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Keeping It Together^{TM}: an information KIT for parents of children and youth with special needs

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Abstract

Background Provision and use of information about their children is a major concern to families who have a child with a disability. Strategies or systems to influence parents' abilities to receive, give and use information in a way that is satisfying to them have not been well validated.

Methods This paper reports on the development and evaluation of a Parent Information KIT ('Keeping It Together') information management system and child advocacy tool. The KIT was designed to assist parents in giving, getting and organizing information in an effective way. The KIT was evaluated by a sample of 440 parents, with outcomes of use, utility, impact and perceptions of family-centred care measured at baseline, and after 6 months, and 15 months.

Results Parents' perceptions of their ability, confidence and satisfaction when using information improved significantly after using the KIT. Parents' perceptions of care, as measured with the Measure of Processes of Care, also improved significantly in the areas of 'Enabling/Partnership' and 'Providing General Information'. Parents' ratings of the use and utility of the KIT were associated with increased impact and, in turn, predicted improved perceptions of care.

Conclusion Parents who received and actively used the Parent Information KIT experienced significant increases in their perception of their ability and self-confidence in getting, giving and using information to assist their child with a disability. Strategies for improving the use of the KIT among parents are discussed.

Keywords
childhood disability, family-centred service, health service research, information

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Introduction

Information is essential for all parents with children or youth with special needs who are involved in health, education and/or social service systems. Not only is information necessary, but strategies to manage and communicate information are also important. Parents of children and youth with special needs have a great deal of information to give, to get and to organize in order to receive the best and most co-ordinated services for their child.

Research indicates that the provision and use of information about their children is a major concern to families (Miller *et al*. 2003). Over the past 6 years, researchers at *CanChild* Centre for Childhood Disability Research at McMaster University in Canada have been working together with parents of children with special needs and service providers to develop a Parent Information KIT

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('Keeping It Together'). The KIT is an information management system and child advocacy tool that includes strategies, tips and resources about giving, getting and organizing information in an effective way. The primary purpose of the Information KIT is to help parents use information as a tool to 'get the best' for their child. In this paper, we describe the development and evaluation of the KIT.

Background information

Parents have indicated their desire for information that can assist them with their child with special needs. When their child has complex and long-term special needs, parents are required to interact repeatedly with many service providers (S. King *et al.* 2000). Through focused interviews completed with 13 parents of children with cerebral palsy, Miller and colleagues (2003) found that parents wanted better information sharing from and between health professionals, particularly information with clarity and brevity. In another qualitative study, parents expressed a strong desire to share the responsibility for assessment of their child with a professional, but lack of confidence inhibited them from sharing their thoughts (Kai 1996). Most parents believed that being more informed about their child's illness would reduce rather than increase this anxiety. In a systematic review of stressors for parents of children with disabilities, Beresford (1994) found that maintaining and systematically using information was a positive coping strategy for parents. Pain (1999) reported that parents found that information assisted them in accessing services and improved their management of their child's behaviour.

Studies of family-centred service have consistently found that parents rate the provision of both general and specific information about their child significantly lower than other aspects of family-centred service (King *et al.* 1998; S. King *et al.* 2000). General information includes items dealing with a wide range of information needs, such as information about disability, how to contact other parents, information on the types of services available at the centre and in the community, and advice on how to get information. Specific information refers to those professional activities that provide parents with particular information about their own child (e.g. providing results of assessments).

Service providers also indicate the importance of involving parents in service provision and ensuring that they have access to all the information necessary for their child to effectively manage their child's needs. Hinojosa and colleagues (2002) surveyed occupational therapists working with parents and children regarding their attitudes and values in their working relationships with parents after 12 years of legislative support for family-centred practice. Findings from a sample of 199 therapists across the United States found that most therapists felt that time spent with the child was equally important to time spent with parents, but felt that time with parents had a greater impact on a child than any other aspect of intervention. Respondents spent approximately two-thirds of this time instructing parents about the care of their child, and 30% of the time discussing parent-directed concerns (i.e. parental needs, feelings, play activities, etc.).

Laurendeau and colleagues (1994) found that a programme that provided information to parents about child development when their child was born was perceived to be very helpful 3 years later. Mothers who were provided information had better knowledge of child development, a more positive attitude about their parenting skills and a better knowledge of how to access resources for their family (compared with a control group).

While some information needs of parents can be met through individual interactions with health-care professionals (Hinojosa *et al.* 2002) or through involvement in a parent support network (Santelli *et al.* 1999; G. King *et al.* 2000), few tools have been developed to assist parents in the management of the information related to their child. The development and utility of a personal child health record for children with disability was studied with 99 families (Moore *et al.* 2000). In this research, a panel of parents, health and education experts developed a supplement to the child health record for children with disabilities. The supplement included space for: recording names of health professionals, listing medical diagnoses/equipment/medications and caregiver diary entries. Feedback from families was positive regarding the supplement and indicated that it was used primarily to record factual information that may need to be recalled by parents. Families had reservations about the commitment of professionals to write in or read the document. There was no evidence that the record improved the parents' perception of their child's general health care, or that it contributed to the overall level of communication between parents and professionals.

In summary, there is widespread agreement about the need for parents to receive and use information effectively for their child with special needs. Strategies or systems to influence parents' abilities to give, get or use information have not been well validated. Few studies have examined the use of information systems by families.

Purpose

The purpose of this research was to develop and evaluate a Parent Information KIT designed to assist parents of children and youth with special needs in getting, giving and using information effectively. We were particularly interested in parents' ratings of the use, utility and impact of the KIT as well as the effect of using the KIT on parents' ability to present information in different situations and their perceptions of service.

Methods

Development of the KIT

To develop ideas and content for the initial KIT, focus groups were held with six parents of children with disabilities who belonged to a local family support network. The research team used the parents' suggestions, along with information from the two parent investigators on the team, to develop the content and structure of the KIT.

The KIT content focused on assisting parents of children with special needs to use information as a tool to communicate and interact with their child's service providers. The KIT included a User's Manual, customized Binder with specially designed record-keeping forms, and an accordion style folder for organizing and storing 'historical' information. It includes strategies, tips and resources about giving, getting and organizing information. It is interactive in nature, and includes a flexible organizational framework that each family can set up in a way that suits their information needs. It is designed for parents of children and youth with all types of special needs (developmental, physical, learning) from birth to 21 years.

The first draft of the KIT was pilot tested with 21 parents and nine service providers in two communities. Feedback was obtained through questionnaires and focus group interviews to evaluate the perceived utility and satisfaction with the design of the KIT. Overall, both groups were satisfied with the KIT's design and utility: the mean score on a 5-point scale was 4.01 ($SD = 0.25$) for parents and 3.52 ($SD = 0.25$) for service providers. Service providers reported that they would recommend the KIT.

Evaluation of the KIT

Based on the findings of the pilot test, a second version of the KIT was developed that incorporated the recommendations made by parents and service providers. To evaluate the final version of the KIT, 440 parents were recruited. A maximum variation sampling strategy (from children's rehabilitation centres, parent support networks, association newsletters) was used to ensure a broad range of families and children from across the province of Ontario. Outcomes were measured at baseline (Time 1, before families received the KIT), 6 months (Time 2) and 15 months (Time 3) later, after families had used the KIT. Quantitative outcomes were measured using the 20-item Measures of Processes of Care (King *et al*. 1996) and a structured questionnaire to gather information from parents regarding the use, utility and impact of the KIT. The Use section of the questionnaire assessed actual use of the KIT over time while the Utility section asked participants' perception of format, content and ease of reading. For impact, we asked participants to rate their perceptions, using a 7-point Likert scale, of their ability, confidence and satisfaction in the use of information in different service contexts. Complete data were collected from 439 participants at Time 1, 268 at Time 2 and 206 at Time 3.

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Descriptive and comparative analyses were completed using SPSS version 11 (SPSS, 2002). Differences in outcomes between baseline and Times 2 and 3, respectively, were evaluated using the Student's *t*-test. Structural equation modelling (Klein 1998) was completed to model the relationships among KIT use, utility, impact and perceptions of care. Data from Time 1 were used for the development of the measurement model and the resultant model was tested with data obtained at Times 2 and 3. Three latent constructs were considered in the model: Use/utility, Impact and Perceptions of Care, as measured by observed variables (total summed scores of items on each measure).

Qualitative interviews were completed by an independent evaluator with 20 parents over 6 months of use of the KIT to explore in greater depth their perceptions of and suggestions for the KIT. Parents who were interviewed were purposely selected to include a broad range of children with special needs, rural and urban settings and differences in actual use of the KIT. Transcripts were analysed using interpretative analysis to identify important themes about the use and impact of the KIT.

Results

Demographic information about study participants and their children at baseline is presented in Tables 1 and 2.

Quantitative results

The Use/Utility questionnaire asked parents to rate their perceptions about the organization, ease of understanding, ease of use and relevance of the KIT for themselves and their child. Mean summary ratings for these four items were 24.3 of a maximum of 28 (SD = 3.2), with a range of 13–28. The results of the Impact questionnaire found parents' perceptions of their ability, confidence and satisfaction when using information improved significantly after using the KIT (Table 3). Parents' perceptions of service providers' care, as measured on the Measure of Processes of Care, also improved significantly in the areas of 'Enabling/Partnership' and 'Providing General Information' (Table 4).

Table 1. Parent demographics at Time 1 (baseline)

Parent's relationship	Frequency reported	%
Mother	404	91.8
Father	16	3.65
Guardian	2	0.45
Foster parent	7	1.6
Grandparent	6	1.4
Step parent	2	0.45
Adoptive parent	2	0.45
Other	1	0.20
Total	440	

Table 2. Child/youth demographics at Time 1 (baseline) ($N = 439$)

	Frequency	%
Gender		
Male	298	67.7
Female	142	32.3
Age		
Under 5 years	115	26.1
5–12 years	222	50.5
13–18 years	66	15.0
Over 19 years	16	3.6
Missing	21	4.8
Primary disability:		
Physical (e.g. CP, SB)	123	28.0
Developmental	130	29.5
Learning	20	4.5
Communication	12	2.7
Sensory	6	1.4
Syndrome	69	15.7
Multiple	34	7.7
Other	46	10.5
Type of community:		
Large urban	165	37.5
Small urban	214	48.6
Rural	61	13.9

CP, cerebral palsy; SB, spina bifida.

Table 3. Change scores: parents' perceptions of the impact of the KIT on their ability to use information in different situations ($N = 206$)

Impact	Mean	SD	*t*-test	Significance
			Time 1–Time 3	
Time 1 scores	102.207	18.75		
Time 3 score	108.05	18.85	−5.123	0.000
			Time 2–Time 3	
Time 2 scores	115.31	20.561		
Time 3 score	109.18	18.2629	4.557	0.000

KIT, keeping it together; SD, standard deviation.

Table 4. Change scores on subtests of the Measure of Processes of Care ($N = 206$)

Time 1 to Time 3	Mean	SD	*t*-test	Significance
Enabling/partnership	4.7905	1.37	−2.285	0.024
	5.0152	1.28		
Providing general information	3.9321	1.57	−2.854	0.005
	4.244	1.48		
Providing specific information	4.744	1.44589	−7.25	0.469
	4.8177	1.38774		
Comprehensive coordinated care	4.83	1.4004	−1.884	0.061
	5.0083	1.24725		
Respectful supportive care	5.1119	1.597	−8.64	0.389
	5.187	1.411		

SD, standard deviation.

It was hypothesized that increased use/utility would lead to increased impact which would in turn relate to increased perceptions of care. We completed a structural equation model to analyse the relationships between use/utility, impact and perceptions of family-centred care. The final model demonstrated that parents' perception of the use/utility of the KIT has a low to moderate positive effect on perception of impact (0.31). There is a moderate positive effect of perception of the impact of the KIT on participants' perceptions of care (0.52). Testing of this mediation model was completed to examine our hypothesis that impact functions as a mediator factor of use/utility and perceptions of care (as per Baron & Kenny 1986). Initially, the relationship between use/utility and perceptions of care was examined with a direct path (positive beta coefficient of 0.17). This coefficient decreased to 0 once impact was included as a mediator between utility and perceptions of care. Thus, increased use/utility of the KIT by participants leads to increased impact and subsequently to significant changes in perceptions of care. Fit statistics indicate a good fit for this model (TFI, CFI > 0.998, RMSEA 0.024).

Qualitative results

Themes emerging from parent interviews indicated that parents were using the KIT in a variety of situations, and within several different service systems (e.g. health care, education, social services). Parents reported increased feelings of empowerment, and also that they were more aware of their needs. They reported that the KIT assisted them in finding new resources, and also increased self-advocacy skills. Parent comments included:

> Best idea that anybody had. Just the amount of files, the tabs you have on it. The information on how to use it was wonderful because it is hard to try to organize something . . . So putting all of that together, it was just amazing.
>
> You can carry a whole bunch of things and then they are ready to use and you can carry things and know where to find stuff, quickly.
>
> Well with my daughter having special needs, she has tons of information and it was just in boxes everywhere. I was tired of that because I couldn't find anything when the doctors needed it, you know. So for forms, filling out forms or anything like that.
>
> I thought it was a really good idea because I know when xxxx first got diagnosed, I was totally lost and I didn't know where to go to for help or anything like that.
>
> I have a stronger voice because everything is at my fingertips not all over the place.
>
> It made me not afraid to ask for what I needed for my son. When you are first a special needs parent, it's very confusing and it's very scary because you feel like you're always asking for something . . . but once you have the KIT and you know you can do your research and you know what you are talking about, then you don't feel that confusion and you feel a lot more confident.

Parents stressed that this tool would be ideal for the parents of a child who is first diagnosed with a problem requiring special services, and is entering the service system. Many excellent suggestions were made to improve on or add forms to meet all families' information needs.

Although most participants found the KIT to be well-organized and easy to understand, not all parents used the KIT. Participants stated that lack of time was the primary barrier to use. Some parents found the initial set-up and amount of record-keeping overwhelming at first. They felt that orientation and training materials to support setting up and using the KIT would potentially save time and increase effective use of the KIT.

Discussion

Parents of children with disabilities have clearly indicated a need to use information effectively to assist their child (Miller *et al*. 2003). The Parent Information KIT was judged by parents to be easy to understand and a useful tool for managing information from health, education and social service sectors with which they and their child interacted. These results support the value of tools to assist parents with giving, getting and managing information effectively. In a system that is based on family-centred service and enhancing families' strengths, information becomes a powerful tool for supporting children and ensuring an equal voice for parents (Maton *et al*. 2004; McKnight 2005).

Parents who received and actively used the Parent Information KIT experienced significant increases in their perceptions of their ability and self-confidence in getting, giving and using information to assist their child with a disability. These changes in their perceptions of self-efficacy, in turn, led to improvements in their perceptions of the care that they and their children were receiving. The areas of care in which significant increases occurred were in the domains that reflect parent's perceptions of enabling/partnership and receiving general information in the Measure of Processes of Care.

Parenting a child with a disability has been shown to be associated with increased parental stress and negative impacts on parents' emotional health (Brehaut *et al*. 2004). In paediatric rehabilitation services, there is strong evidence that a family-centred approach results in greater parental satisfaction with services, better parental psychosocial well-being and better psychological adjustment of children (King *et al*. 1996, 1998, 1999). A tool such as the Parent Information KIT is important for parents because it leads to improved experiences and perceptions of care.

While positive outcomes were documented for parents who actively used the KIT, some families within the study sample did not use the KIT. It will be important to examine whether these parents differed systematically from those who used the KIT and the reasons why they did not use the KIT. Results from the qualitative interviews indicate that parents who were not concerned with their lack of organization did not use the KIT. Parents who considered themselves organized were more likely to use the KIT. For some parents, getting started in using the KIT was difficult, given the many other demands on their time. While the KIT was easy to understand and use, it did take time to set up initially. Many parents commented that they had difficulty finding the time to get started and could have benefited from an easy-to-follow training videotape or script. In particular, parents suggested that the best time to introduce the use of the KIT was when their child was initially diagnosed.

The main limitation of this study is the before–after design of the evaluation which does not allow for comparison with families who did not use the KIT and limits our ability to account for temporal changes and other confounding variables. The before–after design in this exploratory study was reasonable given the developmental nature of the project, however, future research should use a comparative approach. Another limitation is the level of attrition, particularly from Time 2 to Time 3. Although these numbers seem high, this rate of attrition is similar to market-research or product-development types of evaluation, in which large numbers of non-respondents are often reported. Feedback from the participants who did not use the KIT indicated that they could not find the time to set it up: this suggests the need to introduce organizational tools early in the process for parents of children who are newly diagnosed.

While this research indicates that the KIT is effective in improving a family's ability to get, give and use information to assist their child, it has also raised other research questions. For example, the development and evaluation of a video orientation to the KIT for parents was suggested by participants. This process may help families get started, as lack of time appears to be the primary barrier to using the KIT. Information from this study is now being used to revise the KIT so that it can be distributed to parents for ongoing use. Research is being planned to examine the effectiveness of a parent video/DVD orientation to the KIT in improving ease of use. Further research should also examine the effect of parent information strategies on child outcomes.

Use of the Parent Information KIT appeared to increase parents' engagement with service providers in positive directions towards an increased partnership and mutual sharing of information. Thus, providing parents with strategies and an organizational tool for managing information can assist them in their day-to-day self-management in parenting a child who has a disability.

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