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ACCESSING STATE FUNDED SERVICES FOR CHILDREN WITH DISABILITIES: A STRATEGIC COMMUNICATION ISSUE?

Abstract:

The quality of the social and academic integration of children with disabilities depends more and more on their parents' ability to ask for and gain access to various services. Confronted with numerous budget cuts, many social agencies are forced to reexamine their role and the array of services they can afford to offer. In this context, parents are faced with increasing paperwork, numerous go-betweens and complex negotiations when requesting services. Empirical studies dealing with utilization of services for persons with disabilities are scarce and focus mainly on socio-demographic variables associated with high or low rates of utilization. Some sholars have suggested that free and universal access to services that are state funded is a myth. In fact, a large number of complex processes could play the role af an " expectancy cooling down " process, through which parents who do not have access to services for their child are led to believe that they are responsible for this situation. A threefold research was conducted to shed light on this question: 1) a content analysis of various documents parents have to read and fill out when requesting services; 2) results of a survey conducted with a sample of 133 parents of children with a confirmed medical diagnostic of disability; 3) qualitative analysis of interviews involving 30 parents who had filled out requests for state funded services for their child. Results indicated that the processes involved in asking for services is complex and convoluted. Informations and forms prepared by governmental agencies require high level reading abilities. Parents who were successful in gaining access to appear to have better communication skills than those who were not. Implications of these results for the delivery of services for children with disabilities are discussed.

Keywords:

children; disabilities, services, social agencies, communication

JEL Classification: I00, I14, Z18

Parents and families of children who are faced with handicapping conditions bear a heavy burden both in terms of the amount of care required by the child and the complex procedures through which state funded services are accessed (Pathappilil, Bhatt, & Kabler, 2013; Stinson, 2013). Greenley and Robitschek (1991) have shown that when parents are well supported and their child receives appropriate services, they prefer to keep him at home.

The willingness of the parents to invest time, money and energy in caring for a special child is of paramount importance, especially since public services are shrinking both in scope and volume (Frost, Elmer, Best, & Mills, 2010; Vohra, Madhavan, Sambamoorthi, & St Peter, 2014). Respite is a common denominator among all the needs expressed by parents. They will be even more exhausted if they are not able to take leave of their heavy responsibilities to rest or at least engage in other occupations (Axtell, Garwick, Patterson, Bennett, & Blum, 1995; Baxter, Cummins, DaCosta, & Volard, 1991; Molaison, Black, Sachs & Smull, 1995). However, research has shown than most families receive simple basic services such as respite through their extended family or social network (Axtell et al., 1995; Molaison et al., 1995; McConachie, 1994).

 Information and access to services are also linked to demographic and socioeconomic factors, namely SES and education (Coots & Matheson, 1995; Curtis, 1990; Street., 1991; Thompson & Weisberg, 1990). Low family income is linked to less access to various services, while a higher level of education will allow the parent to receive better services and more complete information (Arica, Keyes & Gallagher, 1993; Axtell et al., 1995). Ethnic and cultural differences between parents and agency personnel are also cited as a frequent obstacle (Curtis, 1990; Weller, 1994).

The complexity of the child's disability also affects access, since most social agencies plan and offer services on the basis of disability specific criteria. Children who require multiple services because of overlapping disabilities receive fragmented and uncoordinated services (Shea, Salhani, Leewko, Boshen, Flynn & Volpe, 1993). Access to services is facilitated when laws affirming the importance of intervening within the community help social services to reframe their interventions around the family (Callejas, Hernandez, Nesman, & Mowery, 2010; Crace, Ronco, & Hossler, 2013; Frost et al., 2010).

PROBLEM STATEMENT

The quality of the social and academic integration of children with disabilities depends

more and more on their parents' ability to ask for and gain access to various services. Confronted with numerous budget cuts, many social agencies are forced to reexamine their role and the array of services they can afford to offer. In this context, parents are faced with increasing paperwork, numerous go-betweens and complex negotiations when requesting services. Empirical studies dealing with utilization of services for persons with

disabilities are scarce and focus mainly on socio-demographic variables associated with high or low rates of utilization.

AIM

The aim of this research project is threefold: 1) to assess the complexity of the documentation parents have to read and the paperwork they have to fill out when requesting specialized services for their children (such as special transportation, hearing devices, prostheses, speech therapy and so forth), in terms of required reading abilities; 2) to describe typical communication processes between parents and social agencies when requesting services according to the child's disability; 3) to outline salient characteristics of parents who are successful and unsuccessful in their attempts to gain access to various services for their children. Preliminary interviews indicated that the level of penetration of on-line requests for services was not sufficient to warrant a separate analysis.

RESEARCH QUESTIONS

1)   What variables are the best predictors of access to relevant services?

2)   What are the contextual and situational variables which appear to help or hinder parents' requests for services?

3)   What reading abilities are required to understand relevant documentation?

METHOD

A threefold study was designed: 1) a quantitative analysis of questionnaire data ; 2) a qualitative analysis of interviews ; 3) a quantitative analysis of relevant documentation. The sample included 163 parents of school-age children with various disabilities. Parents with sufficient reading and writing abilities (N=133) filled out a test booklet which included various questionnaires: socio-demographic information, family structure, type and seriousness of the child's disability, requests for and use of services, availability and usefulness of relevant documentation, social support network, etc. A sub-sample of parents (N=30) requested individual appointments which dealt with the same subject matter in an interview format. Relevant flyers, booklets and forms usually handed out to parents and used when requesting services were collected and analyzed. A second sample of parents took part in individual interviews dealing with their satisfaction regarding services.

INSTRUMENTS

- Steps for Services Questionnaire *(ad hoc)*
- Individual Steps for Services Interview Schedule *(ad hoc)*
- User Satisfaction Interview *(ad hoc)*
- Flesch Test of Reading Difficulty (De Landsheere, 1982)

PROCEDURE

A complete list of parents of children with disabilities was used in order to reach the maximum number of participants. This list came from the 7 school boards which offer services in western Quebec. Children were aged between 7 and 19 and were all part of school board registers because of mandatory education. All handicapping conditions were included, except for borderline mental retardation, which is considered as a learning disability. Parents were asked to answer a questionnaire or to take part in an interview. The response rate was 45%, which is satisfactory in a design such as this one. Individual interviews were conducted at home or by phone, according to the participant's wish.

The level of reading difficulty was established with the help of a test elaborated by Flesch (De Landsheere, 1982). This test establishes the difficulty level of documents by analyzing the number of words in the sentences, their length and their number of syllables. Data is then treated with the following mathematical algorithm*: legibility = 206,85 - (S x 1,02 + W x 0,846)*. Three samples of 100 words (sentences or paragraphs) taken from each document were selected at random. Other types of documents were also analysed for comparison purposes.

RESULTS

Discriminant analyses were performed on the quantitative data yielded by the questionnaires. Content analyses and multiple concept classifications were performed on the qualitative data gathered during the interviews. Flyers, booklets and forms were submitted to a content analysis of legibility and semantic complexity.

Table 1 : Variables significantly associated with access to services

Variable	Lambda	F value
Visual disability	.869	5,46***
Auditory disability	.938	2,37
Mental retardation	.995	0,18
Speech impairment	.979	0,77
Reduced mobility	.851	6,34***
Pervasive dev. disorders	.976	0,89
Multiple handicaps	.961	1,45
Severe conduct disorders	.978	0,80
Other disabilities	.950	1,90
School level	.940	2,30
Age	.990	0,35
Gender	.971	1,08
Nuclear family	.962	1,43
Income	.924	2,96*
Age of mother	.986	0,50
Degree	.920	3,13**
Spouse's degree	.996	0,14
Siblings	.995	0,15
Family support	.917	3,28**
Extended family support	.958	1,59
Satisfaction with contacts	.847	6,57***
Dissatisfaction with services	.940	2,30
Number of go-betweens	.923	3,01*
Forms are easy to understand	.962	1,43
Information easy to find	.888	4,59**
Request for technical aids	.869	5,46***
Request for funds	.908	3,66**
Request for program access	.920	3,15**
Help from social agencies	.946	2,04
Help from an hospital	.917	3,27**
Help from a social worker	.932	2,66
Help from support groups	.929	2,78

*p=.05; **p<.05; ***p<.01

Significant variables were categorized in three levels: low, average and high effect on access to services. The same data treatment was used for the number of services reported by parents. A cross tabulation of aggregated variables (with a positive/negative compensation factor) and access was then performed, based on the results of a log-linear analysis. It generated a high percentage of overall correct classifications (85,53%; see figure 1).

Figure 1 : Classification results of predicted and reported levels of access to services
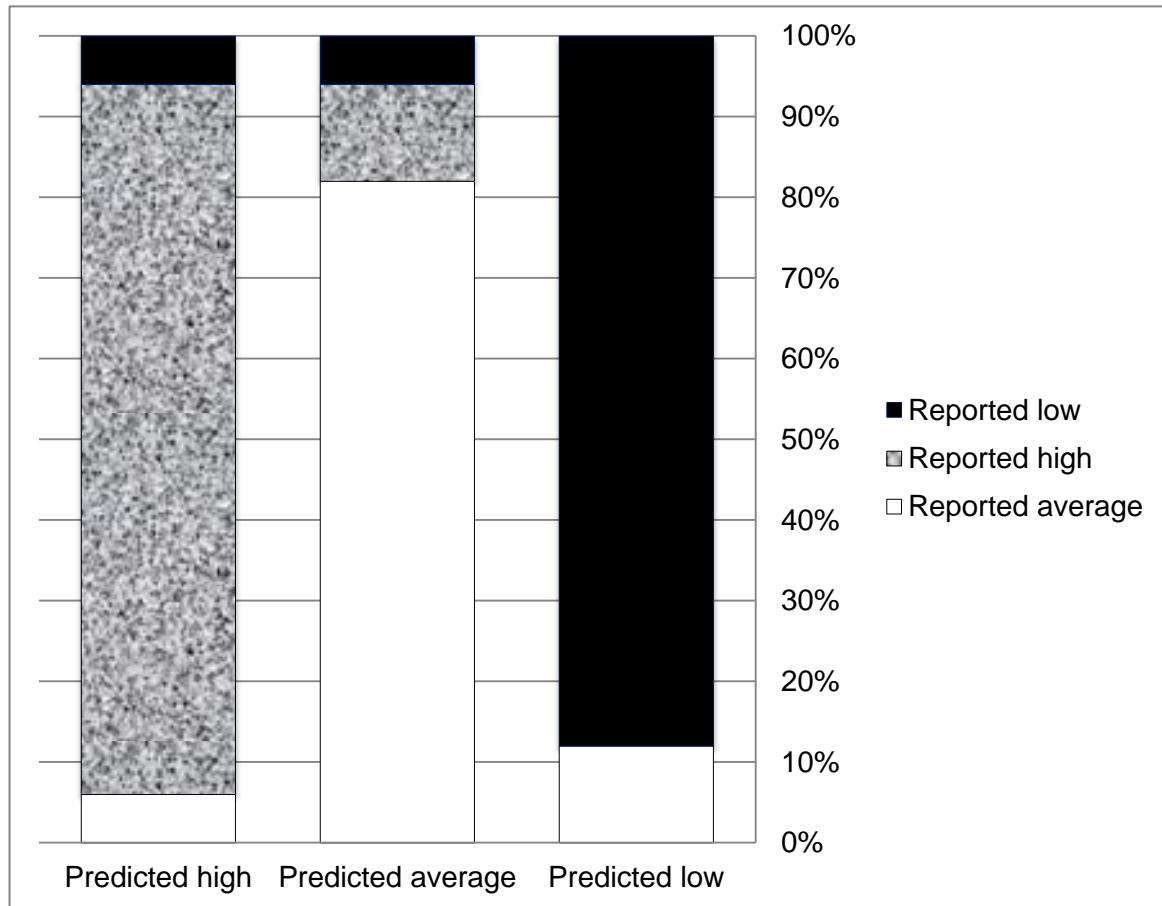
The direction of the effect of each significant variable is presented in Table 2.

Table 2 : Direction of effect for significant variables

Variable	Ranking[1]	Effect on access
Visual disability	L<A<H	Positive
Reduced mobility	L<A<H	Positive
Income	L<A<H	Positive
Degree	L<A<H	Positive
Family support	H<L<A	Differential
Satisfaction with contacts	H<A=L	Negative
Number of go-betweens	L<H<A	Differential
Information easy to find	L=A<H	Positive
Request for technical aids	L<A<H	Positive
Request for funds	L<A<H	Positive
Request for program access	L<A<H	Positive
Help from an hospital	L<A<H	Positive

[1]L:Low; A:Average; H:High.

A content analysis of interview material generated two rankings: 1) the most frequent obstacles they are faced with trying to access services; 2) the most frequently mentioned needs and services (see tables 3 and 4).

Table 3 : Obstacles as ranked by parents

1- Getting the right name and coordinates
2- Knowing the exact wording for the services
3- Having at hand all the required information
4- Appointments with social services during work hours
5- No help in case of emergency
6- Holidays and sick leave of agency personel
7- Children with inter-agency needs
8- Quantity and complexity of paperwork
9- Getting confirmations, approvals and signatures
10- Informal pressure for in-home services

Table 4 : Unmet needs as described by parents

1- Better preparation when announcing a diagnosis
2- Preparing life transitions for the child
3- Support for integration in kindergarten
4- Simple information on service delivery
5- Ensuring stability of service providers
6- Help for daily routines
7- Help with paperwork

Reading skills required to fill out requests and access information were analyzed and compared (see figure 2).

Figure 2: Comparative analysis of reading skills required for various documents

Ease of access in terms of reading skills
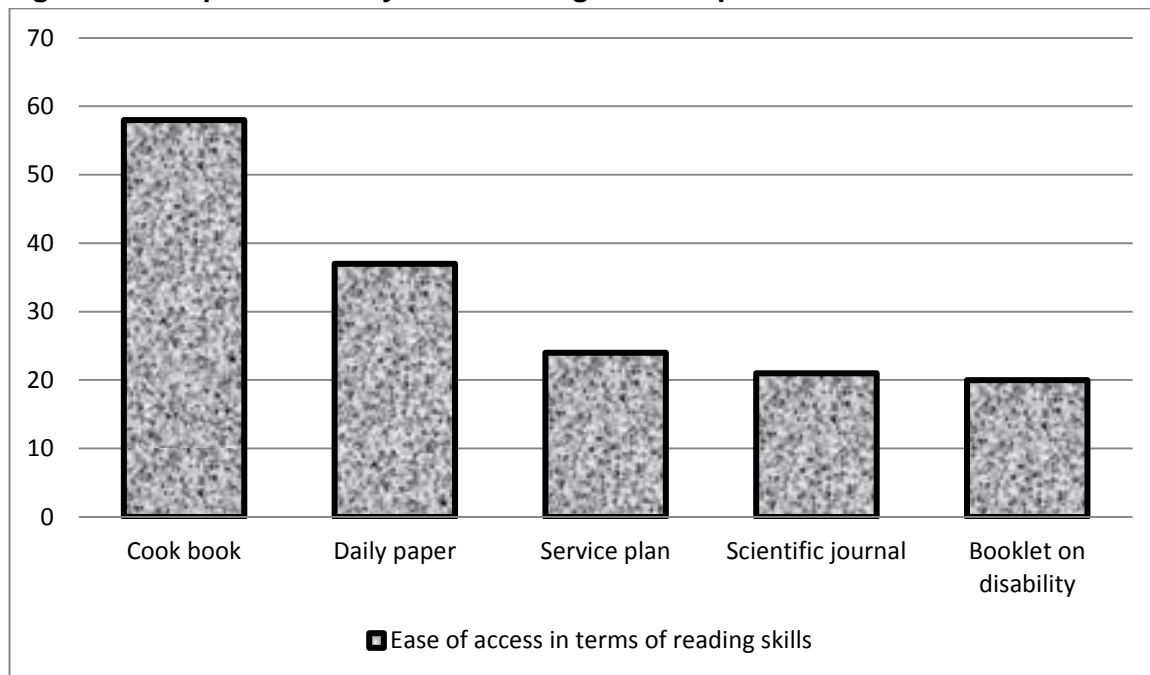
Forms and information booklets require high level reading skills, comparable to those one must use to read a scientific journal. No significant differences were found between the on-line and paper versions of the disability related documents.

DISCUSSION AND CONCLUSIONS

Results pertaining to each objective indicated that: 1) most documents and forms require reading and writing abilities which are out of reach for a substantial proportion of the sample; 2) verbal and written communications between parents and agencies involve a large number of steps and multiple level go-betweens, each of whom is in a position to effectively paralyse or accelerate the processing of a request for services, this being more evident when service overlaps and inter-agency coordination are needed; 3) socio-demographic variables associated with utilization of services in this sample are similar to those reported in the literature, with communication processes between parents and agencies acting as an intermediate variable. Only very persistent or organized parents seem to be successful in gaining access to all the required services for their child. The service delivery system clearly is unable to tend to the needs of all the children and parents who require special services. Even though these services are supposed to be free, specific economic and cultural obstacles prevent an easy access. Services appear to be organized in order to artificially induce attrition, with a backdrop of individual responsibility for those who are unable to communicate effectively with agency personnel.

One could surmise that free and universal access to services that are state funded is a

myth. In fact, a large number of complex processes could play the role an « expectancy cooling down » process, through which parents who do not receive what is rightfully theirs are led to believe that they are responsible for their failure in gaining access to services and resources. Future research should concentrate on the effects of the massive introduction of "lean" management practices in social and medical services, which could restrict access to services even more.

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