

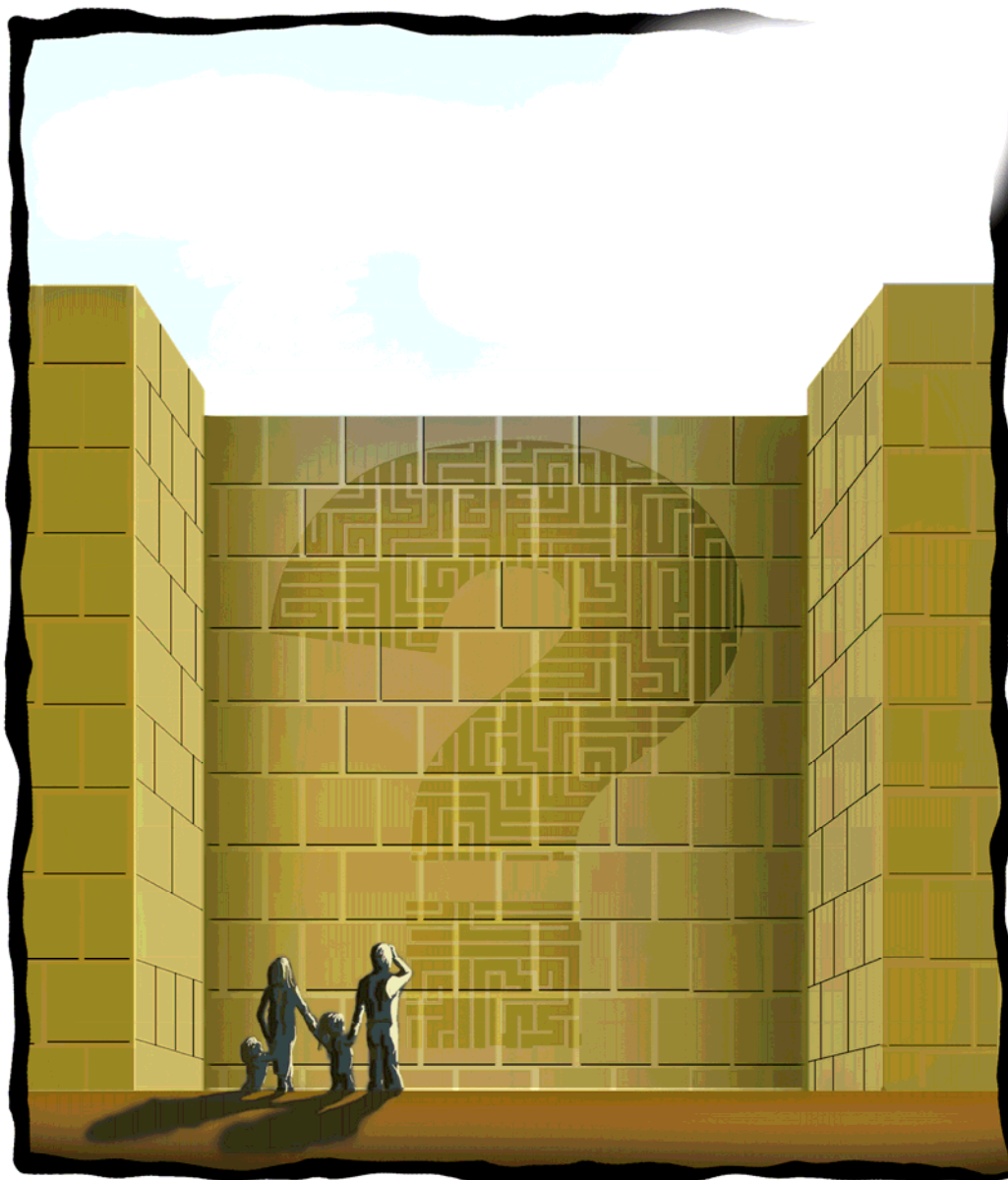
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# WHAT DO I NEED TO KNOW?

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THE PROVISION OF GENERAL INFORMATION TO  
FAMILIES WITH CHILDREN WITH A DISABILITY.

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CEREBRAL PALSY  
ASSOCIATION  
Of Western Australia Ltd

## ACKNOWLEDGEMENTS

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## BACKGROUND

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The Community Development Programme (CDP) at the Cerebral Palsy Association of Western Australia (CPAWA) currently has 126 families who receive services from the Early Intervention Program (EIP) and 301 families who receive services from the School Age Intervention Programme (SAIP). Services are delivered by teams of physiotherapists, occupational therapists, speech pathologists and social workers working within a family centred model of service delivery, according to the Principles of Best Practice.<sup>1</sup>

Contemporary service delivery to children with disabilities and their families embraces the principle of Family Centred Service (FCS). In 1995, the Community Development Programme at CPAWA (then known as Children's Services) made a decision to adopt the FCS approach. There are many definitions of a FCS. It is apparent that FCS '...begins with the child's and family's strengths, needs, hopes...and involves education, support, direct services and self-help approaches, with the role of the service provider to support, encourage, and enhance the competence of parents in their role as caregivers'.<sup>2</sup>(p.41)

The model of FCS developed by the Canchild Centre for Childhood Disability in Canada involves three premises:

- ◆ Parents know their children best and want the best for their children;
- ◆ Families are unique and different; and
- ◆ Optimal child functioning occurs within a supportive family framework and community context. The child is affected by the stress and coping mechanisms of other family members.<sup>3</sup>

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### 1.1 HOW FAMILY CENTRED ARE WE IN OUR PRACTICE?

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In 2003, CPAWA initiated a project to answer the question, How Family Centred Are We In Our Practice? In the seven years since the Association introduced this service delivery approach, there has been no formal evaluation of the effectiveness of FCS. In May 2003, all families in the Early Intervention Program and School Age Intervention Program at CPAWA were sent a questionnaire to complete to determine the perspectives of families at the CPAWA. The questionnaire was developed by

researchers from McMaster University in Canada and is known as the Measure of Processes of Care or MPOC. It was identified as the most appropriate instrument to use as it was developed with extensive input from parents based on aspects of care that parents view as important.<sup>4</sup>

The MPOC-56 consists of 56 questions that are grouped into five key constructs or areas of FCS:

- 1) *Enabling and Partnership*: questions ask families how actively involved they are in their child's care particularly in decision making;
- 2) *Providing General Information*: questions focus on how well services meet parents' general information needs;
- 3) *Providing Specific Information about the Child*: questions relate to parents perceptions of whether they obtain information about their own child;
- 4) *Co-ordinated and Comprehensive Care for Child*: questions ask parents whether services encompass the holistic needs of the child and family, and whether services are provided in a way that is consistent over time, settings and people; and
- 5) *Respectful and Supportive Care*: questions ask parents whether they feel they are viewed as individuals and equals, and all family members are treated with respect.

Forty one per cent (n = 158) of families using the CDP (n = 384) participated in the survey. Generally, responses to the MPOC questionnaire sent to families indicated that the Early Intervention Programme and School Age Intervention Programme at CPAWA are providing services that are highly family centred, particularly the 'enabling and partnerships' and 'respectful and supportive care' constructs.<sup>5</sup> The mean MPOC scores in Table 1.1 indicate that families rate most of the constructs as family centred 'to a moderate extent' (score of 4) to a 'very great extent' (score of 7). Families rated the provision of general information lowest and the least well-done aspect of FCS and not meeting their current needs.

Table 1: Average Scores of Different Areas comparing CPAWA findings for each area of the MPOC

MPOC-56 Key Areas	Average
Respectful and Supportive Care	5.98
Enabling & Partnership	5.61
Co-ordinated & Comprehensive Care	5.52
Providing Specific Information about the Child	5.40
Providing General Information	4.98

The 'Providing General Information' area of the MPOC –56 consists of nine questions which ask families what they think of the activities provided by their service provider that meet parents' general informational needs. These questions are detailed in Table 2.

Table 2: Questions in the 'Providing General Information' area of the MPOC-56.

Question	Providing General Information' question
46.	Have information available to you in various forms, such as booklet, kit
54.	Provide advice on how to get information or to contact other parents
50.	Provide opportunities for special guests to speak to parents on topics of interest
49.	Promote family-to-family gatherings for social, information or shared experiences
55.	Provide opportunities for the entire family to obtain information
56.	Have general information about different concerns eg. Sexuality, financial assistance
53.	Have information available to you about your child's disability eg. It's causes, how it progresses, future outlook
51.	Provide support to help cope with the impact of childhood disability eg. By advocating or informing you of assistance programmes
48.	Give information about the types of services offered at the Centre or in your community

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INTERNATIONAL AND NATIONAL TRENDS

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There is evidence that FCS provided to families of children with intellectual and physical disabilities are respectful and treat the family as equal partners, but fail to meet their informational needs related to disability.

Similar findings have been found with like research undertaken, in particular those of the CanChild Centre for Childhood Disability Research in Canada [ref](#), and most recently Novita Children’s Services in South Australia<sup>31</sup> (Table 1.3)

**Table 3: Comparative findings detailing mean scores for each construct for research carried out at CanChild Centre for Childhood Disability Research in Canada, CPAWA & Novita Children’s Services in South Australia.**

MPOC Constructs	Community Development Programme CPAWA 2003 (n = 158)	Can Child Centre in Canada 2002 (n = 460)	Novita Children’s Services in South Australia 2004 (n = 300)
Respectful and Supportive Care	5.98	5.62	5.51
Enabling & Partnership	5.61	5.33	5.15
Co-ordinated & Comprehensive Care	5.52	5.75	5.09
Providing Specific Information about the Child	5.40	5.33	4.94
<b>Providing General Information</b>	<b>4.98</b>	<b>4.20</b>	<b>4.30</b>

\*used MPOC-20 rather than MPOC-56

The ‘Providing General Information’ area of the MPOC is rated consistently the lowest of the constructs, which supports the growing body of evidence that service providers are not meeting the general information needs of families with children with disabilities.

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## WHAT DO FAMILIES NEED TO KNOW?

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Family functioning is the key to the promotion of a child's individual health and well-being. As evident in many national initiatives, such as 'The Stronger Families and Communities Strategy' being conducted by the Australian Government, provision of information is essential to enable families to make informed choices, to receive appropriate support from service providers, to develop advocacy skills and to engage meaningfully in their communities.<sup>8</sup>

It is recognized that factors that influence family patterns and child developmental outcomes are family characteristics and potential stressors created by the child's disability. This can include information and resource needs, interpersonal and family distress and confidence threats.<sup>9</sup> Components of programmes that can respond to these stressors as:

- ◆ *Resource supports*, such as awareness of, access to, and coordination of services and supplemental supports, such as respite care;
- ◆ *Social supports*, such as family counselling; and,
- ◆ *Information and services*, from parent-professional relationships.

Additionally, children with a disability are more likely to achieve their targeted goals and functional abilities required to function in their school and home environments if they and their families are provided with information that is responsive and targeted to their needs.<sup>10,11</sup> Families then become more able to control their environment and enhance their family functioning which positively impacts on their child's ability to develop successful social inclusive behaviours.

Given the national and international trends of service agencies performing poorly in the provision of general information to families, CPAWA undertook the What Do I Need To Know? Project. The project aimed to primarily determine the general information needs of families with children with cerebral palsy who access the Early Intervention and School Age Intervention Programmes, with an understanding that the outcomes of this project had the potential to be generalized to families who access other service providers for their child with a disability.