

# Meeting the Needs of Parents Around the Time of Diagnosis of Disability Among Their Children: Evaluation of a Novel Program for Information, Support, and Liaison by Key Workers

Jugnoo S. Rahi, MD\*‡§; Irene Manaras, PhD\*; Helena Tuomainen, MSc||; and Gillian Lewando Hundt, PhD||

**ABSTRACT.** *Objective.* Key worker programs for families of children with disabilities, to promote information provision, emotional support, and liaisons among different agencies, have long been advocated but not extensively implemented. We report the impact on the experiences of parents and the practices of health care professionals of a novel, hospital-based, key worker service (Community Link Team [CLT]), implemented in the pediatric ophthalmology department of Great Ormond Street Hospital (London, United Kingdom).

*Design, Setting, and Participants.* The CLT included 2 members, 1 of whom was present during the first outpatient assessment by the consultant ophthalmologist of any child newly diagnosed as visually impaired (corrected acuity of 6/18 or worse in the better eye) and accompanied the family during other assessments performed during that visit. A dedicated room was used by the CLT members to spend time with each family after completion of the clinical assessments. The CLT members reiterated and/or clarified clinical information already provided, specifically advised the families about visual stimulation programs and the benefits and purpose of visual impairment certification, and provided information about educational and social services. The same CLT member met the family at subsequent visits to the department and acted as the first point of contact for parents. Parents of children newly diagnosed with visual impairment and/or ophthalmic disorders at Great Ormond Street Hospital participated in a 2-stage study to assess their needs, their views about the processes of care, and their overall satisfaction. The study included a questionnaire survey with 2 standard instruments, ie, the Measure of Processes of Care, specifically developed and used to assess parents' views of the degree to which health services for a range of childhood disorders are family-centered, and the short form of the Client Satisfaction Questionnaire, used to assess overall parental satisfaction or dissatisfaction with services in the preceding year, as in other studies of parental satisfaction with pediatric services. This was followed by in-depth individual interviews with a subsample of parents who re-

turned completed questionnaires. The views of families with experience with the new service (CLT) were compared with those without. The experiences of health care professionals before and after implementation of the service were elicited through group interviews and were compared. We recognized that any differences would be attributable to both the direct effects of the CLT, ie, actual services provided by the team, and indirect effects, ie, broader changes in approaches or practices within the department resulting from shifting roles and responsibilities regarding specific elements of management. Therefore, both the specific tasks/activities undertaken by the CLT and broader changes in practices within the department were identified.

*Results.* Seventy-nine families from the pre-CLT group and 68 from the post-CLT group (68% and 65% of those invited, respectively) participated in the questionnaire survey, of which 29 and 19 (71% and 79% of those invited), respectively, took part in interviews. The 2 groups were comparable with respect to sociodemographic and clinical characteristics. Parents and health care professionals agreed that the CLT provided important information and facilitated access to specific services, while providing both emotional and social support and facilitating meetings with other families with children with similar conditions. A number of key generic components of the service were identified. First, provision, within the outpatient setting, of a dedicated "quiet room" and office space for key workers was an essential physical requirement. Second, early identification of the key workers as the parents' point of contact was essential; this was achieved in this case by the CLT members attending the first consultation, combined with their detailed debriefing of families at the end of the outpatient visit. Third, the adoption of certain tasks by the key workers, including some previously undertaken by ophthalmologists, helped to define the liaison role of the program. These tasks included discussing the process and benefits of visual impairment certification, contacting the advisory teacher for the visually impaired, and providing written reports to educational and social services; analogous tasks would exist for other disabilities.

*Conclusions.* Research on the needs of families of visually impaired children has been limited but indicates that, as with other childhood disabilities, the greatest needs during the critical period around diagnosis are for information, especially about educational and social services, and emotional support from professionals, informal and formal social networks, and support groups. Although not widely implemented or studied, key worker programs for families of visually impaired children, particularly in the context of multidisciplinary visual impairment teams, have been advocated, on the basis of their potential to facilitate coordination of

From the \*Centre for Paediatric Epidemiology and Biostatistics and †Department of Ophthalmology/Visual Sciences Unit, Institute of Child Health, Great Ormond Street Hospital, London, United Kingdom; ‡Department of Epidemiology, Institute of Ophthalmology, London, United Kingdom; and §School of Health and Social Studies, University of Warwick, Warwick, United Kingdom.

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Reprint requests to (J.S.R.) Centre for Paediatric Epidemiology and Biostatistics, Institute of Child Health, 30 Guilford St, London WC1N 1EH, United Kingdom. E-mail: j.rahi@ich.ucl.ac.uk

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health, educational, and social services. The model of such provision evaluated in this study reflects the fact that it was established as an outpatient service in a tertiary referral center for pediatric ophthalmology in the United Kingdom, with the specific structure and specialized roles for health care professionals that this requires. Different models might be more suitable in other settings in the United Kingdom or elsewhere. However, the important general lessons learned should guide implementation of such services for families of children with other disabilities. The recently launched National Service Framework for Children provides a new context and standards for meeting the needs of disabled children and their families in the United Kingdom and may also guide initiatives elsewhere. The findings of this study support implementation of programs for information provision, support, and liaison by key workers in all specialized centers for the assessment and diagnosis of children with serious visual problems. Implementation of similar services for families with children with other disabilities is likely to be equally valuable. *Pediatrics* 2004;114:e477–e482. URL: [www.pediatrics.org/cgi/doi/10.1542/peds.2004-0240](http://www.pediatrics.org/cgi/doi/10.1542/peds.2004-0240); key worker, visual impairment, disability, children, families, information.

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ABBREVIATIONS. CLT, Community Link Team; GOS, Great Ormond Street Hospital; MPOC, Measure of Processes of Care.

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The time around diagnosis is a key milestone for the parents of children with disabilities or chronic disorders.<sup>1–7</sup> The potential value of a family “key worker” in promoting information provision, emotional support, and liaisons among different agencies and services has long been discussed,<sup>8–10</sup> but such services have not been extensively implemented. We report the effects on the health service experiences of parents and the practices of health care professionals of a novel, hospital-based, key worker service within a tertiary-level pediatric ophthalmology department.

## METHODS

In August 2000, a new service, the Ophthalmology Community Link Team (CLT), was established in the Department of Ophthalmology, Great Ormond Street Hospital (GOS) (London, United Kingdom), where tertiary-level care is provided to children with ophthalmic disorders. Its purpose was to promote information provision, emotional support, and service coordination for the families of children treated in the department. Establishment of the new service required employment of new staff members and refurbishment of the outpatient complex to create a furnished “quiet room” and an office with personal computers.

The team included 2 members, coincidentally both with nursing training but only 1 with experience working with visually impaired children. One CLT member was present during the first outpatient assessment by the consultant ophthalmologist of any child newly diagnosed as visually impaired (corrected acuity of 6/18 or worse in the better eye<sup>11</sup>) and accompanied the family during other assessments undertaken during that visit, such as orthoptic and neurophysiologic testing. The new quiet room was used by the CLT members to spend time with each family after completion of the clinical assessments. The CLT members reiterated and/or clarified clinical information already provided, specifically advised the families about visual stimulation programs and the benefits and purpose of visual impairment certification, and provided information about educational and social services. Provision of emotional support was also a key component; therefore, the same CLT member met each family at subsequent visits to the department and acted as the first point of contact for parents. As the new service evolved, some elements were also

provided, as required, to some parents of children newly diagnosed with less severe visual loss, although the service continued to be aimed primarily at parents of children newly diagnosed as visually impaired.

To assess the impact of the CLT, we compared parents’ and professionals’ views and experiences in the year before program implementation with those in a 1-year period starting 4 months after implementation. Families of all children newly diagnosed with visual impairment, together with a random subsample of those newly diagnosed with milder visual loss, in the pre-CLT era (August 1999 through July 2000) and in the post-CLT era (December 2000 through November 2001) were eligible, as were all health care professionals working within the department during this period. Children potentially eligible for the study were identified from the hospital patient information system records for all new patients during the 2 study periods, and their eligibility was confirmed with review of their case notes.

The concept of “family-centeredness” is being increasingly emphasized in the area of childhood disability, in recognition of the importance of collaborative care-giving, with professionals working in partnership with families to develop, implement, and evaluate services.<sup>12</sup> Therefore, we assessed the health service experiences and needs of parents 12 to 18 months after new diagnoses of ophthalmic disorders among their children, in a 2-stage process. In the first stage, with written informed consent, parents participated in a mailed questionnaire survey with 2 self-report, validated instruments. The first was the Measure of Processes of Care (MPOC), which was specifically developed<sup>13,14</sup> and has been used<sup>15–17</sup> to assess parents’ views of the degree to which health services for a range of childhood disorders are family-centered.<sup>18</sup> It includes 5 analytically determined subscales or domains assessing the processes rather than content of care (Appendix 1). Therefore, although not previously used in the area of childhood visual impairment, it was the most appropriate instrument for our purposes. The second instrument, the short form of the Client Satisfaction Questionnaire<sup>19</sup> (Appendix 2), was used to assess overall parental satisfaction or dissatisfaction with services in the preceding year, as in other studies of parental satisfaction with pediatric services.<sup>13,20</sup> Detailed sociodemographic data, collected with questionnaires with standard classifications, included family structure and history of visual impairment, ethnic group,<sup>21</sup> education,<sup>22</sup> occupation,<sup>23</sup> home and car ownership,<sup>22</sup> and material deprivation.<sup>24</sup> Clinical details were extracted from the case notes. Quantitative data were entered, coded, and analyzed with SPSS software (version 11, 2001; SPSS Inc, Chicago, IL). Nonresponding parents were prompted twice, by telephone and by mail, in the subsequent 4 weeks but no additional contact was made, in accordance with the guidance from the Institute of Child Health/GOS Local Research Ethics Committee, which approved the study protocol.

The second stage involved in-depth individual interviews, which were undertaken with a stratified one-third subsample of parents who had participated in the questionnaire survey. The purpose was to gain a more in-depth understanding of parents’ experiences of services and of caring for their children through a narrative approach. Therefore, purposive selection was used to ensure inclusion of a range of families, with respect to socioeconomic status, family structure, ethnicity, and the degree of visual impairment of their children, so that as full a range of experiences as possible could be evaluated. Interviews were semi-structured and used a topic guide based on a review of the literature, discussions with relevant professionals, and 2 pilot interviews. All interviews were performed in the family home and were taped, with permission, for subsequent transcription. The impact of the service on health care professionals working within the department during the study period was elicited through group interviews held in the pre-CLT ( $n = 2$ ) and post-CLT ( $n = 1$ ) eras. These were conducted with a topic guide and were taped for subsequent transcription. Both parental and professional interview data were entered, coded, and analyzed with a qualitative data analysis program (NVivo QSR 1.3, 2000; QSR International, Melbourne, Victoria, Australia), as described below. Data were handled in accordance with current guidelines on confidentiality, and the Institute of Child Health/GOS Local Research Ethics Committee approved the study.

Scores for the questionnaire instruments were derived according to guidelines on their use, and internal reliabilities were assessed with Cronbach’s  $\alpha$  coefficient.<sup>25</sup> Domain-specific MPOC

and Client Satisfaction Questionnaire scores for each respondent were used to derive the summary scores, after examination of skewness and kurtosis indices.<sup>26</sup>

We compared scores in the pre-CLT era with those in the post-CLT era. We recognized that any differences would be attributable to both the direct effects of the CLT, ie, actual services provided by the team, and indirect effects, ie, broader changes in approaches or practices within the department resulting from shifting roles and responsibilities regarding specific elements of management. Differences between groups were examined with *t* tests or *F* tests<sup>26</sup> or comparisons of differences for 2 proportions.<sup>27</sup> Some data items were incomplete; therefore, denominators are reported for individual analyses.

After descriptive coding of the parents' and health care professionals' interview data, joint higher-order analysis with a content analysis approach was conducted, focusing on the dimensions of the MPOC (in particular, provision of general and specific information) and differences between the pre-CLT and post-CLT eras, with respect to direct and indirect effects on parental experiences and on the organization, roles, and responsibilities of staff members within the department. This triangulation of data allowed elaboration and synthesis of issues.

## RESULTS

Seventy-nine families from the pre-CLT era and 68 from the post-CLT era (68% and 65% of those invited,

respectively) participated in the questionnaire survey. Of these, 29 in the pre-CLT group and 19 in the post-CLT group (71% and 79% of those invited, respectively) took part in interviews. The 2 groups of families were comparable with respect to sociodemographic and clinical characteristics (Table 1).

In both groups, the highest domain-specific score was for respectful and supportive care and the lowest was for provision of general information. All MPOC and satisfaction mean scores were slightly higher in the post-CLT group than in the pre-CLT group, although only the differences in scores for provision of general information and provision of specific information were statistically significant (*P* = .05) (Table 2).

The direct and indirect effects of the CLT on parents' experiences, as revealed by the qualitative data, are summarized in Table 3. Parents and health care professionals agreed that the CLT provided both emotional and social support, while providing information and helping facilitate access to specific services.

**TABLE 1.** Comparison of Child, Family, and Parent Characteristics Between Pre-CLT and Post-CLT Eras

	Pre-CLT Group	Post-CLT Group	Difference*	<i>P</i> Value*
Characteristics of the child, % ( <i>n</i> ) of families†				
Age, y (mean ± SD)	2.48 ± 1.78	2.11 ± 1.67	<i>t</i> = 1.13	.26
Severity of visual loss				
Severe	29 (22)	23 (16)	6 (−8 to 20)	.42
Moderate	39 (32)	37 (25)	2 (−1 to 19)	.84
Mild	32 (25)	40 (27)	8 (−8 to 23)	.31
Associated nonophthalmic disorders				
Absent	49 (38)	60 (41)	11 (−5 to 27)	.19
Present	51 (41)	40 (27)		
Characteristics of the family, % ( <i>n</i> ) of families†				
History of family visual impairment				
Yes	24 (17)	13 (7)	11 (−1 to 23)	.09
No	76 (53)	87 (48)		
Family type				
Single-parent	87 (67)	90 (61)	3 (−7 to 13)	.62
Two-parent	13 (10)	10 (7)		
Deprivation index (population quintiles) <sup>24</sup>				
Quintiles 1, 2, and 3	68 (32)	69 (29)	1 (−19 to 18)	.82
Quintiles 4 and 5	32 (15)	31 (13)		
Car ownership <sup>22</sup>				
None	14 (7)	10 (7)	4 (−6 to 14)	.23
1	43 (21)	51 (34)	8 (−8 to 24)	.37
≥2	43 (21)	39 (26)	4 (−12 to 20)	.49
Housing <sup>22</sup>				
Owned	75 (58)	78 (53)	3 (−16 to 10)	.69
Rented	25 (19)	22 (15)		
Characteristics of the parent, % ( <i>n</i> ) parents‡				
Age, y (mean ± SD)	33.6 ± 5.3	33.8 ± 5.0	<i>t</i> = .28	.78
Main language				
English	97 (112)	99 (81)	2 (−2 to 6)	.31
Other	3 (3)	1 (1)		
Ethnic group <sup>21</sup>				
White	90 (103)	83 (78)	7 (−2 to 16)	.16
All others	10 (12)	17 (12)		
Occupation <sup>23</sup>				
Professional	26 (29)	28 (24)	2 (−14 to 10)	.76
Intermediate	35 (40)	16 (14)	19 (7 to 30)	.002
Working	12 (14)	19 (16)	7 (−3 to 16)	.19
Other	27 (31)	37 (31)	10 (−3 to 22)	.13
Education <sup>22</sup>				
Up to compulsory	33 (34)	18 (16)	15 (3 to 27)	.001
A levels or equivalent	31 (33)	43 (38)	12 (−1 to 25)	.07
Degree	36 (38)	39 (34)	3 (−10 to 16)	.69

\* *t* test for difference in means or test for difference in 2 proportions (95% confidence interval), as appropriate.

† Incomplete data for some items; maximal denominators were 79 families for the pre-CLT group and 68 families for the post-CLT group.

‡ Incomplete data for some items; maximal denominators were 115 parents for the pre-CLT group and 96 parents for the post-CLT group.

**TABLE 2.** Comparison of MPOC and Satisfaction Scores of Pre-CLT and Post-CLT Groups

	Score					Satisfaction <sup>19</sup> (Range: 0–5)
	MPOC <sup>14</sup>					
	General Information (Range: 0–7)	Specific Information (Range: 0–7)	Respectful and Supportive Care (Range: 0–7)	Coordinated and Comprehensive Care (Range: 0–7)	Enabling and Partnership (Range: 0–7)	
Pre-CLT (N = 115)						
Mean	2.84	4.6	5.04	4.18	4.79	4.02
SD	1.6	2.6	1.3	1.48	1.48	0.84
Minimum	0	0	1	1	1	1
Maximum	7	7	7	6	7	5
Post-CLT (N = 96)						
Mean	3.32	5.3	5.24	4.29	4.88	4.18
SD	1.9	3.0	1.2	1.33	1.33	0.65
Minimum	0	0	1	1	1	1
Maximum	7	7	7	6	7	5
T	-1.95	-1.95	-1.10	-.55	-.45	-1.49
P*	.05	.05	.27	.56	.65	.14

\* *t* test for difference in means between pre-CLT and post-CLT groups.

**TABLE 3.** Effects of CLT Reported in Parental Interviews and Health Professional Interviews

Direct Effects (N = 19 families)	Indirect Effects
Emotional support at time of diagnosis and subsequently, including additional discussions about the diagnosis	Freeing up of time for clinical staff members to discuss diagnosis, investigations, and management
Increased information provision in relation to available educational, social, and other services and how to make contact with parent support groups	Provision and use of a quiet room, facilitating provision of emotional support for families
Liaison through (1) specific referrals to services and (2) information and support for certification as visually impaired, enabling access to benefits	Increased support for other health professionals within the department in their clinical roles

I think we were introduced, it must have been probably the first time. And she basically said she was a shoulder for us. . . .She said, “if you need anything, if you need to talk to other parents, if you need advice on what to do next, support groups,” all that sort of stuff. She seems to wander around and mingle with all the families there but she does take the time out to come and talk to people and ask how things are going. It’s not just a sort of a nod hi and actually walking past. You don’t feel like just one of a number...you actually feel like you’re recognized as a unique family, an individual. I appreciated that, you know, because that doesn’t happen often.

Father (36B)

Well, my perception of them is as an information buffer. They are an interface between core professionals and the outside world, and I think “buffer” is quite a nice word, too, because I’ve perceived them as a soft cushion, enveloping the patient and family and surrounding them wherever they should go, so there’s filtering of information each way.

Health care professional

It was clear to parents that contact with the CLT improved their knowledge about, and access to, services.

If I hadn’t been to that appointment, if that letter hadn’t been written...we probably would have missed out on 2 other services that have been essential to R’s development. . . .It’s nice to know that there is a hospital that knows the system and knows how to advise the parents and...to know that you have got somebody there running through everything with you.

Father (49B)

She helped write letters to my council so that we moved here.

Mother (48B)

Meeting other families with children with similar conditions was frequently reported by parents as

being very important. The CLT referred families to each other directly through the Contact a Family directory ([www.cafamily.org.uk](http://www.cafamily.org.uk)), as well as through support groups run by a charity or through the teacher for the visually impaired. In addition, some families were introduced to each other by their consultant ophthalmologist, and a few reported meeting other families informally in the outpatient waiting area while attending appointments.

J [the CLT member] put us in touch with another family who had a child with a number of problems who needed a corneal transplant and had had that done. So, you know, my wife phoned up the other boy’s mother and spoke to her and actually I ended up speaking to the boy’s father as well. And they were great, you know. It was really good just to be able to talk to somebody who’d been through it. . . .Everyone has similar sorts of worries outside of the specifics of the condition.

Father (36B)

Indirect effects on the daily working of the clinic were identified by health care professionals and included their feeling supported in their own roles by the CLT. The consultant ophthalmologists reported the benefits of delegating some activities and responsibilities to the CLT, allowing them more time for discussion of clinical issues.

It’s relieved me of some of the things I was doing...that were inappropriate. The tea and sympathy I would be offering, the best I could, dashing in and out of the room, if they were in another room, and sometimes they would be left crying by themselves and then, while another patient was dilating, dashing in the room to see if they’re alright, see if they could

cope with another bit of conversation. I'd be phoning up a GP [general practitioner], saying, "I can't really send this family home without knowing someone's going to pop round and see they're OK." So I did make a lot more phone calls; I've never phoned a GP since I've had the CLT. I know that, if that family has set off home and someone needs to check they're OK the next day, the CLT would have done that, I don't have to do that anymore. I spend, in some cases, less time going through the blind registration form, because they would have prepared them for it or discussed it, so actually I'm spending less time doing that, it's more time-efficient; I can talk more about the medical diagnosis.

Ophthalmologist 1

Well, I don't know how the clinic ran without them before. They are an essential part of my communication with the patient. There is no doubt that there is a white coat syndrome...Patients, time and time again, will discuss things with the CLT after they've been with me that I just did not realize they needed to discuss. It means a second go at trying to explain things better...I found that it has strengthened the relationship between myself and the parent. Not so much the child, but definitely the parent. That's about it in a nutshell.

Ophthalmologist 2

Finally, the provision of a designated physical space (the quiet room) within the clinic was thought to be essential in enabling the parents and CLT to spend time together.

It's a space you need, as well as a person; the service needs to go with space. We have actually got a room, which we protect; it has a sitting room design to it and that has been very, very important. So wherever you want to set up a service, you need to give them a space that hasn't got a slit-lamp and a couch and "doctory" things in it.

Ophthalmologist 3

## DISCUSSION

This evaluation of the early performance of a new, hospital-based, key worker program demonstrates the direct and indirect effects that can be anticipated when information and support are provided to parents in this way, around the time of diagnosis of ophthalmic disorders and visual impairment among their children. Although families were not randomized to the intervention (because this was considered unethical), the 2 groups of parents were comparable with respect to the important factors that might have influenced their views. Combining detailed robust qualitative and quantitative data elicited from parents and health care professionals has provided a rich picture of the impact of this novel key worker program on the needs of parents and the practices of health care professionals.

Research on the needs of families of visually impaired children has been limited but indicates that, as with other childhood disabilities, the greatest needs during the critical period around diagnosis are for information, especially about educational and social services, together with emotional support from professionals, informal and formal social networks, and support groups.<sup>2-4</sup> Although not widely implemented or studied, key worker programs for families of visually impaired children, particularly in the context of multidisciplinary visual impairment teams,<sup>28</sup> have been advocated<sup>3,8,9</sup> on the basis of their potential to facilitate coordination of health, educational, and social services. The model of such provision evaluated in this study reflects the fact that it was established as an outpatient service in a tertiary re-

ferral center for pediatric ophthalmology in the United Kingdom, with the specific structure and specialized roles for health care professionals that this requires. Different models might be more suitable in other settings in the United Kingdom or elsewhere. However, important general lessons can be learned, to guide implementation of such services for families of children with other disabilities. First, provision, within the outpatient setting, of a dedicated quiet room and office space for key workers is an essential physical requirement. Second, early identification of the key workers as the parents' point of contact is essential; this was achieved in the present model by the CLT members attending the first consultation, combined with their detailed debriefing of families at the end of the outpatient visit. Third, the adoption of certain tasks by the key workers, including some previously undertaken by ophthalmologists, helped to define the liaison role of the program. These tasks included discussing the process and benefits of visual impairment certification, contacting the advisory teacher for the visually impaired, and providing written reports to educational and social services; analogous tasks would exist for other disabilities.

There are currently a number of international initiatives aimed at providing a new context and standards for meeting the health needs of disabled children and their families. In the United Kingdom, within the National Service Framework for Children,<sup>29</sup> a number of themes have been identified, including promoting inclusion, partnership, and participation, coordinating multiagency services, addressing inequalities and family support, and meeting complex and continuous health needs. All have relevance to visual impairment, but the evidence base required for development of new interventions or policies in this area is incomplete. Therefore, much additional interdisciplinary work will be required if meaningful innovations are to be implemented. Nevertheless, the findings of this study support implementation of programs for information provision, support, and liaison by key workers in all specialized centers for the assessment and diagnosis of children with serious visual problems. It is likely that implementation of similar services for families with children with other disabilities would be equally valuable.

## APPENDIX 1. MPOC DOMAINS<sup>14</sup>

1. Provision of general information focuses on activities related to meeting parents' general information needs, eg, about education or social services.
2. Provision of specific information about the child relates to information provision specific to a given child, eg, about the timing and purpose of clinical investigations or treatments.
3. Enabling and partnership assesses the degree to which parental input is elicited and the extent of parental involvement in decision-making about the care of the child.
4. Respectful and supportive care describes the extent to which parents are treated respectfully as individuals and equals.

5. Coordinated and comprehensive care for the child and family encompasses the holistic needs of the family and the extent to which services are continuous and consistent across time, settings, and people.

## APPENDIX 2. CLIENT SATISFACTION QUESTIONNAIRE (SHORT FORM) ITEMS<sup>19</sup>

1. To what extent has the care provided met your needs?
2. Has the care you have received helped you deal better with your child's problems?
3. In an overall, general sense, how satisfied are you with the care you have received at the hospital?

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