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# The effects of the functional levels of children with cerebral palsy on the quality of life of caregivers

**Bilinc Dogruoz Karatekin [1], Afitap Icagasioglu [2]**

[1] Istanbul Medeniyet University, Goztepe Prof Dr Suleyman Yalcin City Hospital, Physical Medicine and Rehabilitation, Istanbul, Turkey
[2] Istanbul Medeniyet University, Faculty of Medicine, Physical Medicine and Rehabilitation, Istanbul, Turkey

**ORCID ID of the author(s)**
BDK: 0000-0002-0568-9498
Aİ: 0000-0003-4612-4634

**Corresponding Author**
Bilinc Dogruoz Karatekin
Istanbul Medeniyet University, Goztepe Prof Dr Suleyman Yalcin City Hospital, Physical Medicine and Rehabilitation, Istanbul, Turkey
E-mail: bilincdogruoz@hotmail.com

**Ethics Committee Approval**
The ethics committee of the Istanbul Medeniyet University Goztepe Training and Research Hospital approved the study (Approval date and number: 09.08.2021/0396).
All procedures in this study involving human participants were performed in accordance with the 1964 Helsinki Declaration and its later amendments.

**Conflict of Interest**
No conflict of interest was declared by the authors.

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## Abstract

**Background/Aim:** Psychological status and quality of life of caregivers with children with cerebral palsy are lower than the population. The functional status of the child is one of the factors affecting the caregiver's quality of life. However, the relationship between gross motor and hand functions, communication, oromotor skills, oropharyngeal functions and the caregiver's quality of life remains unclear. The aim of the study is to examine the effects of the functional levels of children with cerebral palsy on the quality of life of their caregivers.

**Methods**: Two hundred and seventeen children with cerebral palsy and their caregivers were included in this cross-sectional study. Inclusion criteria were; (i) Children aged 0-18, diagnosed with cerebral palsy (CP), followed in the pediatric rehabilitation outpatient clinic of the university, (ii) individuals who care for children with CP and volunteer to participate in the study, (iii) individuals who have a literacy level of understanding the purpose of the study and the forms to be filled in. Children's demographic information (age, gender), cerebral palsy types were recorded and detailed functional evaluation was made. The identity of the caregiver was recorded and quality of life was evaluated with the Short Form-12 (SF-12). Functional classification of the children were evaluated with Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), Communication Function Classification System (CFCS) and Eating and Drinking Ability Classification System (EDACS). The relationship between the child's functional level in each scale and the caregiver's SF-12 score was investigated.

**Results**: Of the 117 children with a mean age of 7.62 (4.08), 52.5% were male (n=114) and 47.5% (n=103) female. According to CP types, 89.3% were spastic (n=191) (78.1% of them bilateral, 21.9% unilateral), 5.6% ataxic (n=12) and 5.1% dyskinetic (n=11). Median SF-12 PCS and MCS were 51.69 (25.76-62.92) and 55.36 (26.64-60.69), respectively. When the SF-12 scores were evaluated according to the functional levels of the children, both SF-12 PCS and SF-12 MCS scores differed significantly according to the GMFCS, MACS, CFCS and EDACS levels ($P<0.01$).

**Conclusion**: The caregiver's quality of life is related to the gross motor and hand functions, oropharyngeal functions, communication and oromotor skills of the children with cerebral palsy. Therefore, comprehensive functional evaluation of children with cerebral palsy is important.

**Keywords:** Cerebral palsy, Caregiver, Functional status, Quality of life

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## Introduction

Cerebral Palsy (CP) refers to a group of permanent disorders of movement and posture that occurs in the developing fetus or infant brain, and causes activity limitation. Neurological and musculoskeletal disorders may be accompanied by sensorial, perceptual and cognitive problems, communication and behavioral problems, and epilepsy [1].

Because of all these primary and secondary problems, children with CP need help at various levels in their daily life activities and social interactions. Different needs of care arise, especially depending on the severity of the limitations caused by CP. Personal care includes services such as washing, feeding, going to the toilet, dressing, while social care includes services such as shopping and household chores, money management, financial assistance and living together [2]. The mentioned care services are usually provided by family members, and they do not only increase the functional, psychosocial and personal development of the child, but also bring many negativities and difficulties for the caregiver [3].

In the literature, it has been reported that the psychological status and quality of life of caregivers with children with cerebral palsy are lower than the population [3-5]. However, the results are contradictory in studies investigating the relationship between the child's functional status and the caregiver's quality of life [4,6-9]. Also most of the studies have investigated the functional status of the child only with GMFCS [3,5,6].

International Classification of Functioning, Disability and Health (ICF) of the World Health Organization (WHO) created a new system for health and disease classification which describes a universal way to define health conditions and suggests a relationship between these conditions and contextual factors. It represents a biopsychosocial approach to health, functioning and disability. ICF model has been used to guide clinical thinking in patients with CP [10]. Thus, functional scales are being used currently for evaluation of various functions in CP such as communication, gross motor, hand function, and oral motor/oropharyngeal functions.

To the best of our knowledge there is no study investigating the relationship between gross motor, hand function, communication, oromotor/oropharyngeal functions specified in the ICF core set and the caregiver quality of life.

Therefore in this study, it is aimed to examine the quality of life levels of caregivers whose children have cerebral palsy, depending on the impairments in the child's functional status (gross motor, hand function, communication, oromotor/oropharyngeal functions).

## Materials and methods

### Study design

The design of this study was conducted in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology Statement (STROBE) guidelines as an observational cross-sectional study. The medical ethics committee of the Istanbul Medeniyet University Goztepe Training and Research Hospital approved the study (Approval date and number: 09.08.2021/0396) in accordance with the Declaration of Helsinki and written informed consent was obtained from all patients.

### Sample selection

Inclusion criteria were; (i) Children aged 0-18, diagnosed with CP, followed in the pediatric rehabilitation outpatient clinic of the university, (ii) individuals who care for children with CP and volunteer to participate in the study, (iii) individuals who have a literacy level to understand the purpose of the study and to fill in the forms. Patients were excluded if they did not have a definitive diagnosis of cerebral palsy.

217 children with cerebral palsy and their caregivers who met the inclusion criteria were included in the study.

### Data collection

Demographic data and functional status of the children were evaluated by an experienced physical medicine and rehabilitation specialist.

The protocol recommended by the SCPE group was used for SP classification. SCPE grouped children with CP into four categories: spastic (bilateral, unilateral), dyskinetic (dystonic, chorea-athetoid), ataxic, and unclassifiable [11].

Functional classification of the children were evaluated with Gross Motor Function Classification System (GMFCS), Manual Ability Classification System (MACS), Communication Function Classification System (CFCS) and Eating and Drinking Ability Classification System (EDACS) according to the ICF model. [10]. Short Form-12 was used to evaluate the quality of life of the caregivers participating in the study.

#### 1. Gross Motor Function Classification System (GMFCS)

Gross motor function levels of people with CP were determined using GMFCS. GMFCS based on self-initiated movements with an emphasis on sitting, relocation and mobility. The main criterion in five-level classification system is having significant differences between the levels in daily life [12]. The Turkish validity and reliability of the scale was established [13].

#### 2. Manual Ability Classification System (MACS)

Manual Ability Classification System was developed to classify the ability to handle objects in children. It was developed as a 5-point likert scale, similar to GMFCS. It is a scale that evaluates the ability of the children to take necessary objects and use their hands in activities of daily living, such as eating and dressing. It does not distinguish different capacities between hands [14]. The Turkish validity and reliability of the scale was established [15].

#### 3. Communication Function Classification System (CFCS)

Communication Function Classification System was developed in a 5-point Likert type to determine daily communication performance in individuals with CP. CFCS classifies individuals according to the effectiveness of their daily communication performance. All elements of communication performance are considered when defining the CFCS level. The child's communication performance items include ability to speak, using facial expressions, having verbal behaviors, making eye contact, using facial expressions as well as using alternative communications. In this scale, the changes in the levels are determined according to the communication flow between the source and the receiver [16].

4. **Eating and Drinking Ability Classification System (EDACS)**

Eating and Drinking Ability Classification System (EDACS) is developed to classify how individuals with CP eat and drink in daily life. The focus is on functional activities such as sucking, biting, chewing, swallowing, and holding food or liquid in the mouth. The distinction between different levels of EDACS is based on functional skills, the need for adaptation in the texture of the food or drink, the used technique, and some other environmental characteristics. It classifies overall performance, including both the motor and sensory components of eating and drinking [17]. The Turkish validity and reliability of the scale was established [18].

### Quality of life assessment

Short Form-12 (SF-12) was used to determine quality of life. SF-12 is a scale that was developed in 1994 to evaluate the quality of life for the last four weeks without focusing on a specific age and disease group. It consists of 12 questions, all selected from SF-36 Health Questionnaire. SF-12 consists of physical functioning, role physical, pain, general health, role emotional, mental health, social functioning and vitality sub-components. The Physical Component Summary Score (PCS), which is a single score showing the physical domain of quality of life, was calculated from the sub-components of physical functionality, role physical, general health, and pain. The Mental Component Summary Score (MCS) was calculated from the role emotional, mental health, vitality, and social functioning sub-components. The score that can be obtained from each sub-component and summary score ranges from 0-100, and a high score indicates a high quality of life. A score of 50 or less in PCS-12 is recommended as the cut-off point to identify a physical problem, whereas a score of 42 or less on the MCS-12 may indicate 'clinical depression' [19]. The Turkish validity and reliability of the scale was established [20].

### Statistical analysis

The descriptive statistics of the categorical variables in the study are given as numbers and percentages, and the descriptive statistics of the numerical variables are given as median, minimum and maximum. The conformity of the variables to the normal distribution was examined using the Shapiro Wilk test. Kruskal Wallis Analysis of Variance test was used for the median comparisons of the groups consisting of more than two categories. Bonferroni Corrected Mann Whitney U test was used for the analysis of the groups that caused the difference. The incidence of cerebral palsy in Turkey has been determined as 4.4 per 1000 live births. According to this rate, the sample size was determined as 60 with 5% margin of error at 95% confidence level. Statistical significance level was taken as 0.05 and SPSS 22.0 package program was used in the analysis.

## Results

In table 1, descriptive statistics for categorical and numerical variables are given as numbers and percentages. The functional status of children is shown in table 2 as median (min-max) and number of children in each level (n-%).

Table 1: Characteristics of the children and caregiver

| | n (%), median (min-max) |
|---|---|
| Gender, n(%) | |
| Male | 114 (52.5%) |
| Female | 103 (47.5%) |
| Age, median (min-max) | 6 (2-16) |
| Cerebral palsy subtype, n(%) | |
| Spastic | 191 (89.3%) |
| Spastic bilateral | 150 (78.1%) |
| Spastic unilateral | 42 (21.9%) |
| Right | 26 (61.9%) |
| Left | 16 (38.1%) |
| Dyskinetic | 11 (5.1%) |
| Ataxic | 12 (5.6%) |
| Caregiver, n(%) | |
| Mother | 201 (92.6%) |
| Father | 15 (6.9%) |
| Grandmother | 1 (0.4%) |
| SF-12 PCS, median (min-max) | 51.69 (25.76-62.92) |
| SF-12 MCS, median (min-max) | 55.36 (26.64-60.69) |

Table 2: Functional status of the children

| | n (%), median (min-max) |
|---|---|
| GMFCS, median (min-max) | 2 (1-5) |
| Level 1 | 55 (25.3%) |
| Level 2 | 28 (12.9%) |
| Level 3 | 50 (23.0%) |
| Level 4 | 42 (19.4%) |
| Level 5 | 42 (19.4%) |
| MACS, median (min-max) | 2 (1-5) |
| Level 1 | 57 (26.3%) |
| Level 2 | 52 (24.0%) |
| Level 3 | 45 (20.7%) |
| Level 4 | 31 (14.3%) |
| Level 5 | 32 (14.7%) |
| CFCS, median (min-max) | 1 (1-5) |
| Level 1 | 67 (30.9%) |
| Level 2 | 46 (21.2%) |
| Level 3 | 32 (14.7%) |
| Level 4 | 40 (18.4%) |
| Level 5 | 32 (14.7%) |
| EDACS, median (min-max) | 1 (1-5) |
| Level 1 | 59 (27.2%) |
| Level 2 | 50 (23.0%) |
| Level 3 | 31 (14.3%) |
| Level 4 | 38 (17.5%) |
| Level 5 | 39 (18.0%) |

GMFCS: Gross Motor Functional Classification System, MACS: Manual Ability Classification System, CFCS: Communication Function Classification System, EDACS: Eating and Drinking Ability Classification System

When the quality of life of the caregivers was examined according to GMFCS levels of their children, it was found that the quality of life of caregivers differed according to GMFCS level of the children, and SF-12 score decreased with the increase in GMFCS level of the children with CP ($P<0.01$) (Table 3). According to GMFCS between 1st and 2nd, 1st and 3rd, 1st and 4th, and 1st and 5th levels of caregivers of children with CP, both SF-12 PCS and SF-12 MCS of the caregivers were differed ($P<0.01$), while other levels were similar ($P>0.05$) in the pairwise comparison.

Table 3: Evaluation of caregiver's quality of life according to GMFCS levels

| GMFCS | SF-12 PCS | | | | SF-12 MCS | | | |
|---|---|---|---|---|---|---|---|---|
| | Mean (SD) | Min-Max | Chi Square † | P-value | Mean (SD) | Min-Max | Chi Square † | P-value |
| Level I | 52.98 (5.90) | 25.68-62.92 | 32.87 | <0.001 | 53.32 (8.64) | 26.41-60.69 | 47.14 | <0.001 |
| Level II | 48.30 (6.51) | 24.55-55.91 | | | 52.12 (6.93) | 32.72-64.44 | | |
| Level III | 49.11 (5.91) | 37.40-59.49 | | | 48.89 (7.64) | 17.31-59.74 | | |
| Level IV | 45.86 (8.04) | 24.93-61.93 | | | 46.01 (9.74) | 16.54-57.96 | | |
| Level V | 46.43 (9.06) | 25.76-59.53 | | | 45.06 (7.02) | 26.64-57.82 | | |

† Kruskal Wallis Analysis of Variance, GMFCS: Gross Motor Functional Classification System, SF-12 PCS: Short Form-12 physical component score, SF-12 MCS: Short Form-12 mental component score

When the quality of life of the caregivers was examined according to MACS levels of their children, it was found that the quality of life of the caregivers differed according to MACS level of the children, and SF-12 score decreased with the increase in MACS level of the children with CP ($P<0.01$) (Table 4). According to MACS levels between 1st and 3rd, 1st and 4th, and 1st and 5th levels of caregivers of children with CP, SF-12

PCS of the caregivers were differed ($P<0.01$), and MACS levels between 1st and 2nd, 1st and 4th, 1st and 5th, and 3rd and 5th levels of caregivers of children with CP, SF-12 MCS of the caregivers were differed ($P<0.01$), while other levels were similar ($P>0.05$) in the pairwise comparison.

Table 4: Evaluation of caregiver's quality of life according to MACS levels

| MACS | SF-12 PCS |  | Chi Square † | P-value | SF-12 MCS |  | Chi Square † | P-value |
|---|---|---|---|---|---|---|---|---|
|  | Mean (SD) | Min-Max |  |  | Mean (SD) | Min-Max |  |  |
| Level I | 52.62 (5.07) | 33.03-62.92 | 24.99 | <0.001 | 52.68 (9.33) | 17.31-60.69 | 34.97 | <0.001 |
| Level II | 49.31 (7.37) | 24.93-59.53 |  |  | 48.66 (8.58) | 23.83-64.44 |  |  |
| Level III | 46.43 (7.50) | 24.55-56.81 |  |  | 50.13 (6.61) | 32.43-58.09 |  |  |
| Level IV | 47.27 (7.40) | 28.50-61.93 |  |  | 46.32 (8.38) | 28.10-56.93 |  |  |
| Level V | 46.24 (9.18) | 25.76-59.37 |  |  | 44.89 (8.37) | 16.54-57.82 |  |  |

† Kruskal Wallis Analysis of Variance, MACS: Manual Ability Classification System, SF-12 PCS: Short Form-12 physical component score, SF-12 MCS: Short Form-12 mental component score

When the quality of life of the caregivers was examined according to CFCS levels of their children, it was found that the quality of life of the caregivers differed according to CFCS level of the children, and SF-12 score decreased with the increase in CFCS level of the children with CP ($P<0.01$) (Table 5). According to CFCS levels between 1st and 4th, and 1st and 5th levels of caregivers of children with CP, SF-12 PCS of the caregivers were differed ($P<0.01$), and CFCS levels between 1st and 2nd, 1st and 3rd, 1st and 4th, and 1st and 5th levels of caregivers of children with CP, SF-12 MCS of the caregivers were differed ($P<0.01$), while other levels were similar ($P>0.05$) in the pairwise comparison.

Table 5: Evaluation of caregiver's quality of life according to CFCS levels

| CFCS | SF-12 PCS |  | Chi Square † | P-value | SF-12 MCS |  | Chi Square † | P-value |
|---|---|---|---|---|---|---|---|---|
|  | Mean (SD) | Min-Max |  |  | Mean (SD) | Min-Max |  |  |
| Level I | 52.08 (5.34) | 33.03-62.92 | 18.78 | <0.001 | 53.15 (8.78) | 17.31-64.44 | 45.02 | <0.001 |
| Level II | 48.38 (7.13) | 24.93-59.10 |  |  | 49.02 (8.58) | 23.83-57.96 |  |  |
| Level III | 48.29 (6.61) | 27.82-56.81 |  |  | 49.31 (5.04) | 37.16-57.88 |  |  |
| Level IV | 46.49 (8.70) | 25.68-59.49 |  |  | 45.93 (9.28) | 16.54-56.93 |  |  |
| Level V | 46.19 (9.30) | 24.55-61.93 |  |  | 44.69 (7.50) | 26.64-57.82 |  |  |

† Kruskal Wallis Analysis of Variance, CFCS: Communication, Function Classification System, SF-12 PCS: Short Form-12 physical component score, SF-12 MCS: Short Form-12 mental component score

When the quality of life of the caregivers was examined according to EDACS levels of their children, it was found that the quality of life of the caregivers differed according to EDACS level of the children, and the SF-12 score decreased with the increase in EDACS level of the children with CP ($P<0.01$) (Table 6). According to EDACS levels between 1st and 4th, and 1st and 5th levels of caregivers of children with CP, SF-12 PCS of the caregivers were differed ($P<0.01$), and EDACS levels between 1st and 2nd, 1st and 3rd, 1st and 4th, and 1st and 5th levels of caregivers of children with CP, SF-12 MCS of the caregivers were differed ($P<0.01$), while other levels were similar ($P>0.05$) in the pairwise comparison.

Table 6: Evaluation of caregiver's quality of life according to EDACS levels

| EDACS | SF-12 PCS |  | Chi Square † | P-value | SF-12 MCS |  | Chi Square † | P-value |
|---|---|---|---|---|---|---|---|---|
|  | Mean (SD) | Min-Max |  |  | Mean (SD) | Min-Max |  |  |
| Level I | 52.21 (5.27) | 33.03-62.92 | 17.94 | <0.001 | 53.61 (8.66) | 17.31-64.44 | 44.96 | <0.001 |
| Level II | 49.04 (5.86) | 37.40-59.49 |  |  | 49.00 (8.10) | 16.54-57.88 |  |  |
| Level III | 47.34 (9.43) | 24.93-59.53 |  |  | 47.82 (9.07) | 23.83-58.79 |  |  |
| Level IV | 47.33 (8.26) | 24.55-57.50 |  |  | 48.01(7.65) | 27.72-56.93 |  |  |
| Level V | 46.11 (8.46) | 25.76-61.93 |  |  | 44.66 (7.52) | 26.64-57.82 |  |  |

† Kruskal Wallis Analysis of Variance, EDACS: Eating and Drinking Ability Classification System, SF-12 PCS: Short Form-12 physical component score, SF-12 MCS: Short Form-12 mental component score

## Discussion

Cerebral palsy is the most common cause of motor disability in childhood. Disability has a significant impact not only on the child with disability, but also on the family responsible for the child. The quality of life of individuals with disabilities and their families has become an important area of research [21].

In this study, it was investigated whether the quality of life of the caregivers of children with CP changes according to the functional status of the children.

Having a child with disability, regardless of the type of disability, brings in some special difficulties. These difficulties are psychological and educational status, financial situation, lifestyle, family environment and relations with the social environment, besides the child's disability. Caring for a child with cerebral palsy and meeting his needs throughout his development affect all members in the family [22]. The mother takes a more active role in solving all these difficulties and puts more effort. The relationship of a mother with her disabled child is a lifelong relationship starting at birth. The majority of the participants in this study were mothers, in accordance. Mothers who spend most of their time and energy for their child with cerebral palsy cannot spare enough time for their spouses, other children and social life.

It has been reported that caregivers of children with cerebral palsy face more mental and physical difficulties than those who care for healthy children [23, 24]. Decreased participation in work and social life, decreased physical and mental health together with economic difficulties negatively affect the quality of life [6-8, 25].

Xia et al. evaluated the quality of life in the parents of children with different disabilities in their study and reported the mean SF-12 PCS score of 51.73 (6.72) and SF-12 MCS score of 29.32 (3.44) for mothers of children with cerebral palsy [26]. Yilmaz et al. [25] also evaluated the quality of life in the parents of children with cerebral palsy in their study and reported the mean SF-36 PCS score of 51.83 (23.10) and MCS score of 51.20 (24.49) for mothers of children with cerebral palsy. The results of Yilmaz et al. are consistent with this study. However, MCS scores of Xia et al. [26] were well below these values. They explained this result with China's one-child policy, which had been implemented for 30 years and parents had relatively poor capability of adapting themselves to the adversity.

Although it is a common result of studies that the quality of life of caregivers of children with cerebral palsy is decreased, there are conflicting results regarding the determinants of quality of life. Dilek et al. [6], Ones et al. [8] and

Tuna et al. [9] reported no relationship between the child's functional status and the mother's quality of life. Tuna et al. interpreted this result as once a catastrophic event occurs, its severity seems to have minor importance [9]. However, the number of participants in all three studies was limited and only GMFCS was used in functional assessment. Denghan et al. [5] investigated the relationship between quality of life and GMFCS in mothers of 494 children with cerebral palsy and reported a significant relationship between physical component summary score of SF-36 and motor function level. Eker et al. [27] also reported the relationship between quality of life of mother and GMFCS of children with CP in their study. Yun investigated the relationship between GMFM-88 and SF-36 in caregivers of 106 children with cerebral palsy and showed a significant relationship between physical functioning, physical role functioning, mental health, and bodily pain domains of SF-36 and GMFM-88 total score [7]. In this study, a significant relation was found between GMFCS and SF-12 PCS and MCS scores, concordant with studies of Denghan, Eker, and Yun.

Jamali et al. [28] reported that age, gender, GMFCS, MACS, EDACS, CFCS could not predict difficulty in caregiving, but could be correlated with them. Supporting our study, Yığman et al. [29] reported a relationship between GMFCS, MACS, and CFCS and caregiver burden. Otherwise there is no study in the literature investigating the relationship between MACS, EDACS and CFCS and the caregiver's quality of life. In this study, gross motor, hand function, communication and oromotor/oropharyngeal functions were all associated with caregiver's quality of life. The strong correlation between GMFCS, MACS, EDACS and CFCS in the literature supports our findings [30, 31].

### Limitations

One of the main limitations of this study is being a single-center study. Moreover, the majority of the caregiver population consisted of mothers, and the limited participation of fathers may have affected the results of the study. Different results can be obtained in a study with a more homogeneous parent group. However, this is the first study in which the functional evaluations in the ICF core set are comprehensively discussed in a large sample. In this study, only functional evaluation was considered and sociodemographic (employment status, economic status, household data, etc.) evaluation was not made. In further studies, investigating the relationship between eating-drinking and communication functions and sociodemographic characteristics will contribute to the literature.

### Conclusion

Evaluation of the child with GMFCS, MACS, EDACS and CFCS included in the ICF core set is important for the determination of child’s comprehensive functional status. Trying to improve motor functions solitary is not a sufficient goal for functionality. Hand functions, eating-drinking and communication functions should not be forgotten in rehabilitation goals.

This study showed that comprehensive functional assessment of the child with cerebral palsy is important not only for the child but also for the caregiver's quality of life.

Evaluating and providing support for the caregivers of children with impaired motor functions, communication, eating and drinking functions can provide important gains such as enabling parents, who have a crucial role in the rehabilitation of the child, to take care of their children more effectively.

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