

## RESEARCH ARTICLE

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# Translation, reliability and validity of the Greek version of the Child Engagement in Daily Life in children with cerebral palsy

Rigas Dimakopoulos<sup>1</sup>  | Marianna Papadopoulou<sup>1</sup> | Roser Pons<sup>2</sup> | Arietta Spinou<sup>3</sup>

<sup>1</sup>Laboratory of Neuromuscular and Cardiovascular Study of Motion, Physiotherapy Department, University of West Attica, Athens, Greece

<sup>2</sup>1st Pediatric Clinic, University of Athens, "Agia Sofia" Children's Hospital, Athens, Greece

<sup>3</sup>Population Health Sciences, Faculty of Life Sciences and Medicine, King's College London, London, UK

## Correspondence

Dr Rigas Dimakopoulos, University of West Attica (UNIWA) Deliyanni 1, Athens, Greece.  
Email: [rigasd@yahoo.com](mailto:rigasd@yahoo.com)

## Abstract

**Background:** Participation in family, recreational activities and self-care is an integral part of health. It is also a main outcome of rehabilitation services for children and adolescents with disabilities. However, there are currently no available tools in Greek to assess participation in young children.

**Methods:** The Child Engagement in Daily Life (CEDL) was cross-culturally translated into Greek using forward-backward translation, review by expert committee, pretest application and final review. Parents with children who have been diagnosed with cerebral palsy (CP) and were 18 months to 5 years old were recruited. Internal consistency was evaluated using the Cronbach alpha and test-retest reliability in 2 weeks using intra-class correlation coefficient (ICC) and Bland-Altman plot for the agreement of each domain score. Measurement error was assessed utilising the standard error of measurement (SEM) and the smallest detectable change (SDC) and interpretability was assessed using the floor and ceiling effects. Validity was evaluated using the 'known groups' method, that is, assessing parents of children with typical development (TD).

**Results:** One hundred and seven children with CP (mean age  $43.63 \pm 13.5$  months), Gross Motor Function Classification System (GMFCS) levels I-V and 97 children with TD (mean age  $43.63 \pm 14.4$  months) were included. Significant differences ( $p < 0.01$ ) between children with CP and children with TD were recorded for all CEDL domains. Mean  $\pm$  standard deviation of the CEDL domains 'frequency of participation', 'enjoyment of participation' and 'self-care' were  $58.8 \pm 14.5$ ,  $3.9 \pm 0.9$  and  $49.7 \pm 23.5$ , respectively for children with CP and  $62.3 \pm 9.1$ ,  $4.4 \pm 0.9$  and  $74.2 \pm 15$  for children with TD. Internal consistency of all domains was high; Cronbach alpha for 'frequency of participation' was 0.83, for 'enjoyment of participation' was 0.76 and for 'self-care' was 0.92. Test-retest reliability (ICC) was excellent for the 'self-care' (0.95) and good for 'frequency of participation' and 'enjoyment of participation' domains (0.90 and 0.88, respectively) while Bland-Altman analysis revealed no systematic differences or bias between the two measurements. SEM was 0.8, 0.05 and 1.6 for frequency of participation, enjoyment and self-care with SDC of 2.4, 0.16 and 4.5, respectively. No relevant floor and ceiling effects were observed.

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**Conclusion:** The Greek CEDL has good reliability, validity and interpretability. It can be used to evaluate participation in Greek young children with CP. Future studies should investigate the validity of this tool in longer periods and its responsiveness to intervention.

**KEYWORDS**

child, Child Engagement in Daily Life, disabilities, participation

## 1 | INTRODUCTION

The publication of the International Classification of Functioning, Disability and Health, known as ICF, by the World Health Organization (WHO) in 2001 (World Health Organization (WHO), 2001) challenged our perceptions of health and disability worldwide and provided a standardised language to facilitate interdisciplinary communication. The ICF configuration shows that disability is no longer considered a biological or medical phenomenon, but the result of the interaction between the individual and the environment. The focus is not on the physical disability per se, but on the individual's functionality and experiences.

For children and adolescents with disabilities, this conceptual shift on disability highlighted the concept of 'participation' as the key dimension of health (Adair et al., 2015) and an inalienable human right (United Nations (UN), 2006), which is also now recognised as one of the main therapeutic goals (Resch et al., 2020a). According to WHO's definition, a person's 'involvement in life situations' is vital to child development (World Health Organization (WHO), 2001). It is precisely in these situations that children develop skills and abilities, socialise, make friendships and relationships, develop their self-image, self-esteem, ideas and beliefs, understand their preferences and interests and develop, both emotionally and physically (Longo et al., 2014). Still, even nowadays, the participation of children and young people with disabilities is often limited compared with peers with typical development (TD). This significantly affects their development and quality of life (Bedell et al., 2013; Coster & Khetani, 2008).

Understanding and describing the concept of participation is a challenge. Since 'life situations' are not specific and common for everyone, it is necessary to focus both on life situations that have meaning and value for each individual and on those that are associated with different cultures and customs. Imms et al. (2016) identified two key themes as linked to experiencing and personalising 'participation': involvement and attendance. Attendance means 'being there'; it is measured by the frequency of an activity and/or the range of activities in which one participates. Involvement refers to the child's subjective experience while participating in an activity; it includes elements such as affect, motivation, engagement, persistence and social connection.

In recent years, the scientific community has focused on framing the participation construct and defining the factors that influence participation. According to the family of Participation Related Constructs (fPRC) (Imms et al., 2016), there are three intrinsic person-related

### Key messages

- The Greek version of CEDL was developed and validated and can be used by Greek health care professionals and parents to record participation of young children with CP.
- 'Participation' is a key dimension of health and one of the main therapeutic goals and should be taken into consideration when planning therapeutic interventions and services.
- Although participation is an integral part of the design and management of therapeutic interventions, still young children with disabilities participate less in family, recreational activities at home and in the community and self-care compared with children with TD.

factors, that is, activity competence, sense of self and preferences. These factors directly influence participation by setting the individual's personal background and potentials for participation. At the same time, these three factors are also influenced by participation, and they are shaped by the experience of participation. Furthermore, participation is influenced by extrinsic factors, that is, the context and the environment. Since participation takes place in a certain context, which is personal and relates to the people, place, activity, objects and time (Batorowicz et al., 2016), it is very important to consider the context when referring to participation. Still, environment is external and refers to a broader and more objective structure that people live, such as the geographical place, building constructs etc. The most important contexts in which children participate are home, community and school (Khetani et al., 2014). Particularly for younger children, self-care activities and play appear to be the most important activities in which they participate, mostly in the context of home and community (Chiarello et al., 2010; McConachie et al., 2006).

In order to better understand and describe the concept of participation in different contexts and activities, we need to use properly designed measures. According to two recent systematic reviews (Adair et al., 2018; Resch et al., 2020b), there are several measures designed to quantify participation in children with disabilities. Most of them measure primarily the frequency of participation but only a few measures are aligned with the attendance/involvement concept. In addition, since fPRC is a relatively recent framework, not many of the

existing measures are designed to account for the environment, context or other factors such as the activity competence, sense of self or preferences (Adair et al., 2018). Such a consideration would greatly contribute to the clearer conceptualisation of participation.

Although worldwide participation is now an integral part of the design and management of therapeutic interventions for children with disabilities, there is still no valid and reliable tool for measuring participation in Greek (Dimakopoulos et al., 2022). The Child Engagement in Daily Life (CEDL) is a parent-completed tool designed to measure participation in daily self-care and recreational activities in young children. It is a relatively short, easy to complete, and comprehensive tool. It was originally developed in English and it has been translated in Hebrew, Spanish and Greek (<https://canchild.ca/en/research-in-practice/current-studies/move-play-study-understanding-determinants-of-motor-abilities-self-care-and-play-of-young-children-with-cerebral-palsy/measures>), although there are currently no published data on the psychometric properties of the CEDL translations. Internal consistency of the CEDL is for overall and all domains scores, with Cronbach alpha between 0.86 and 0.91. Test-retest reliability on 23 days was acceptable for frequency of participation in family and recreational activities and enjoyment of participation (both ICC = 0.7) and high for self-care (ICC = 0.96) (Chiarello et al., 2014). However, there are no data available for the standard error of measurement (SEM), smallest detectable change (SDC) and interpretability. CEDL is one of the few measures that is aligned with the main constructs of participation according to the fPRC as it captures both frequency and involvement, as well as the feature of activity competence in the domain of self-care (Adair et al., 2018). All these make CEDL one of the most complete measure tools to assess participation available until today.

The present study aims to translate the CEDL in Greek and determine the psychometric properties, that is, reliability, validity and interpretability, of the Greek version in children with CP. Our hypothesis was that the Greek CEDL is conceptually and structurally equivalent to the original English version and can distinguish differences in the participation patterns of children with CP.

## 2 | METHODS

Our study followed the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) taxonomy for the design of studies on measurement properties (Mokkink et al., 2010).

## 3 | MEASURE

CEDL measures the 'participation' of children aged 18 months to 5 years in daily life activities and is completed by parents or other caregivers. The measure has 18 items, in two domains. The first domain has 11 items and assesses the child's participation in family and recreational activities at home and in the community. In each item, the parent rates how often the child participates in a specific

type of activity (frequency subdomain) and how much the child enjoys it (enjoyment subdomain). The second domain has seven items and assesses the child's participation in self-care. In this domain, the parent rates the child's independence to participate in specific self-care activities or how much help is required (Chiarello et al., 2014).

CEDL was initially developed for children with CP, although the items regarding family activities and self-care were adapted from the Paediatric Physical Therapy Outcomes Management System (Palisano et al., 1999). It is quick and easy to complete; based on the original pilot, CEDL can be completed in 10 min and the items have clarity (Chiarello et al., 2014). Additionally, CEDL is sensitive in recording change for children Gross Motor Function Classification System (GMFCS) levels I-III over a period of one year but not particularly sensitive for levels IV and V (Palisano et al., 2014). The original validation study of CEDL, which included the parents of 429 children with CP and 110 parents of children with TD, supports the use of the measure as a valid and reliable tool to assess participation in family and recreational activities and self-care of young children with CP (Chiarello et al., 2014).

## 4 | TRANSLATION

The CEDL translation was based on the steps by Beaton et al. (2000) and included the following: 1. Preparation, 2. Forward translation, 3. Back translation, 4. Review conducted by the review committee, 5. Pilot study with a representative population sample, and 6. Final revision and completion of the translation and cross-cultural adaptation process. The following section describes each step.

**Stage 1: Preparation:** To establish that the CEDL has never been translated into Greek, we contacted the authors of the original measure. We obtained permission to use and adapt the measure and asked for clarifications, guidance and suggestions regarding its cross-cultural adaptation. We then formed an expert committee, consisting of a paediatric physiotherapist (RD), a paediatric occupational therapist, a neurologist and a linguist. All clinical members have over 10 years of working experience and expertise in the field of childhood disability, and the linguist is specialising in medical texts. The committee reviewed the measure and decided that it has clinical value for the population it targets and can be translated into Greek.

**Stage 2: Forward translation:** The committee evaluated the necessity of adapting specific terms and activities to better reflect the Greek culture. The translation from English to Greek was performed by a bilingual translator, who is familiar with the concepts of the measure, permanent resident of Greece and native Greek speaker.

**Stage 3: Back translation:** The Greek version of the CEDL was translated back into English by a different bilingual professional translator, who is a permanent resident of Greece and native

Greek speaker. The translator highlighted points in the translation, which were challenging or lacked relevance.

- Stage 4: Review conducted by the review committee: The review committee compared the CEDL original version and the English translation that resulted from the back translation, and investigated any discrepancies. The back translation was then sent to the authors of the original CEDL for comparison and comments. Following the discussion of all proposals and the necessary adjustments, the provisional Greek version of the CEDL was created.
- Stage 5: Pilot study: To investigate the content validity of the provisional Greek version, a pilot study was conducted. Twelve parents were randomly selected, six of whom had a child with CP aged 2 to 5 years, complete the CEDL and then participated in semi-structured cognitive interviews. During the interviews, which lasted 30–40 min, the relevance of each item, the comprehensiveness of the Greek items, response options and instructions were investigated. A semi-structured questionnaire based on the COSMIN criteria and rating system for evaluating the content validity of patient-reported outcome measures (PROMs) (Terwee et al., 2018) was used (Appendix 1). The interviews were audio recorded and transcribed using verbatim. Fifty parents of children with CP participated in the test–retest process. These participants completed the measure at baseline and two weeks later, during a clinically stable stage.
- Stage 6: Final revision of the Greek version: The committee revised the provisional Greek version, considering the parents' views from the semi-structured interviews. Consequently, the final version of the Greek CEDL was completed and provided to the original CEDL creators for distribution. The CEDL in Greek is available on the CanChild centre website at the following link: [https://canchild.ca/system/tenon/assets/attachments/000/002/202/original/Greek\\_child\\_engagement\\_Updated.pdf](https://canchild.ca/system/tenon/assets/attachments/000/002/202/original/Greek_child_engagement_Updated.pdf).

## 5 | PARTICIPANTS

Participants were parents or other primary caregivers, whose children were between 18 months and 5 years old and had a diagnosis of cerebral palsy (CP), of levels I to V on the GMFCS (Palisano et al., 2010). Participating parents should be living with the child and know its daily activities well. Participants were recruited through the First Pediatric Clinic of 'Agia Sophia' Children's Hospital, private rehabilitation centres and special schools throughout Greece, from November 2020 to May 2022. All participants provided written informed consent and participation was voluntary; participants could withdraw from the research at any time without providing a reason or affecting the care that their children received. The study was approved by the Research Ethics and Deontology Committee of the University of Western Attica and the scientific committee of 'Agia Sophia' Children's Hospital (ethics reference: 96751/25-11-2020).

For parents, the inclusion criteria were 1) to be the child's parent and legal guardian, 2) to be able to speak and read Greek, 3) to have at least one child with CP, aged 18 months to 5 years during the research period, 4) to be permanent resident in Greece. Additionally, their child should have been born and lived in Greece since birth. Parents of children with TD, aged 18 months to 5 years, also participated in the study.

## 6 | PROCEDURE

All eligible parents were approached during their child's routine medical or rehabilitation appointment. A researcher informed potential participants about the purposes of the study, procedures, and potential benefits and risks of participation. All participants provided written informed consent. Demographics and clinical characteristics of the children with CP were collected directly from the participants or from the child's clinical records. For the children, age, sex, motor dysfunction, GMFCS level, family siblings and type of school were recorded. Additionally, demographics of the adult participants who completed the questionnaire were collected directly, including relationship with the child and parental education.

All parents completed the CEDL in written form after sort explanations about the context and the nature of the questions and while a researcher was present in order to answer potential questions. A convenience sample of 50 parents participated in the test–retest process by completing the CEDL for a second time after a period of 2 weeks. Parents of children with TD completed the CEDL in written form as well.

All data were collected manually and extracted in Microsoft excel and then entered in SPSS software. The presence of a researcher during the completion of CEDL items minimised the missing data. Still, in line with the original scoring system, when one or two item scores were missing, the average rating across the answered CEDL items was used for imputation (Chiarello et al., 2014).

## 7 | STATISTICAL ANALYSIS

SPSS statistics 23 software was used for statistical analysis. Descriptive statistics for all variables are presented in Table 1. To assess the measurement properties of the CEDL in a systematic way, COSMIN taxonomy was applied (Mokkink et al., 2010).

### 7.1 | Reliability

According to COSMIN definition, reliability refers to the extent to which score for patients who have not changed are the same for repeated measurements under several conditions (Mokkink et al., 2010). To assess the reliability of the Greek CEDL, we utilised the measurement properties internal consistency, test–retest reliability and measurement error. Internal consistency reliability is defined as degree of the interrelatedness among the items (Mokkink

**TABLE 1** Child and parents demographic characteristics for children with cerebral palsy and those with typical development.

Variable	Children with cerebral palsy (n = 107)	Children with typical development (n = 97)
Child's age		
18 months–3 years	32 (30.0)	30 (31.0)
3–4 years	33 (30.8)	31 (32.0)
4–5 years	42 (39.2)	36 (37.1)
Sex		
Male	59 (55.1)	44 (45.4)
Female	48 (44.9)	53 (54.6)
Motor distribution		
Unilateral	18 (16.8)	
Bilateral	89 (83.2)	
GMFCS		
Level I	48 (44.9)	
Level II	26 (24.3)	
Level III	11 (10.3)	
Level IV	13 (12.1)	
Level V	9 (8.4)	
Siblings		
No siblings	51 (47.7)	40 (41.2)
1	46 (43.0)	52 (53.6)
>1	10 (9.3)	5 (5.2)
Type of school		
No school	46 (43.0)	19 (19.6)
General school	39 (36.4)	78 (80.4)
Special education school	22 (20.6)	0
Participant who completed the measure		
Mother	90 (84.0)	88 (91.0)
Father	15 (14.0)	9 (9.0)
Other (grandfather/mother, caregiver)	2 (2.0)	0
Father's education		
Less than high school	5 (5.7)	2 (2.0)
High school	45 (42.0)	31 (32.0)
College/university	32 (30.0)	43 (44.4)
Postgraduate studies (MSc)	18 (16.8)	19 (19.6)
Postgraduate studies (PhD)	7 (6.5)	2 (2.0)
Mother's educations		
Less than high school	4 (3.7)	2 (2.1)
High school	31 (29.0)	32 (33.0)
College/university	50 (46.8)	46 (47.4)
Postgraduate studies (MSc)	17 (15.9)	16 (16.5)
Postgraduate studies (PhD)	5 (4.7)	1 (1.0)

Abbreviation: GMFCS, Gross Motor Function Classification System.  
Results presented as mean (standard deviation).

et al., 2010). Internal consistency was determined using the Cronbach alpha coefficient for the domains of participation in family and recreational activities, frequency and enjoyment subdomains, and self-care.

Internal consistency was considered excellent if >0.9, good if >0.8, acceptable if >0.7, questionable if >0.6, poor if >0.5 and unacceptable if <0.5 (George & Mallery, 2003). Test-retest reliability is defined as

the degree to which repeated measurements provide similar results (Mokkink et al., 2010). Test-retest reliability on two weeks was investigated using the intra-class correlation coefficient (ICC) for all CEDL domains. According to Fleiss (1981) values of ICC > 0.75 were considered excellent, between 0.6 and 0.74 good, between 0.4 and 0.59 moderate and below 0.4 poor. Measurement Error is the systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured (Mokkink et al., 2010). Measurement error was assessed using the SEM and the SDC. Measured changes higher than the SDC are considered real changes. The Bland and Altman plot was used to assess the agreement between measurements and assess how close the domain scores of CEDL were for two consecutive measurements.

## 7.2 | Validity

Validity refers to the degree to which an instrument measures the construct(s) it purports to measure (Mokkink et al., 2010). In our study, conceptual construct validity was tested using the known groups method; testing the hypothesis that CEDL can differentiate between children with CP and children with TD. Independent-samples *t* tests were used to examine the differences in participation between children with CP and children with TD. Significance level was set at  $\alpha = 0.05$ .

## 7.3 | Interpretability

Interpretability refers to the degree one can assign qualitative meaning to an instrument's quantitative scores or change in scores (Mokkink et al., 2010). In our study, we assessed interpretability using the floor and ceiling effects for the CEDL domains of children with CP. Percentage lower than 15% of the maximum (90–100%) or minimum (0–10%) score range is considered acceptable floor or ceiling effects (Wiertsema et al., 2014).

## 8 | RESULTS

### 8.1 | Characteristics

One hundred and seven children with CP, GMFCS level I to V, and 97 children with TD, participated in the study, age range 18 months to 5 years. Demographics and clinical characteristics on all children and the parents are presented in Table 1.

### 8.2 | Translation and cross-cultural process

We encountered no particular language difficulties in the forward translation. Minor differences in the way the item concepts were conveyed, such as word or sentence sequence, were resolved through

minor interventions in the Greek version. Minor ambiguities in the instructions of the CEDL were identified through the semi-structured interviews and were addressed (Table 2). Specifically, parents seemed to ignore or misinterpret the instruction stating that 'your child does not have to participate in all examples' of the participation in family and recreational activities domain. This was resolved by emphasising the specific instruction, through using underlined and bold fonts. In addition, in the Greek version, we decided to add a word in the description of the answer 'Often' regarding the regularity of carrying out an activity, so as to better distinguish between the options 'Often' and 'Very Often'.

## 9 | MEASUREMENT PROPERTIES

### 9.1 | Reliability

The Cronbach's alpha coefficient of the CEDL was 0.83, 0.76 and 0.92 for the participation frequency, enjoyment and self-care, respectively, indicating high internal consistency for all domains (Table 3). Test-retest reliability was excellent for the self-care domain, with an ICC of 0.95 (95% confidence interval [CI]: 0.91–0.98), and good for the participation frequency and enjoyment subdomains, with an ICC of 0.90 (95% CI: 0.77–0.95) and 0.88 (95% CI: 0.76–0.95), respectively (Table 3).

The SEM for the participation frequency, enjoyment and self-care domains was 0.8, 0.05 and 1.6, respectively. Consequently, the SDC was 2.4, 0.16 and 4.5, respectively, which is 2.4–4.5% of the maximum scores obtained for each domain (Table 3).

Figures 1, 2 and 3 show the Bland-Altman plots for the participation frequency, enjoyment and self-care domains, respectively. No systematic differences or bias was observed between the two consecutive measurements for all CEDL domains.

**TABLE 2** Linguistic issues encountered during the forward translation and adaptations of the Child Engagement in Daily Life (CEDL) in Greek.

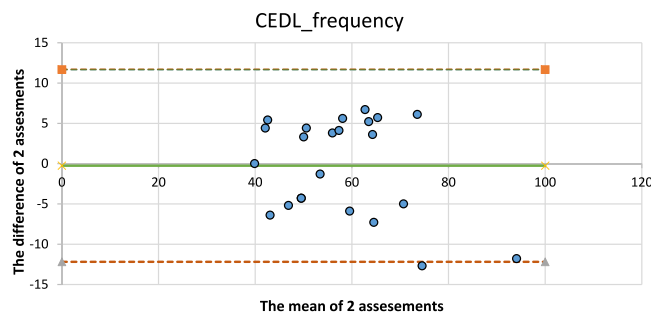
Original item	Issue to be solved	Adaptation
Your child does not need to participate in all of the examples	Parents neglect or misunderstood the prompt 'your child does not need to participate in all the examples'	Underlined and in bold
Often – your child frequently participates in the activity	Parents needed more clarifications to understand the meaning of the response 'often'	Added a word to the Greek translation, so as to clarify the option 'often', to show that it describes that the child participates in the activity 'often', in the sense of 'regularly'



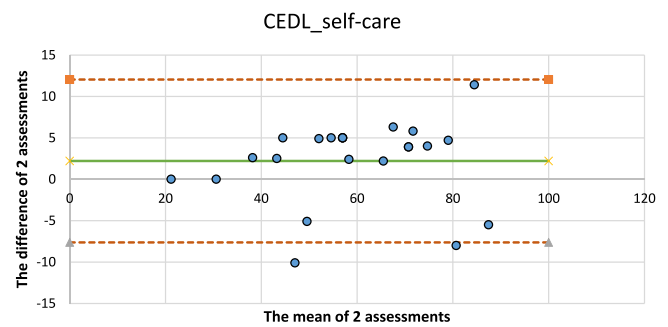
**TABLE 3** Internal consistency, test–retest reliability in 2 weeks and measurement error of the Child Engagement in Daily Life (CEDL) in Greek.

CEDL domains	Internal consistency (Cronbach's $\alpha$ )	Test–retest reliability (ICC with 95% CI)	SEM	SDC
CEDL frequency	0.83	0.90 (0.77–0.95)	0.80	2.40
CEDL enjoyment	0.76	0.88 (0.76–0.95)	0.05	0.16
CEDL self-care	0.92	0.95 (0.91–0.98)	1.60	4.50

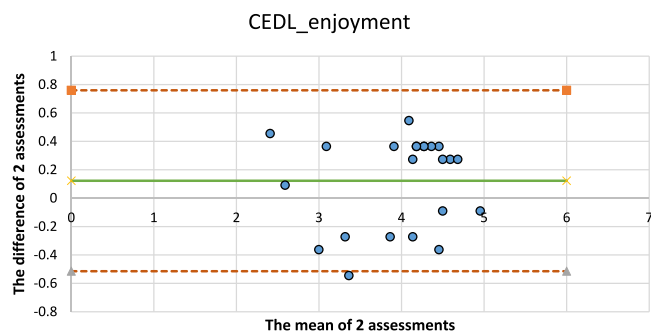
Abbreviations: CEDL, Child Engagement in Daily Life; CI, confidence interval; ICC: intra-class correlation coefficient; SDC, smallest detectable change; SEM, standard error of measurement.



**FIGURE 1** Bland–Altman plot for the Child Engagement in Daily Life (CEDL) frequency of participation score. The solid line indicates the mean difference score. The dotted lines represent 95% limits of agreement (1.96 standard deviation).



**FIGURE 3** Bland–Altman plot for the Child Engagement in Daily Life (CEDL) self-care score. The solid line indicates the mean difference score. The dotted lines represent 95% limits of agreement (1.96 standard deviation).



**FIGURE 2** Bland–Altman plot for the Child Engagement in Daily Life (CEDL) enjoyment score. The solid line indicates the mean difference score. The dotted lines represent 95% limits of agreement (1.96 standard deviation).

**TABLE 4** Mean differences in participation between children with cerebral palsy (CP),  $n = 107$  and children with typical development (TD),  $n = 97$ , based on the Greek version of the Child Engagement in Daily Life.

		Mean	Std. dev	Std. error	$p$
CEDL frequency	CP	58.8	14.5	1.4	<0.001
	TD	62.3	9.1	0.9	
CEDL enjoyment	CP	3.9	0.9	0.1	<0.001
	TD	4.4	0.6	0.1	
CEDL self-care	CP	49.7	23.5	2.3	<0.001
	TD	74.2	15.0	1.5	

Abbreviations: CEDL, Child Engagement in Daily Life; CP, cerebral palsy; Std, standard; TD, typical development. Data presented as mean (standard deviation).

### 9.2 | Validity

Regarding ‘Participation’, there were statistically significant differences ( $p < 0.001$ ) between children with CP and children with TD in all CEDL domains. All children with CP had lower scores compared with children with TD (Table 4). Regarding the ‘Participation in family and recreational activities’ at home and in the community, children with CP had a mean  $\pm$  standard deviation score of  $58.8 \pm 14.5$  in the frequency subdomain and  $3.9 \pm 0.9$  in the enjoyment subdomain, while the corresponding scores for children with TD were  $62.3 \pm 9.1$  and  $4.4 \pm 0.9$ , respectively. In the self-care domain, the scores were

$49.7 \pm 23.5$  for children with CP and  $74.2 \pm 15$  for children with TD. The ability of the CEDL to identify the Participation differences between two well-known different groups of children provides evidence for the construct validity of the measure.

### 9.3 | Interpretability

We calculated floor and ceiling effects to evaluate an aspect of interpretability of the CEDL, as suggested by the COSMIN taxonomy (Mokkink et al., 2010). Less than 15% of the participants obtained the

**TABLE 5** Floor and ceiling effect of the CEDL scores.

	Score range	Floor effect: N (%)	Ceiling effect: N (%)
CEDL frequency	0–100	0	4 (3.8)
CEDL enjoyment	0–5	1 (0.9)	17 (15.9)
CEDL self-care	0–100	5 (4.7)	1 (0.9)

Abbreviation: CEDL, Child Engagement in Daily Life.

N (%): Number and percentage of children obtaining minimum (0–10%) or maximum (90–100%) score.

maximum or the minimum scores for the participation frequency and self-care, while 17 children (15.9%) obtained the maximum score for the enjoyment subdomain, indicating a mild ceiling effect (Table 5).

## 10 | DISCUSSION

CEDL is a measure that records the participation of children aged 18 months to 5 years in activities of daily life and self-care. The purpose of this study was to cross-culturally adapt the CEDL in Greek, and investigate the reliability, the validity and interpretability in a Greek population. The availability of validated measures to assess participation could help reinforcing participation of Greek children with motor disabilities. Our study supports the reliability and validity of the Greek version of the CEDL and shows that it is suitable for Greek children with CP.

The value of participation for children with disabilities has now been universally recognised (Whiteneck & Dijkers, 2009), and it should be a permanent objective for children with disabilities. This is the first study that adapted a participation measure in Greek; it provides a valuable tool in Greek, which supports participation in the therapeutic process.

Regarding the translation of the CEDL into Greek, we did not encounter any particular difficulties. The Greek language has a remarkably rich vocabulary, which allowed us to articulate all the specific concepts and activities of the measure, as well as the authors' instructions. As the Greek culture does not differ significantly from other Western countries, there were no issues in adapting the various activity examples and the overall style of the measure. Moreover, regarding the self-care domain of the CEDL, the activities described are daily activities that most children do with their parents regardless of country of residence, cultural differences or beliefs, thus, it was relatively straightforward to translate these and ensure understanding.

One aspect of the CEDL translation that required special attention was the way parents interpreted the prompt 'Your child does not need to participate in all the examples'. Most parents tended to stick to the examples that were mentioned indicatively, to facilitate the parents' understanding of the type of activities involved. As a result, they either replied based on whether their children participated only in these example activities, ignoring any other activities that may had been relevant, or they replied based on whether their children participated in all the activities mentioned in the examples, that is, they did

not follow the prompt. In order to solve this issue, we provided additional clarifications, and in the final Greek version of the CEDL, the prompt was written in bold.

Regarding the scale that describes 'how often' the child participates in family and recreational activities, it was difficult for parents to distinguish between 'very often' and 'often' in their responses. An additional clarification was provided, that the response 'very often' should be selected when the child always participates in the activity when they have the opportunity, that is, 'at every opportunity', versus 'often', which should be selected when the child often participates in the activity. In our pilot study, the parents reported a difficulty regarding the use of the term 'always' or 'at every opportunity': When we refer to an activity in which the child desires to participate, the child is bound to participate in this activity at every opportunity presented (always), though this may also correspond to a lower frequency (often), depending on how often the child is provided with an opportunity to participate in the corresponding activity. In order to overcome this difficulty, we added a word to the Greek version, so as to clarify the option 'often', and show that it describes that the child participates in the activity 'often', in the sense of 'regularly', and not 'very often', in the sense of 'at every opportunity'.

The CEDL was able to differentiate in the participation of children with CP and children with TD in all domains. Distinguish between two different groups of individuals that differ in terms of a specific characteristic is an important indication of the construct validity of the measure, also referred to as the known groups method. Children with TD display a greater degree of participation in all CEDL domains, compared with children with CP (see Table 3) and this is demonstrated by the higher score they recorded. These results confirm previous studies reporting a lower degree of participation for children with disabilities (Alghamdi et al., 2017; Bedell et al., 2013; Ehrmann et al., 1995). In addition, previous studies show that, among children with CP, the children who participate more are those with higher functionality and fewer motor limitations, that is, GMFCS levels I and II compared with those with GMFCS levels III, IV and V (Law et al., 2012). These observations highlight the motor ability as a key criterion regarding the degree of participation of young children with CP in activities of daily living.

According to our measurements, the most noted differences between children with CP and children with TD were in the domain of self-care. This is likely due to the difficulty of children with motor difficulties when it comes to this type of activities, while it could also indicate that children with CP adopt self-care goals at an older age. When it comes to younger children with CP, both the parents and the therapeutic team focus on goals that relate to gross mobility, such as independent movement (particularly walking), independent sitting, standing, etc. In contrast, only small differences were observed in the subdomain of enjoyment, while more parents than in any other domain reported the maximum option, describing their children's enjoyment to the activities as 'a great deal'. This observation suggests that children with CP enjoy the same activities in a similar way with children with TD, regardless of their frequency or how well they perform them. We consider this observation of particular value, as it



supports that the reduced participation frequency of children with CP is not caused by different interests or lack of interest and enjoyment for specific activities, but by other factors that act as inhibitors.

Although the aim of our study was not to report on the participation patterns, this work is the first to record the frequency of participation of young children with motor disabilities in recreational, family and self-care activities in Greece. While the participation of children with disabilities is lower than the corresponding participation of children with TD worldwide (Adair et al., 2015), our data are specific to the Greek population. Greece features have many elements in common with other Western countries but have some particularities, in terms of its topography, the structure of the family, social beliefs and attitudes, as well as the structure of the state and welfare. Future research should investigate the factors responsible for the lower levels of participation in children with motor disabilities and compare with other countries.

The internal consistency reliability of the Greek version of the CEDL was excellent for the self-care and the participation frequency domains and good for the enjoyment subdomain (Cronbach's alpha was 0.92, 0.83 and 0.76, respectively). Similarly, test-retest reliability was excellent for the self-care domain and good for the other two subdomains; ICC of 0.95, 0.90 and 0.88, respectively. These results support the internal consistency of the Greek version of the CEDL and its stability for short periods. The results of the Greek version of the CEDL were comparable with those of the original version in all domains (Chiarello et al., 2014).

Regarding internal consistency, the most significant difference between the Greek version and the original English one appears in the enjoyment subdomain; Cronbach's alpha coefficient 0.91 versus 0.76 for the English and Greek versions, respectively. The value of the Cronbach alpha coefficient of the Greek version is acceptable. As the enjoyment from participating in an activity is a subjective experience, it can be very difficult to record it in a similar way among many people and across a variety of activities. This difficulty further intensifies when the degree of the child's enjoyment is reported by the parent, meaning that the judgment of another person is involved. Without detracting from the value of the parent's answer about the child's enjoyment, this observation may account for the reduced homogeneity of the respondents' answers, leading to somewhat dissimilar answers and therefore lower internal consistency on this domain.

In CEDL, the concept of involvement as described by the fPRCs (Imms et al., 2016), which is a key component of participation, is supposed to be conceptually covered by the concept of enjoyment. By determining how much children enjoy the activities in which they participate, we also determine, to a certain extent, how much they are involved in these activities, in the sense that the more they enjoy an activity the more they are involved. Although the concept of enjoyment is a very important element of participation, especially regarding young children participating in recreational and family activities, it does not completely coincide with the concept of involvement, as the latter includes additional elements such as impact, motivation, engagement, persistence and social connection (Imms et al., 2016). In

this light, we understand that the CEDL is a valid measure for 'Participation', covering the entire domain of attendance and an important part of involvement.

## 10.1 | Strengths, limitations and future research

CEDL is the first measure for participation that is available and validated in Greek. Clinically, it can be used in several settings, such as hospitals, rehabilitation centres, paediatric clinics or at home, to evaluate children's participation in family and recreational activities and self-care. It can also support clinical thinking and intervention of health care professionals in the field of childhood onset disability. It can be used by therapists and medical doctors to facilitate the establishment of participation-focused goals for children with disabilities. Based on its validity, parents and families can use CEDL in order to identify useful and meaningful aims for their children regarding participation in family and recreational activities and self-care, alongside with simple ideas on how to engage in these activities with their children. Overall, CEDL is an outcome measure that could support shifting our mentality in Greece, from disability to participation.

Regarding the limitations of the study, our sample consists mostly of children who lived in Athens during the study. Athens is the capital of Greece, with a large urban area. This must be considered, as topographical features and local customs may affect how children participate in daily life activities. Although we tried to recruit participants from the entire geographical region of Greece and aimed to a considerable sample size, it was difficult to collect completed evaluations from all areas, particularly rural areas and the Greek islands. Future multi-centred studies should be conducted and prioritise these places.

Considering intrinsic limitations of the measure, the CEDL is completed by parents, therefore there might be a discrepancy between how much a parent thinks that their child enjoys an activity and how much the child actually enjoys it. This is because parents may project parts of their own personality and preferences in relation to specific activities. However, considering the age of our population this is an acceptable limitation.

Future work should focus on the responsiveness and minimal clinical important difference for CEDL in young children with CP. Moreover, we should also explore the validity of the CEDL in Greek for children with other disabilities apart from CP and in different ages. Finally, cross-cultural adaptation and validation of other measures for participation in Greek is required, to allow assessment on more aspects of the engagement concept.

## 11 | CONCLUSIONS

The Greek version of the CEDL was developed and validated and can be used by Greek health care professionals and parents to record participation patterns and manage the therapeutic and daily needs of children with CP aged 18 months to 5 years. The translation and

cross-cultural adaptation of the CEDL used a standardised procedure and the validity and reliability of the Greek version are equivalent to the original English version. This measure can be used in clinical or home settings to assess participation in family and recreational activities and self-care for young children with CP and establish participation-focused goals that are meaningful for the children and their families.

## AUTHOR CONTRIBUTIONS

**Rigas Dimakopoulos:** Conceptualization; investigation; writing—original draft; methodology; writing—review and editing; supervision; validation. **Marianna Papadopoulou:** Supervision; conceptualization. **Roser Pons:** Conceptualization; methodology; resources. **Arietta Spinou:** Writing—review and editing; methodology.

## CONFLICT OF INTERESTS STATEMENT

None of the authors has conflicts of interest to disclose.

## DATA AVAILABILITY STATEMENT

The data that support the findings will be available in polynoec at <https://polynoec.lib.uniwa.gr/xmlui/> following an embargo from the date of publication to allow for commercialization of research findings.

## ORCID

Rigas Dimakopoulos  <https://orcid.org/0009-0005-8033-467X>

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## APPENDIX A

Questionnaire used in the semi-structured interviews for assessing the content validity of the provisional Greek version. This is modified from the COSMIN criteria and rating system for evaluating the content validity of PROMs.

1. Do you believe that the items included in CEDL are relevant to the participation of your child in family and recreational activities and self-care?  
Yes/No/Please Specify
2. Do you believe that the items included in CEDL are appropriate for children aged from 18 months to 5 years?  
Yes/No/Please Specify
3. Do you believe that the response options in CEDL are appropriate answers for the participation of your child in family and recreational activities and self-care?  
Yes/No/Please Specify
4. Are the instructions of CEDL clearly formulated, so that you as a parent who completes the questionnaire can understand them?  
Yes/No/Please Specify
5. Are the items and response options of CEDL clearly formulated, so that you as a parent can understand them?  
Yes/No/Please Specify
6. Are there any words or phrases that you as a parent who completes the questionnaire cannot understand?  
Yes/No/Please Specify
7. Do you think that response options of CEDL match the questions?  
Yes/No/Please Specify
8. Are there any key concepts that you believe are not included regarding your child's participation in family and recreational activities and self-care?  
Yes/No/Please Specify
9. Can you go through each item of CEDL and explain to me, in your own words, what do you think it says?  
Please Specify.