5)                |
| Level of education                                   |   |                          |   |                           |
| Secondary education Intermediate vocational training | 1 (3.7)                                       | 2 (6.7)                  | 15 (22.7)   | 15 (13.8)                 |
| Secondary vocational training                        | 9 (33.3)                                      | 14 (46.7)                | 18 (27.3)   | 43 (39.4)                 |
| University degree                                    | 11 (40.7)                                     | 7 (23.3)                 | 24 (36.4)   | 44 (40.4)                 |
| Missing  | 5 (18.5)                                      | 7 (23.3)                 | 8 (12.1)  | 7 (6.4)                   |
|  | 1 (3.7)                                       | 0 (0.0)                  | 1 (1.5)   | 0 (0.0)                   |
| Paid work  |   |                          |   |                           |
| Yes  | 24 (88.9)                                     | 20 (66.7)                | 48 (72.7)   | 73 (70.6)                 |
| No   | 2 (7.4)                                       | 10 (33.3)                | 8 (12.1)  | 24 (22.0)                 |
| Missing  | 1 (3.7)                                       | 0 (0.0)                  | 10 (15.2)   | 12 (11.0)                 |

PIMD, profound intellectual and multiple disabilities; SD, standard deviation.

the children (51.6%) also visited a facility for respite care for at least one night per month.

### Response and characteristics comparison group

The comparison group consists of 175 people (109 mothers and 66 fathers). There are no significant differences ( $P < 0.001$ ) between the parents raising children with PIMD and the comparison group in terms of the characteristics described in Tables 2 and 3.

### Contracted time

As is shown in Table 4, on average, the mothers of children with PIMD spent 3.6 h per day on contracted time ('paid work' and 'educational activities') and the fathers of children with PIMD 5.2 h per day. This duration is comparable with the time

spent on contracted time by parents raising typically developing children.

### Necessary time

Mothers raising children with PIMD spent on average 10.3 h per day on necessary activities, consisting of the subcategories 'sleeping', 'eating and drinking' and in 'personal or medical care' and fathers 10.4 h per day. The amount of time spent on necessary activities is not statistically significantly different from parents of typically developing children.

### Committed time

Mothers of children with PIMD ( $M = 6.2$ ,  $SD = 2.4$ ) spend significantly more time on committed activities ('domestic work', 'shopping and services' and 'care and supervision of

**Table 3.** Characteristics of the children with profound intellectual and multiple disabilities (PIMD)

| Characteristics (n = 31)  | M (SD)     | n  | %    |
|---|------------|----|------|
| Age (years)   | 9.8 (6.4)  |    |      |
| 2–4   |            | 4  | 12.9 |
| 4–8   |            | 9  | 29.0 |
| 8–12  |            | 13 | 41.9 |
| 12–21   |            | 3  | 9.7  |
| 21–35   |            | 2  | 6.5  |
| Developmental age (months)                                      | 12.1 (9.6) |    |      |
| Sex   |            |    |      |
| Male  |            | 11 | 35.5 |
| Female  |            | 20 | 64.5 |
| Gross Motor Function Classification System (GMFCS) <sup>†</sup> |            |    |      |
| I   |            | 0  | 0    |
| II  |            | 5  | 16.1 |
| III   |            | 4  | 12.9 |
| IV  |            | 10 | 32.3 |
| V   |            | 12 | 38.7 |
| Manual Ability Classification System (MACS) <sup>‡</sup>        |            |    |      |
| I   |            | 1  | 3.2  |
| II  |            | 8  | 25.8 |
| III   |            | 3  | 9.7  |
| IV  |            | 9  | 29   |
| V   |            | 10 | 32.3 |
| Additional impairments and health problems                      |            |    |      |
| Visual problems   |            | 19 | 61.3 |
| Auditory problems   |            | 2  | 6.5  |
| Epilepsy  |            | 24 | 77.4 |
| Reflux  |            | 10 | 32.3 |
| Chronic obstipation   |            | 16 | 51.5 |
| Behavioural problems  |            | 18 | 58.1 |
| Sleep disorders   |            | 16 | 51.6 |
| Use of feeding tube   |            | 14 | 45.2 |
| Scoliosis   |            | 10 | 32.3 |
| Chronic respiratory infection                                   |            | 12 | 38.7 |
| Formal support for the children with PIMD in hours per week     |            |    |      |
| <20   |            | 1  | 3.2  |
| 20–30   |            | 1  | 3.2  |
| 31–40   |            | 15 | 48.4 |
| 41–50   |            | 11 | 35.5 |
| 51–60   |            | 4  | 12.9 |

<sup>†</sup> Palisano et al. 1997.

<sup>‡</sup> Eliasson et al. 2006.

typically developing children and children with PIMD') than the mothers of typically developing children ( $M = 4.6$ ,  $SD = 2.3$ );  $t(137) = 3.23$ ,  $P = 0.001$ . The same trend is visible for fathers (fathers of children with PIMD,  $M = 4.1$ ,  $SD = 3.0$ ; fathers of typically developing children,  $M = 2.7$ ,  $SD = 1.8$ ), but the difference is not significant. Mothers of typically developing children also spent more hours per day ( $M = 4.6$ ) on committed activities than fathers ( $M = 2.7$ ).

A closer look at the subcategories shows that mothers of children with PIMD spend on average 2.8 h per day ( $SD = 1.7$ ) on the care and supervision of their children, which can be divided into time spent on their child with PIMD ( $M = 2.6$ ,  $SD = 1.6$ ) and time spent on their typically developing children ( $M = 0.2$ ,  $SD = 0.3$ ). Mothers raising only typically developing children spent on average 0.2 h per day ( $SD = 0.7$ ) on the care and supervision of their children, which is significantly less than the mothers of children with PIMD spend on all children;  $U = 111$ ,  $z = -8.932$ ,  $P = 0.001$ . The fathers of children with PIMD spend on average 2.1 h per day ( $SD = 2.5$ ) on their children, while fathers of typically developing children spent significantly less time on their children ( $M = 0.2$ ,  $SD = 0.7$ );  $U = 200$ ,  $z = -6.522$ ,  $P = 0.001$ . The time spent on all children by fathers can be divided into 1.9 h per day ( $SD = 1.7$ ) on the children with PIMD and 0.3 h per day ( $SD = 0.6$ ) on the typically developing children. Mothers of children with PIMD spend 2.8 h per day ( $SD = 1.3$ ) on domestic work, while mothers of typically developing children spend significantly more (4.3 h) per day ( $SD = 2.2$ ) on domestic work;  $t(78.905) = -4.670$ ,  $P = 0.000$ . The same trend can be seen for fathers of children with PIMD ( $M = 1.7$ ,  $SD = 1.4$ ) and fathers of typically developing children ( $M = 2.5$ ,  $SD = 1.8$ ), but this difference is not significant.

### Free time

Mothers raising children with PIMD spend on average 4.0 h per day ( $SD = 1.9$ ) on free time, and the fathers of children with PIMD spend on average 4.1 h per day ( $SD = 1.5$ ). Free time consists of the following subcategories: 'social contacts', 'television, listening to the radio or reading', 'browsing the Internet or using a computer' and 'other leisure activities'. Both parents of typically developing children have significantly more free time. The mothers of typically developing children use on average 5.5 h per day ( $SD = 1.9$ ) for free time;  $t(137) = -3.885$ ,  $P = 0.000$ . The fathers of typically developing children use on average 5.8 h per day ( $SD = 2.4$ ) for free time,  $t(74.595) = -4.151$ ,  $P = 0.000$ . Parents of children with PIMD spend a less time on all the separate subcategories compared with parents of typically developing children, although these differences are not significant.

### Discussion

The aim of this study was to increase our understanding of how raising a child with a PIMD at home affects the time use of parents in all the activities of daily life. Our results show that

**Table 4.** Mean time use during the week and weekend days

| Category  | Parents of a child with PIMD |                                 | Parents of a typically developing child |                                 |
|---|------------------------------|---------------------------------|---|---------------------------------|
|   | <i>n</i>                     | Mean time in hours per day (SD) | <i>n</i>                                | Mean time in hours per day (SD) |
| Total contracted time                                 |                              |                                 |   |                                 |
| Mothers <sup>†</sup>                                  | 19                           | 3.6 (2.1)                       | 48                                      | 3.7 (2.2)                       |
| Fathers <sup>†</sup>                                  | 21                           | 5.2 (1.7)                       | 58                                      | 4.1 (2.0)                       |
| Paid work   |                              |                                 |   |                                 |
| Mothers <sup>‡</sup>                                  | 30                           | 2.2 (2.4)                       | 109                                     | 1.6 (2.3)                       |
| Fathers <sup>‡</sup>                                  | 27                           | 4.1 (2.7)                       | 66                                      | 3.6 (2.3)                       |
| Paid work (only participants who have paid work)      |                              |                                 |   |                                 |
| Mothers <sup>†</sup>                                  | 19                           | 3.4 (2.2)                       | 48                                      | 3.6 (2.2)                       |
| Fathers <sup>†</sup>                                  | 21                           | 5.2 (1.7)                       | 58                                      | 4.0 (2.0)                       |
| Educational activities                                |                              |                                 |   |                                 |
| Mothers <sup>§</sup>                                  | 30                           | 0.1 (0.2)                       | 109                                     | 0.0 (0.2)                       |
| Fathers <sup>§</sup>                                  | 27                           | 0.1 (0.7)                       | 66                                      | 0.2 (0.7)                       |
| Total necessary time                                  |                              |                                 |   |                                 |
| Mothers <sup>†</sup>                                  | 30                           | 10.3 (0.9)                      | 109                                     | 10.9 (1.3)                      |
| Fathers <sup>†</sup>                                  | 27                           | 10.4 (2.2)                      | 66                                      | 10.5 (1.4)                      |
| Sleeping time   |                              |                                 |   |                                 |
| Mothers <sup>†</sup>                                  | 30                           | 8.2 (0.9)                       | 109                                     | 8.4 (1.0)                       |
| Fathers <sup>†</sup>                                  | 27                           | 8.1 (1.3)                       | 66                                      | 8.4 (1.3)                       |
| Eating and drinking                                   |                              |                                 |   |                                 |
| Mothers <sup>†</sup>                                  | 30                           | 1.3 (0.5)                       | 109                                     | 1.7 (0.7)                       |
| Fathers <sup>‡</sup>                                  | 27                           | 1.6 (1.4)                       | 66                                      | 1.6 (0.7)                       |
| Personal medical care                                 |                              |                                 |   |                                 |
| Mothers <sup>†</sup>                                  | 30                           | 0.8 (0.2)                       | 109                                     | 0.8 (0.4)                       |
| Fathers <sup>†</sup>                                  | 27                           | 0.7 (0.5)                       | 66                                      | 0.6 (0.4)                       |
| Total committed time                                  |                              |                                 |   |                                 |
| Mothers <sup>†</sup>                                  | 30                           | 6.2 (2.4)***                    | 109                                     | 4.6 (2.3)                       |
| Fathers <sup>†</sup>                                  | 27                           | 4.1 (3.0)                       | 66                                      | 2.7 (1.8)                       |
| Domestic work   |                              |                                 |   |                                 |
| Mothers <sup>†</sup>                                  | 30                           | 2.8 (1.3)***                    | 109                                     | 4.3 (2.2)                       |
| Fathers <sup>‡</sup>                                  | 27                           | 1.7 (1.4)                       | 66                                      | 2.5 (1.8)                       |
| Shopping and use of services                          |                              |                                 |   |                                 |
| Mothers <sup>§</sup>                                  | 30                           | 0.6 (0.3)                       |   | —                               |
| Fathers <sup>§</sup>                                  | 27                           | 0.2 (0.3)                       |   | —                               |
| Care and supervision of all children                  |                              |                                 |   |                                 |
| Mothers <sup>‡</sup>                                  | 30                           | 2.8 (1.7)***                    | 109                                     | 0.2 (0.7)                       |
| Fathers <sup>‡</sup>                                  | 27                           | 2.1 (2.5)***                    | 66                                      | 0.2 (0.5)                       |
| Care and supervision of typically developing children |                              |                                 |   |                                 |
| Mothers <sup>‡</sup>                                  | 30                           | 0.2 (0.3)                       | 109                                     | 0.2 (0.7)                       |
| Fathers <sup>‡</sup>                                  | 27                           | 0.3 (0.6)                       | 66                                      | 0.2 (0.5)                       |
| Care and supervision of children with PIMD            |                              |                                 |   |                                 |
| Mothers <sup>§</sup>                                  | 30                           | 2.6 (1.6)                       | —                                       | —                               |
| Fathers <sup>§</sup>                                  | 27                           | 1.9 (1.7)                       | —                                       | —                               |
| Total free time                                       |                              |                                 |   |                                 |
| Mothers <sup>†</sup>                                  | 30                           | 4.0 (1.9)***                    | 109                                     | 5.5 (1.9)                       |
| Fathers <sup>†</sup>                                  | 27                           | 4.1 (1.5)***                    | 66                                      | 5.8 (2.4)                       |
| Social contacts                                       |                              |                                 |   |                                 |
| Mothers <sup>‡</sup>                                  | 30                           | 1.5 (1.2)                       | 109                                     | 1.9 (1.6)                       |
| Fathers <sup>‡</sup>                                  | 27                           | 1.7 (1.8)                       | 66                                      | 1.7 (1.8)                       |
| Leisure time  |                              |                                 |   |                                 |
| Mothers <sup>‡</sup>                                  | 30                           | 0.3 (0.3)                       | 109                                     | 0.6 (1.1)                       |
| Fathers <sup>‡</sup>                                  | 27                           | 0.2 (0.2)                       | 66                                      | 0.4 (0.7)                       |
| Computer and Internet                                 |                              |                                 |   |                                 |
| Mothers <sup>‡</sup>                                  | 30                           | 0.7 (0.5)                       | 109                                     | 1.0 (0.9)                       |
| Fathers <sup>‡</sup>                                  | 27                           | 0.6 (0.7)                       | 66                                      | 1.1 (1.0)                       |

Continues



**Table 4.** (Continued)

| Category              | Parents of a child with PIMD |                                 | Parents of a typically developing child |                                 |
|-----------------------|------------------------------|---------------------------------|---|---------------------------------|
|                       | <i>n</i>                     | Mean time in hours per day (SD) | <i>n</i>                                | Mean time in hours per day (SD) |
| Reading, TV and radio |                              |                                 |   |                                 |
| Mothers <sup>†</sup>  | 30                           | 1.5 (0.9)                       | 109                                     | 2.0 (1.2)                       |
| Fathers <sup>‡</sup>  | 27                           | 2.1 (1.0)                       | 66                                      | 2.5 (1.4)                       |

PIMD, profound intellectual and multiple disabilities.

<sup>†</sup> Independent samples *t*-test.

<sup>‡</sup> Mann–Whitney test.

<sup>§</sup> No test was performed.

\*\*\**P* < 0.001.

parents of children with PIMD and typically developing children spend similar amounts of time on contracted and necessary time, but there are substantial differences in committed time (e.g. care and supervision of children with PIMD and domestic work) and free time. Notwithstanding the substantial professional support, both parents spend on average 2.1 to 2.8 h per day on care and supervision of their children as their primary activity. This is significantly more than the average time parents of typically developing children spend on childcare and supervision (average of <20 min per day). Parents raising children with PIMD spend significantly less time on average on domestic work when compared with parents raising typically developing children. Parents raising children with PIMD thus spend on average 1.5 h per day less on free activities than parents raising typically developing children, which is a striking difference. This reduction in free time cannot be traced back to one or more specific leisure activity; both parents seem to cut a little time from all subcategories.

The reduction in free time for parents is consistent with a study by Axelsson and Wilder (2014), who showed that the majority of family activities happened less often in families with children with PIMD than in families with typically developing children. However, participation in leisure activities has been identified as a coping strategy for day-to-day stress (Qian *et al.* 2014). Because several studies state that parents raising children with a disability experience increased levels of stress (Baker-Ericzén *et al.* 2005), the availability of free time seems to be of great importance for these parents. Also, because leisure participation/free time substantially contributes to people's well-being (Sirgy 2012), several methodological strengths can be described. First, fathers also participated in this study, while few studies have examined the impact of raising a child with disabilities on the time use of fathers (Crettenden 2008). Thereby, the diary method used in this study is widely described as a very accurate procedure (Stinson 1999; Frazis & Stewart 2012), avoiding problems (Stinson

1999). By listing all the activities during one (or more) 24-h period, instead of a few specific activities, data are less distorted because of 'social desirability bias' (Stinson 1999; Frazis & Stewart 2012). Also, the participants in this study used an app to keep track of their time use, which is easier and less burdensome than a paper time use diary (Sonck & Fernee 2013). Last, in our study, we were able to effectively compare the time use of parents raising children with PIMD and parents raising typically developing children using the same time tracking method. Time use studies are usually difficult to compare, because the used data collection method influences the results, and used categories (for example, 'childcare') have been inconclusively defined (Crettenden 2008; McCann *et al.* 2012). Also, time use of parents is determined by national policies on the support for families raising children with a disability, which can distort comparisons between time uses in different countries.

In addition to methodological strengths, there are also methodological weaknesses in our study. First, analysing the data across seven consecutive days has distorted data for some categories in the results. For example, in the category free time, the mean time per day is expected to be higher on weekend days and lower on weekdays, while only the average number of hours per day was displayed in the results. It is important to be aware of this when interpreting the results. Furthermore, only the parents' primary activities were described and analysed in this study. Previous research has shown that a substantial part of the care and supervision of a child with a disability is described as a secondary activity, undertaken at the same time as other activities (Crettenden 2008). This may have led to underreporting of the actual time spent on the care and supervision of the children with PIMD. Several parents in this study mentioned during the home visit that their child with PIMD could not be left out of sight and was in constant need of supervision. It would therefore be interesting to analyse the secondary activities of parents raising children with PIMD further. Finally, average times (average hours per day) per



activity are described in this study. The high standard deviations, however, show that there is substantial individual variation in the time spent on all categories. Because this individual variation is observed not only in both groups in our study but also in several other time use studies (Padeliadu 1998; Crowe & Michael 2011), this seems to be a common aspect of time use. Future research should focus on the differences in time use of individual parents raising children with PIMD and should provide greater insight into the relationship between family (e.g. ethnicity, single or two parents family) and child characteristics (e.g. additional impairments) and the impact of a person with PIMD on family members. This study shows that both parents of children with PIMD have to spend a significant amount of time on care tasks and have on average 1.5 h less free time per day than the parents of typically developing children. The radical impact on parental time use patterns and the limited amount of free time makes taking care of children with PIMD, 24/7, an extremely demanding task for parents. Support adapted to the needs and preferences of families is therefore of great importance.

### Key Messages

- Notwithstanding the substantial amount of time provided by professional support (average: 41 h), mothers and fathers spend on average 2.1 to 2.8 h per day on the activity care and supervision of their children.
- Mothers and fathers raising children with PIMD have on average 1.5 h less free time per day than parents of typically developing children.
- The limited amount of free time makes taking care of children with PIMD, 24/7, an extremely demanding task for parents.
- Formal support interventions for families raising children with PIMD (such as short breaks/respite care) appear to be extremely important for families to improve or maintain their well-being and quality of life.

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