

How well do care providers know the children with developmental disabilities they care for?

Anke Meester-Delver (a.meester@amc.uva.nl)¹, Anita Beelen¹, Katinka Folmer², Dorien Medema³, Mijna Hadders-Algra⁴, Frans Nollet¹

1. Department of Rehabilitation, Academic Medical Center, Amsterdam, The Netherlands

2. Paediatric Rehabilitation Department, Rehabilitation Centre 'De Trappenberg', Huizen, The Netherlands

3. Paediatric Rehabilitation Department, Rehabilitation Centre 'De Hoogstraat', Utrecht, The Netherlands

4. Department of Paediatric-Developmental Neurology, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

Keywords

Additional care, Children, Developmental disabilities, Impairments, Rehabilitation

Correspondence

Anke Meester-Delver, Department of Rehabilitation, Academic Medical Centre, PO Box 22660, 1100 DD Amsterdam, The Netherlands.

Tel: +31-20-5669111 |

Fax: +31-20-5669154 |

Email: a.meester@amc.uva.nl

Received

11 September 2007; revised 29 December 2007; accepted 08 January 2008.

DOI: 10.1111/j.1651-2227.2008.00712.x

Abstract

Aim: To assess the knowledge from memory of caregivers about the most significant impairments contributing to additional care needs in children with developmental disabilities in therapeutic toddler groups.

Methods: Children's needs for additional care due to impairments of physical health, motor, sensory, mental and voice and speech functions were separately classified using the capacity profile (CAP). Twenty-three therapists and teachers of toddler groups in two regional centres for paediatric rehabilitation assessed the CAP individually, unprepared and without consulting their notes or the clinical record. These CAP scores (150 CAPs of 44 children) were compared with those based on the clinical record using weighted kappa statistics.

Results: Weighted kappa values for the two sets of CAP scores ranged from 0.22–0.74 (median 0.53), with the lowest scores for the sensory domain (median 0.32, range 0.22–0.52) and the highest scores for the motor domain (median 0.62, range 0.56–0.74).

Conclusion: Team members in general had only moderate remembered knowledge of the current impairments determining need of additional care. Remembered knowledge was the poorest for domains not easily observable, such as sensory functions. As this knowledge is essential for optimizing the child's daily environment, improvement of this type of knowledge should be facilitated.

INTRODUCTION

Children with neurodevelopmental disabilities exhibit a range of motor impairments as well as various associated impairments such as epilepsy, cognitive impairments, decreased sensitivity, speech impairments, low visual acuity, hearing deficit and feeding and growth abnormalities (1). The children are usually thoroughly examined by a child neurologist, ophthalmologist, audiologist and paediatrician. However, knowledge about a child's impairments mainly serves diagnostic purposes. During daily contact with the child, such knowledge becomes meaningful only if used to identify consequences for daily practice. One consequence for daily practice is the ongoing need for additional care, care above the normal care for the age group (2–8). Although

use of additional care is influenced by environmental, cultural and personal factors (9), the need for additional care is mainly determined by the child's impairments (10–12).

Many children with a neurodevelopmental disorder are referred to a paediatric rehabilitation centre and attend a preschool group. Thorough assessment by the members of the rehabilitation team, physiotherapist, occupational therapist, speech therapist, teacher, psychologist and doctor specialized in paediatric rehabilitation, of children with developmental disabilities is recommended to analyse the consequences of the current impairments for limitations in capacities and consequently need for additional care. This knowledge is essential for care providers to arrange optimal environmental factors (7). The results of the assessments used to develop and evaluate an individualized education plan during team conferences and to arrange optimal care are stored in the clinical record. Previous research showed that therapists and teachers exhibit reasonable agreement in rating the performance of a child using this information (13).

But to what extent do they know by memory how the child's current impairments contribute to limitations in his or her capacities? Parents take for granted that the professionals who care for their preschool children know the children well and know how to arrange the environment so that the needs of the child in terms of adaptations, modifications and handling of the child, are met (14,15). However, this

Abbreviations

ICF: International Classification of Functioning, Disability, and Health; CAP: Capacity Profile; CAP-ph: Capacity Profile-physical health; CAP-mo: Capacity Profile-neuromusculoskeletal and movement related functions; CAP-s: Capacity Profile-sensory functions; CAP-me: Capacity Profile-mental functions; CAP-v: Capacity Profile-voice and speech functions; PEDI: Paediatric Evaluation of Disabilities Inventory; WeeFIM: Functional Independence Measure for Children.

requires that the professionals know the child's needs by memory. Of course, the professional may consult notes when in doubt, but generally he or she should know directly why the child cannot do some activities (7,16–18).

Although the clinical record is accessible to each team member, there are many occasions, especially in classroom situations, such as play sessions, meals or therapeutic sessions, during which the team member does not have the opportunity to consult notes or the clinical record and is compelled to rely on remembered knowledge about the most significant impairments contributing to additional care needs for the child. To the best of our knowledge, no one has investigated this type of knowledge amongst team members.

In this study, team members' remembered knowledge of preschool children with neurodevelopmental disabilities was assessed. Specifically, we evaluated their ability to classify the consequences of children's current impairments within each domain of body function in terms of additional care needs without consulting the clinical record. We assessed the agreement between these classifications and those developed using the clinical record.

PARTICIPANTS AND METHODS

Measures

To establish the composition of the additional care needs of the child, we used the capacity profile (CAP). (19) The CAP is the classification of the type and intensity of the additional care needs resulting from impairments in five domains of body functions, according to the International Classification of Functioning, Disability and Health (ICF) (20)

1. Additional care to compensate for *impairments in physical health functions*, such as need for medication, special diet, tube feeding, intermittent catheterization and long-term ventilation.
2. Additional care to compensate for *impairments in neuromusculoskeletal and movement-related functions*, such as orthopaedic footwear, braces, environmental adaptations and modifications and personal help.
3. Additional care to compensate for *impairments in sensory functions*, such as visual or hearing aids, environmental adaptations and modifications and personal help.
4. Additional care to compensate for *impairments in mental functions*, such as intermittent, limited, extensive or pervasive support.
5. Additional care to compensate for *impairments in voice and speech functions*, such as augmentative communication.

The intensity of the care is assessed as follows:

0. Only the typical care for the age is required; there is no need for additional care.
1. Minor forms of additional care are required, such as taking medication or the need for orthopaedic footwear, but this level of additional care does not involve modifica-

tions of the environment or adaptation of the daily program or personal help. In case of mental impairment, additional care may consist of intermittent support, but the individual takes adequate initiative to request help.

2. Environmental modifications or adaptation of the daily program are required. This level of additional care does not involve personal help. In the case of mental impairments, additional care may consist of intermittent support, and the person who gives this support has authorities.
3. Personal help on a daily basis is required, but appointments can be made. This level of additional care implies that the subject can be left alone for part of the day. In the case of mental impairments, additional care may consist of limited support.
4. Personal help must always be available, but is not required for each activity (in the case of mental retardation, extensive support is required).
5. Personal help is required for each activity in the domain (in the case of mental retardation, pervasive support is required).

Assessment of the intensity of additional care needed by the individual child for each domain of body functions separately and irrespective of the need for care in the other domains results in the CAP (CAP-ph for the impairments in the physical health domain, CAP-mo for the impairments in the domain of neuromusculoskeletal and movement-related functions, CAP-s for the impairments in the domain of sensory functions, CAP-me for the impairments in the domain of mental functions, and CAP-v for the impairments in the domain of voice and speech functions). The profile reflects in a concise way the dependency on additional care as a result of the current impairments and shows which impairments are most prominent in influencing the need for care. The CAP is a classification that provides comprehensive information on not only the type of additional care needed, but also on the intensity of the additional care needed across and within medical conditions. Research has shown that the CAP has good inter-rater reliability and is stable over time for children with nonprogressive conditions such as cerebral palsy, myelomeningocele and other congenital and acquired conditions (19).

Participants

Forty-four children visiting the toddler groups of two centres for paediatric rehabilitation were subject of the assessments. These children had a variety of impairments due to neurodevelopmental disabilities including cerebral palsy ($n = 23$), myelomeningocele ($n = 1$), mental retardation ($n = 12$), congenital deformities ($n = 3$) and other causes ($n = 5$). Thirty-one children were boys. The mean age was 3.4 years (SD 0.6, range 2.4–4.4 years). In addition, all rehabilitation team members who regularly provided these children with therapy and care and developed their individual education plans were invited to participate. In both centres the individual education plans were developed based on the same method (21). The team members participated

voluntarily, and the executive staff gave permission for the team conference (see below). As no patient effort was involved, approval by the institutional ethics committees was not required.

Procedure

A team conference was arranged; the team members were invited to join this meeting, but were not informed about its purpose. During this team conference, the team members were asked to develop the CAP for those children they cared for and knew well. The clinical record or other notes were unavailable, such that the team members had to rely on remembered knowledge. During this conference, the team members were given support for technical questions about the assessment for the CAP, but not for questions about the children's current impairments. The team members were asked not to communicate with each other.

The CAP scores of the team members were compared with the CAP scores assessed by the child's rehabilitation specialist based on the reports in the clinical record. The clinical record encompassed the results of assessments of the children's impairments by the child neurologist, ophthalmologist, audiologist, paediatrician and any other specialists involved and the team-member reports, addressing the child's abilities and disabilities. All children were diagnosed according to the customary professional standards.

Statistical analysis

Contingency tables were constructed to compare the CAP scores of the team members with those based on the clinical record. Agreement between CAP scores was assessed by calculating the percentage of exact agreement and weighted Kappa statistics, with weights according to the linear model. The guidelines for interpretation of Kappa proposed by Altman et al. (22) were used. Furthermore, we examined systematic differences between the assessments of the team members and the clinical record using the Wilcoxon signed ranks test. Probability values less than 0.05 were considered statistically significant.

RESULTS

Twenty-three team members had the opportunity to join the team conference, and all agreed to participate in the study.

They included five physiotherapists, three occupational therapists, four speech therapists and 11 teachers. The 23 team members completed 150 CAPs for the 44 children. For one child, only one CAP was completed (by the speech therapist). For all other children, three ($n = 23$) or four ($n = 20$) CAPs were completed. The results (Table 1) show that in most cases agreement between the team members and the specialist was fair to moderate. Highest agreement was for the domain of neuromusculoskeletal and movement-related functions (CAP-mo) and lowest agreement was for the domain of sensory functions (CAP-s). Disagreement between CAP scores was sufficiently large in the domain of sensory functions to reach statistical significance.

The CAPs based on the clinical records are shown in (Fig. 1). Most of the children experienced impairments in more than one domain of body function (one domain: 4, two domains: 9, three domains: 15, four domains: 9, five domains: 7). Of the four children who had impairments in only one domain, two had motor impairments and two had mental impairments. Most children had a combination of motor and mental impairments, which is expected, as these children are likely to be referred to a paediatric rehabilitation centre. In 15 of the 44 children, sensory deficits were detected. More than half of the children had problems with physical health (e.g. epilepsy, gastro oesophageal reflux or constipation) and had a CAP-ph score of 1 in most cases, which implies taking medicine or special diet). Half had problems with speech, needing more of the listener's attention because of dysarthria (CAP-v score: 1) or requiring a communication aid (CAP-v score: 2 or more).

DISCUSSION

We sought to determine how well the care providers in preschool groups know by memory the current impairments of children with developmental disabilities and how they contribute to their need for additional care. We used the CAP as method to investigate this knowledge and the clinical record as a reference since this is the source of information that the rehabilitation team uses to determine the individual treatment and education plan. Agreement appeared moderate in most cases, especially for the sensory functions. The outcome of this study was not unexpected.

Table 1 Capacity profile: agreement between team members and the clinical record

	Occupational therapists			Physiotherapists			Speech therapists			Teachers		
	Weighted kappa	Percentage exact agreement	p-value*	Weighted kappa	Percentage exact agreement	p-value	Weighted kappa	Percentage exact agreement	p-value	Weighted kappa	Percentage exact agreement	p-value
Physical health functions (CAP-ph)	0.57	52	0.53	0.32	47	0.92	0.59	65	0.20	0.53	63	0.53
Neuromusculoskeletal and movement-related functions (CAP-mo)	0.59	45	0.64	0.74	70	0.64	0.65	58	0.11	0.56	51	0.43
Sensory functions (CAP-s)	0.22	32	0.00	0.29	46	0.01	0.52	64	0.02	0.35	56	0.00
Mental functions (CAP-me)	0.58	50	0.79	0.40	29	0.74	0.55	48	0.06	0.37	30	0.50
Voice and speech functions (CAP-v)	0.56	58	0.32	0.36	41	0.14	0.45	56	0.68	0.28	33	0.00

*Wilcoxon signed rank test, p-values <0.05 were considered statistically significant.

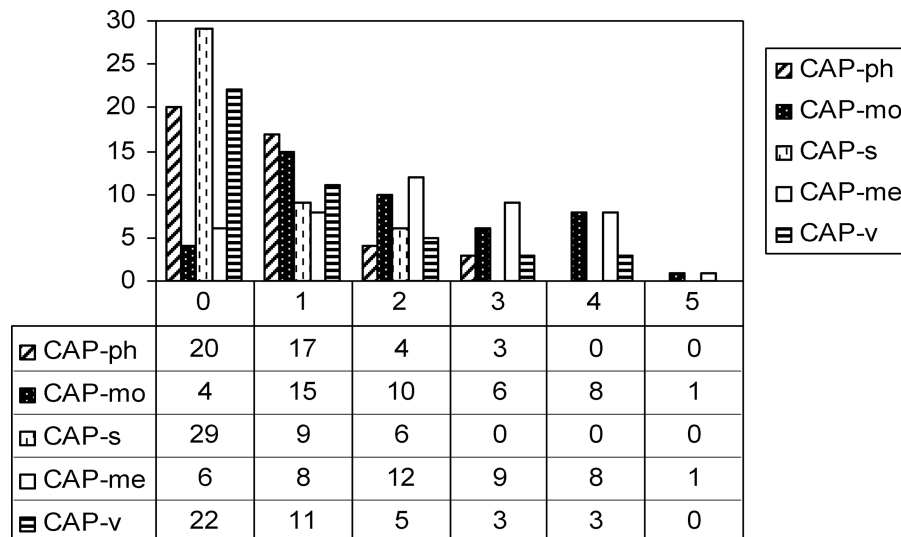


Figure 1 Capacity profile (CAP) scores developed based on the information in the clinical record for the children ($n = 44$) in the toddler groups of two regional centres for paediatric rehabilitation. Cap-ph = Physical health; CAP-mo = neuromusculoskeletal and movement-related functions; CAP-s = sensory functions; CAP-me = mental functions; CAP-v = voice and speech functions. The vertical axis denote the frequencies of the CAP scores and the horizontal axis the CAP scores.

Almost all children had a combination of impairments in different domains; this makes a child's behaviour difficult to understand. For example, when there is a combination of voice and speech problems, a hearing deficit and mental retardation, it is not easy to analyse what impairments create what need for care, but for effective communication with the child it is still essential. Analyzing the child's behaviour is even more difficult when there are also motor and visual impairments involved. These results are in line with several studies conducted in adults with intellectual disabilities, which showed substantial numbers of patients in whom the variety of impairments appeared to be underappreciated (23,24).

Care providers usually describe the need for additional care in the activity and participation domain of the ICF (needs help with eating, toileting, etc.) using instruments such as the Paediatric Evaluation of Disabilities Inventory (PEDI) (25) and the Functional Independence Measure for Children (WeeFIM) (26). However, these instruments do not comprehensively analyse the underlying impairments that determine the need for care. Moreover, with regard to arrangement of the environment and the handling of the child, the most significant consequences of the impairments should be known by memory. A suitable instrument for measuring this type of knowledge is not easy to find, but the CAP seems appropriate, providing a concise classification of the consequences of the current impairments in terms of additional care needs. For care providers who know which impairments contribute to the need for additional care, the scoring is easy. Previous research showed good inter-rater reliability between raters who based their assessment on the same written information about children in a study population (19). However, it should be considered that the CAP is a relatively new method and it has not yet been widely established in practice.

During recent years much effort is devoted to implementing diagnostic procedures for comprehensive examination of the children with disabilities. In addition, guidelines are developed for creating the individual education plan. The child should benefit as much as possible from his individual education plan. We feel that it is acceptable to expect all team members involved with a child to know the child's impairments and needs by memory to a certain reasonable extent. Our study underlines the need to improve this type of knowledge.

ACKNOWLEDGEMENTS

We would like to thank the team members of the preschool groups of the rehabilitation centres 'De Trappenberg' and 'De Hoogstraat' who participated in this study.

References

1. McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, et al. A new definition of children with special health care needs. *Pediatrics* 1998; 102:137-140.
2. Roberts K, Lawton D. Acknowledging the extra care parents give their disabled children. *Child Care Health Dev* 2001; 27: 307-19.
3. Perrin JM, Kuhlthau K, Walker DK, Stein RE, Newacheck PW, Gortmaker SL. Monitoring health care for children with chronic conditions in a managed care environment. *Matern Child Health J* 1997; 1: 15-23.
4. Liptak GS. The child who has severe neurologic impairment. *Pediatr Clin North Am* 1998; 45: 123-44.
5. Esperat MC, Moss PJ, Roberts KA, Kerr L, Green AE. Special needs children in the public schools: perceptions of school nurses and school teachers. *Issues Compr Pediatr Nurs* 1999; 22: 167-82.
6. Ciner EB, Appel S, Graboyes M, Zambone AM. Assessment and rehabilitation of children with special needs. *Optom Clin* 1996; 5: 187-226.

7. Cass H, Price K, Reilly S, Wisbeach A, McConachie H. A model for the assessment and management of children with multiple disabilities. *Child Care Health Dev* 1999; 25: 191–211.
8. Shonkoff JP, Meisels SJ. *Handbook of early childhood intervention*. 2nd ed. New York: Cambridge University Press, 2000.
9. Ostensjo S, Carlberg EB, Vollestad NK. The use and impact of assistive devices and other environmental modifications on everyday activities and care in young children with cerebral palsy. *Disabil Rehabil* 2005; 27: 849–61.
10. Beckung E, Hagberg G. Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Dev Med Child Neurol* 2002; 44: 309–16.
11. Lepage C, Noreau L, Bernard PM, Fougere P. Profile of handicap situations in children with cerebral palsy. *Scand J Rehabil Med* 1998; 30: 263–72.
12. Ostensjo S, Carlberg EB, Vollestad NK. Everyday functioning in young children with cerebral palsy: functional skills, caregiver assistance, and modifications of the environment. *Dev Med Child Neurol* 2003; 45: 603–612.
13. Bailey DB Jr., Simeonsson RJ, Buysse V, Smith T. Reliability of an index of child characteristics. *Dev Med Child Neurol* 1993; 35: 806–15.
14. King SM, Rosenbaum PL, King GA. Parents' perceptions of caregiving: development and validation of a measure of processes. *Dev Med Child Neurol* 1996; 38: 757–72.
15. Hendriks AH, de Moor JM, Oud JH, Franken WM. Service needs of parents with motor or multiply disabled children in Dutch therapeutic toddler classes. *Clin Rehabil* 2000; 14: 506–17.
16. Liptak GS, O'Donnell M, Conaway M, Chumlea WC, Wolrey G, Henderson RC, et al. Health status of children with moderate to severe cerebral palsy. *Dev Med Child Neurol* 2001; 43: 364–70.
17. Simeonsson RJ, Scarborough AA, Hebbeler KM. ICF and ICD codes provide a standard language of disability in young children. *J Clin Epidemiol* 2006; 59: 365–73.
18. Shonkoff JP, Hauser-Cram P, Krauss MW, Upshur CC. Development of infants with disabilities and their families: implications for theory and service delivery. *Monogr Soc Res Child Dev* 1992; 57(6): v153.
19. Meester-Delver A, Beelen A, Hennekam R, Nollet F, Hadders-Algra M. The capacity profile: a method to classify additional care needs in children with neurodevelopmental disabilities. *Dev Med Child Neurol* 2007; 49(5): 355–60.
20. World Health Organization. *International classification of functioning, disability and health*. World Health Organization, Geneva, 2001.
21. Roelofsen EE, The BA, Beckerman H, Lankhorst GJ, Bouter LM. Development and implementation of the rehabilitation activities profile for children: impact on the rehabilitation team. *Clin Rehabil* 2002; 16: 441–53.
22. Altman DG. *Practical statistics for medical research*. London: Chapman and Hall/CRC; 1999.
23. Evenhuis HM. Frequently occurring but little recognized disorders in adults with Down's syndrome. *Ned Tijdschr Geneesk* 1991; 135: 1581–84.
24. Meuwese-Jongejeugd A, Vink M, van ZB, Verschuure H, Eichhorn E, Koopman D, et al. Prevalence of hearing loss in 1598 adults with an intellectual disability: cross-sectional population based study. *Int J Audiol* 2006; 45: 660–69.
25. Haley SM, Coster WJ, Ludlow LH, Haltiwanger JW, Andrellos PJ. *Pediatric Evaluation of Disability Inventory (PEDI)*. 1st ed. Boston: New England Medical Centre, 1992.
26. Msall ME, DiGaudio K, Rogers BT, LaForest S, Catanzaro NL, Campbell J, et al. The Functional Independence Measure for Children (WeeFIM). Conceptual basis and pilot use in children with developmental disabilities. *Clin Pediatr (Phila)* 1994; 33: 421–30.