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Building Capacity: Autism Ontario's Realize Community Potential Program

Abstract

The Realize Community Potential (RCP) Program was developed to directly support parents of children with autism spectrum disorder (ASD) through: greater access to information, direct contact between parents and Autism Ontario chapters, improved access to experts in local communities, and increased community-based learning opportunities for children with ASD. Several tools were developed to track chapter activities and to evaluate the capacity of the program to meet stated objectives. There was a substantial increase in the number of chapter events offered since the inception of the RCP program. Event topics of most interest to families included: behaviour, followed by social skills development, and communication. The average number of calls to RCP chapters per month has greatly increased since the program started. The majority of families contacted the chapter via email, reflecting a change in the dynamics of how families are communicating with professionals. The most common reasons for contacting chapters were: knowledge of Autism Ontario activities and resources, school-related issues, and community services. This research is important in identifying the effective components of the RCP program to guide future program development and allocation of funding resources.

Autism Ontario is a primary source of information and referral on autism spectrum disorders (ASD) and one of the largest collective voices representing the autism community in the province of Ontario, Canada. Members of Autism Ontario are connected through a network of chapters and guided by a Board of Directors composed of parents of individuals with ASD, volunteers, and respected professionals within the province. Since 1973, Autism Ontario has worked with government and community leaders towards a vision of *"acceptance and opportunities for all individuals with Autism Spectrum Disorder"* (www.autismontario.com). This work has included increasing public awareness of ASD and the day-to-day challenges faced by individuals with ASD and their families, as well as providing support to parents of children on the spectrum, advocating for programs and services, and supporting and promoting ASD research.

One initiative of Autism Ontario was to develop a program that would provide direct support to families of children with ASD. In 2006, with funding support by Ontario's Ministry of Children and Youth Services, the Realize Community Potential (RCP) Program was developed to be piloted in six regions within Ontario: Durham, London, Niagara, Ottawa, Thunder Bay, and York. Based on preliminary data from these regions, two additional chapters were established in Windsor and Hamilton. More specifically, the RCP Program sought to directly support parents of children with ASD

through direct contact between parents and Autism Ontario chapters, greater access to information and experts within local communities, and provision of community-based learning opportunities for children with ASD (www. autismontario.com/rcp). Specifically, there are two primary ways in which RCP funding is used to provide services to families. First, the RCP funding is used to provide families with opportunities to connect with one another and with professionals through speaker workshops, and for children to participate in leisure activities (e.g., bowling, movie nights) with other children with ASD and their families. The RCP program also provides the identified chapters with a paid staff member, referred to as an RCP Coordinator.

Description of RCP Program Evaluation

An evaluation component was included within the RCP Program to identify strengths and improvements needed in the program. The team carrying out this evaluation is an integral part of the Permanent Knowledge Project of Autism Ontario's RCP Program. The team consisted of experienced external research consultants (Dr. James Bebko, Kristen McFee, Jessica Schroeder), and an internal working group at Autism Ontario (Margaret Spoelstra, Executive Director; Marilyn Thompson, RCP Program Manager; Layne Verbeek, Communications Consultant; Karen Manuel and Shona Vincent, RCP Coordinator representatives). This team has been responsible for clarifying program objectives and operationalizing variables, creating a data collection toolset, training RCP coordinators and volunteers on tools tracking community support and parent contact, analyzing data and disseminating results at appropriate venues. Data-collection tools were developed with two major goals in mind: to provide information directly to RCP front-line staff in order to best support families of children with ASD and to support the continual development of the RCP Program in the establishment of evidence-based services.
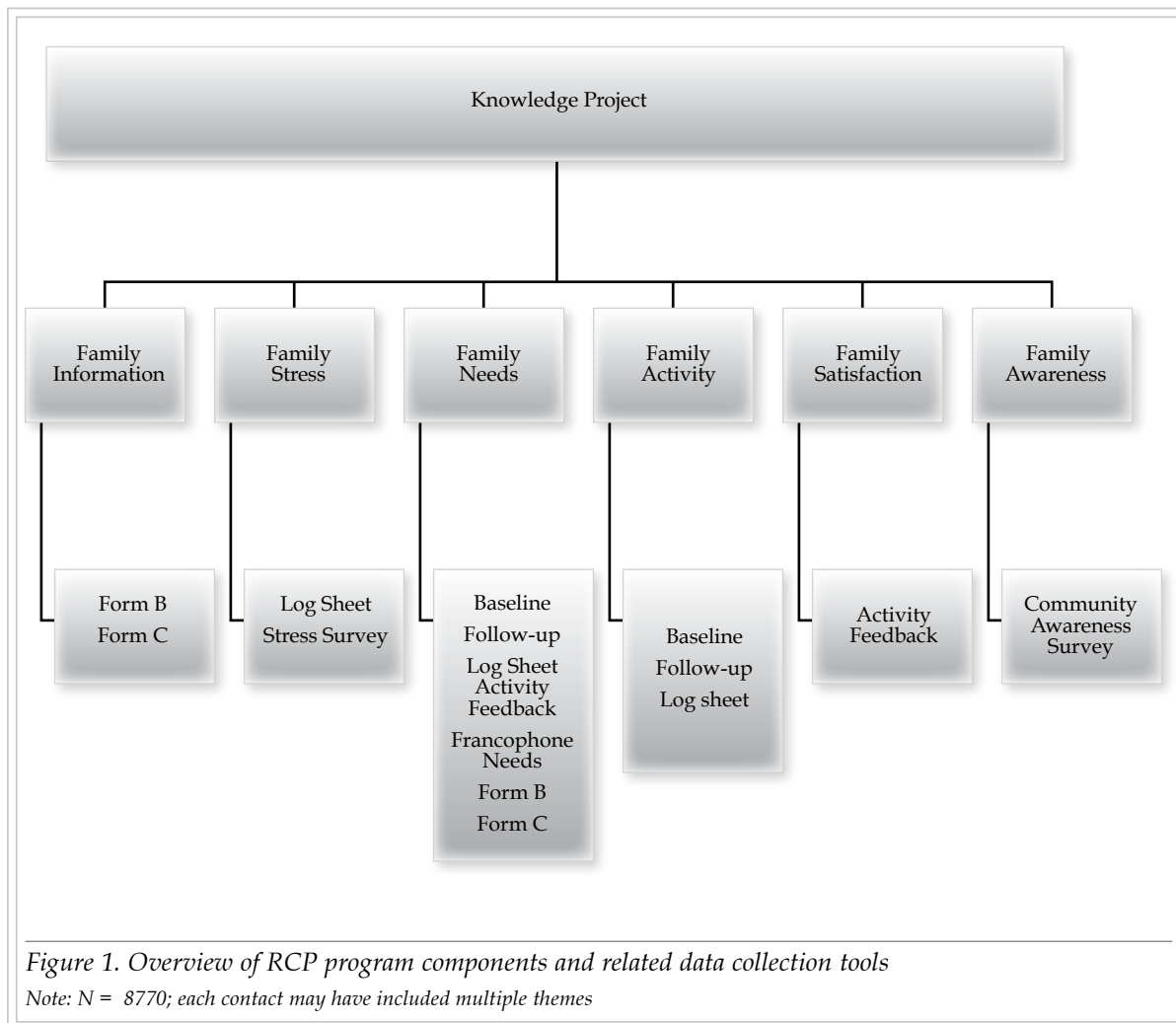
The evaluation team identified eight major objectives of RCP: (1) to help reduce stress in families of children with an ASD; (2) to provide resources and long-term support for families; (3) to build sustainable capacity within local chapters to support families; (4) to increase the

resource networks within local communities; (5) to increase the number and variety of social opportunities for families of children with ASD; (6) to provide opportunities for contact with other parents and professionals; (7) to ensure follow-up with families after initial contact when appropriate; and (8) to increase awareness and provision of Francophone services within the RCP Programs. The present study will focus on the evaluation of objectives (2, 3, 4, 5 and 6). There are insufficient data to date to evaluate the remaining objectives.

Six components, (see Figure 1) were identified as being central to the objectives of the RCP Program: (1) family information, (2) family stress, (3) family needs, (4) RCP chapters activity, (5) satisfaction with services offered, and (6) community awareness of Autism Ontario. A number of data collection tools have been developed to evaluate each of these directly (see Figure 1). The current study is informed by family information, family needs and RCP Program activity. Data was collected using four major data collection tools: Baseline and Follow-up questionnaires, Activity Feedback forms, and two tracking forms: RCP Log Sheet (Form A) and Family Intake (Form C).

One of the primary objectives of the program is to be able to provide a "one-stop-shop" of information on ASD and community services to families. The value of this objective is supported by existing research. According to Whitaker (2002), information regarding treatment is the primary need of parents that is often not met after receiving a diagnosis. Searching for information has been found to be an important component in problem-solving that aids families in the process of adjustment (Hopson, 1986). Tehee, Honan and Hevey (2009) found an association between amount of information received and quality of support services accessed by 23 families with a child with an ASD. They propose that providing families with information may impact how these families access support services, which, in turn, may reduce parent stress and improve their coping ability.

Another key objective of the RCP program is to offer opportunities for families and individuals with autism to engage in a variety of social/recreational activities together. Participation in recreational activities is important for child and adolescent development (Geisthardt, Brotherson, & Cook, 2002;

Figure 1. Overview of RCP program components and related data collection tools

Note: N = 8770; each contact may have included multiple themes

Mactavish & Schleien, 2004). In fact, access to recreational activities is identified as a fundamental right by the United Nations' Convention on the Rights of the Child (1989). Recreational participation has been found to be associated with a variety of benefits for children with disabilities, including the development of friendships and improvement in physical and mental health. In addition, participation in recreational activities is also linked to improvements in family relationships and satisfaction with life (Mactavish & Schleien, 2004). Despite their importance, research indicates that peer relationships in children and youth with ASD are rare (Konging & Magill-Evans, 2001). Orsmond, Krauss, and Seltzer (2004) conducted a large study of 235 adolescents and adults with autism and found that only 8% of the sample reported friendships with similarly-aged peers, while 46% reported having no peer relation-

ships outside of organized settings. In addition to social challenges, a variety of traits characteristic of ASD may be associated with these difficulties with friendships and social interaction, including: lower verbal abilities (Hauck, Fein, Waterhouse, & Feinstein, 1995; Sigman & Ruskin, 1999), externalizing problems (Solish, Minnes, & Kupferschmidt, 2003), and stereotypical behaviour (Duncan, Matson, Bamburg, Cherry, & Buckley, 1999; Lee & Odom, 1996). The RCP program provides social opportunities to individuals with ASD (e.g., special movie screenings in theatres) where the environment is structured for success. By providing these initial opportunities in a safe and supportive environment, individuals and families are more likely to feel confident to engage in their community in the future which may facilitate appropriate peer interaction and the development of peer relationships.

The RCP Program also provides families with increased opportunities for parent-to-parent and parent-to-professional interaction. Increased access to professionals is important as relationships between parents and professionals can impact family outcomes (Dunst & Dempsey, 2007; Summers et al., 2007). Similarly, parent-to-parent support has been found to be an effective mechanism to help parents of children with disabilities to cope with their own situation by learning from the experiences of others, sharing personal experiences and taking on a mentorship role (Hartman, Radin, & McConnell, 1992; Kerr & McIntosh, 2000; Turnbull, Blue-Banning, Turbiville, & Park, 1999). In addition, parents can gain practical knowledge and emotional support from one another (McCabe, 2008). Finally, contact with other parents provides families with the opportunity to develop relationships with families who understand their experiences (Dunlap & Fox, 2007).

Current Study

The primary objective of this project was to identify the effective components of the RCP program so that RCP and other Autism Ontario chapters across the province will be able to continue or begin to implement the most effective components in order to offer a sustainable support system for families through their local chapters. If the RCP program is successful, then the evaluation would be expected to generate a number of findings derived from the following questions: (1) Was there an increase in the number of calls, members, volunteers, staff, and events offered by chapters since the inception of the RCP program compared with non-RCP Autism Ontario chapters?; (2) Which topics are of most interest to families who participate in RCP events?; (3) How are families contacting the RCP? What is the nature of the contacts made to RCP, what is the duration of these contacts, and how are these related to one another?; (4) What are the demographics of the families that contact RCP?

Materials and Methods

Database

A subset of measures that have been collected in the course of an ongoing quality assurance evaluation were used for these analyses (see Measures section). Baseline surveys from the seven chapters who participated in the RCP program were completed by chapter Presidents at the beginning of the RCP program. Seven follow-up surveys were completed by the RCP coordinators three and 12 months after the RCP program started. Non-RCP comparison surveys were completed by four non-RCP chapters matched on population size and urban vs. rural community. In total, there were 1181 Activity Feedback surveys completed by families who participated in chapter activities that were included in analyses, 925 from programs or workshops, and 256 from social learning opportunities. Data from the RCP logs completed by RCP coordinators summarized 8,770 contacts with families of children with ASD.

Ethical Clearance and Other Permissions

This paper is based on a review of information gathered in the course of providing support services to families by Autism Ontario. The goal of the information was to provide quality assurance feedback to the agency to evaluate the effectiveness of its services. The government of Canada's Tri-Council Policy on Research Ethics, Article 1.1d indicates: "Quality assurance studies, performance reviews or testing within normal educational requirements should also not be subject to REB review." (www.pre.ethics.gc.ca/eng/archives/tcps-eptc/section1-chapitre1/#1p1).

Measures

Baseline Questionnaire

The Baseline Questionnaire was developed to determine the capacity of chapters to support families of children with ASD before and after the inception of the RCP program. In addition, the questionnaire addressed the degree to which chapters are aware of and have made use of information about what is available in the community (e.g., community agencies and service providers). Data was examined with non-RCP comparison chapters to determine any differences and similarities in volume, capacity, and integration within communities.

This initial Baseline Questionnaire was completed by RCP chapter presidents in December

2006, right before initiation of the RCP program. Information for questionnaires was based on informed estimates of chapter activities occurring during the time period August to December 2006.. For estimates of chapter events and workshops, the initial baseline period spanned from January to December 2006. Some chapters had recorded considerable or partial data, while others had minimal notes or records. The three-month and one-year follow-up questionnaires were completed by the RCP coordinators, in collaboration with the presidents of the chapters. The three-month follow-up spanned the initial months of the RCP program, from January to March 2007, and the one-year follow-up was from April 2007 to March 2008. All three questionnaires were completed for six of the seven RCP chapters. Data collection is ongoing for the newest RCP chapter that was established approximately a year after the other six chapters and thus data will not be summarized here. The comparison group consisted of four Autism Ontario chapters without the RCP program. These non-RCP chapters were matched to the RCP chapters based on approximate population size being represented. These surveys were completed by the chapter presidents and covered the first two time intervals (August to December 2006 and January to March 2007). Results comparing pre- and post-RCP activity and RCP and non-RCP chapters will be reviewed in the present study.

Activity Feedback Form

The Activity Feedback Form was developed out of a need to simplify and standardize the event rating system. The Activity Feedback evaluated RCP program services, such as workshops, speaker events, and social learning opportunities. One form was used across all of the RCP chapters to rate both social opportunities and speaker events, to enable combining and comparing data. The form included questions to assess the following topics: (1) participant satisfaction (did the event meet their expectations); (2) marketing (where did they hear about the event); and (3) future needs/interests (future events families are interested attending). Data regarding future interests and needs are reviewed in the present paper.

A total of 1,345 Activity Feedback forms were completed by parents between 2007 and 2008 after workshops and social learning opportuni-

ty events. A total of 925 parents who completed Activity Feedback forms after workshops and 256 who completed the form after social learning opportunity events answered the question regarding interest in future activities.

Tracking Forms

Three forms were created to support the enhancement of RCP capacity and provide a coherent system to monitor contact with families seeking services within the RCP Program.

RCP Log (Form A). The RCP Log refers to a paper-based, easy-to-use one-page form that is completed by the RCP coordinator after every contact with a family (phone calls, emails, face-to-face meetings). Between 2007 and 2009 a total of 8,770 contacts were recorded across the seven chapters. This form was used to collect information on Autism Ontario membership status, type, duration and reason for contact, and the need for follow-up. Coordinators were also asked to evaluate perceived stress at the start and completion of a contact. Stress was approximated by RCP staff using a brief, five-point Likert scale. Key indicators for each level of stress were identified in consultation with RCP coordinators and were included in a glossary for ease of use. Verbal cues were used at each point in the scale. For example, "I'm looking for information" corresponded with a rating of 1, "I'm wondering if you could help me" was rated at a 2, "I need you to help me" was the anchor point for a 3, "Help me now" was given a 4, and "I give up!" at a level 5. Further examples and descriptors of each rating were also provided to assist in rating stress levels. Data on short-term stress will not be presented in the current study.

Family Consultation (Form B). Form B refers to an online form that was developed to summarize contact with families that is more extensive and requires follow-up. This form outlined client needs, recommendations and referrals in detail. Future goals for this form include a computerized system for alerting RCP staff that time to follow-up is pending. These data are currently being collected and will not be summarized in this paper.

Family Intake (Form C). Form C was developed to provide a family long-term record. This form

included information on contact details, the child (i.e., date of birth, diagnoses), siblings, current services receiving, financial support(s), and membership status. This form seeks to greatly improve continuity of care between RCP staff as it provides coherent and organized information about each family involved with the RCP program. Data collection is continuous. Preliminary data collected between 2007 and 2009 totaling 816 contacts recorded across seven chapters regarding the number and age of children with ASD in the families contacting the RCP is reviewed in this paper. Other data from these forms are currently being collected and will not be presented.

Data Analyses

Data collected were primarily descriptive in nature, comprised of reports on frequency counts and means. Data from the Baseline and Follow-up questionnaires were reviewed in two ways: across time and relative to a non-RCP comparison group. Frequency data are reported from these questionnaires, along with between group comparisons of RCP and non-RCP chapters, and analyses across time within the RCP chapters, where available data permits. Frequency counts of the top-rated needed services were summarized from the Activity Feedback forms. For the RCP log, frequencies of types of contact, duration of contact, and topic of interest were reviewed. Descriptive statistics of demographic information regarding families are summarized from the Family Intake (Form C).

Results

Baseline/Follow-up Questionnaire

A summary of the results from the RCP and non-RCP Baseline and Follow-up Questionnaires can be found in Tables 1 through 4. The average number of calls to RCP chapters per month increased two- to eight-fold in all but one chapter since the program started (Table 1). The mean number of calls received per month by RCP chapters during the baseline time period was 28 (range = 2–48 calls/month). In the three months immediately following the inception of the program, chapters reported an average of 65 calls per month (range = 16–117 calls/month). The mean number of calls received by

RCP chapters for the following 12 months was 68 (range = 14–152 calls/month). There were a number of inconsistencies in collecting comparable data for the non-RCP chapters. Only one chapter of the non-RCP chapters had the capacity to track the number of calls received during both the baseline and the three-month follow-up time periods. In this chapter there was a very slight increase in the number of calls received, from a mean of 37 to a mean of 39. Data were not tracked for either time period for non-RCP chapter 2, and chapter 3 only began tracking calls during the three-month follow-up period. Chapter 4 reported that it did not have the volunteers available to answer phone calls. A voicemail system was in place in that chapter, and on rare occasion families would leave messages asking the president of the chapter to contact them.

The number of members remained almost constant in both the RCP and non-RCP chapters (Table 2) based on reports from all chapters surveyed. There was a small increase in the number of volunteers in both the RCP and non-RCP chapters from 2006 to January/March 2007, while the number of staff remained the same.

There was an increase in the number of all types of chapter events offered since the inception of the RCP program (Table 3). This is particularly notable given that the time periods that are being compared are not equivalent; that is, data collected prior to RCP spanned one year, while post-RCP only three months. This increase was not found in the four non-RCP chapters. There was also an increase in the number of chapter parent-to-parent (Table 4) and parent-to-professional opportunities after the start of the RCP program. A similar trend was not found in non-RCP chapters.

Activity Feedback

Topics of most interest to parents who participated in workshops, programs, and speaker events and who completed Activity Feedback forms (n = 925) included: behaviour (59%), social skills development (55%), and communication (42%; Table 5). Similar results were found for parents who attended social learning opportunity events (n = 256): behaviour (53%), social skills (60%), communication (38%), and education (40%).

Table 1. Mean Number of Calls/Month to RCP and Non-RCP Chapters

Chapter	Calls/mo: Aug. 06–Dec. 06	Calls/mo: Jan.07–Mar. 07	Calls/mo: Apr. 07–Mar. 08
RCP 1	26	56	66
RCP 2	42	24	No data
RCP 3	44	101	152
RCP 4	40	117	123
RCP 5	14	75	35
RCP 6	2	16	14
RCP Sum	168	389	n/a
RCP Mean	28	65	68
Non-RCP 1	37	39	–
Non-RCP 2	No data	No data	–
Non-RCP 3	No data	24	–
Non-RCP 4	None	None	–
Non-RCP RCP Sum	n/a	n/a	–
Non-RCP RCP Mean	n/a	n/a	–

Table 2. Number of Members, Volunteers and Staff

		Up to Dec. 2006	Jan.-Mar. 2007
RCP	Members	119	118
	Volunteers	213	243
	Staff	5	6
Non-RCP	Members	52	54
	Volunteers	55	59
	Staff	1.5	1.5

Table 3. Types and Numbers of Events Provided by RCP and Non-RCP Chapters

	Jan.–Dec. 2006		Jan.–Mar. 2007	
	RCP	Non-RCP	RCP	Non-RCP
Social Learning Opportunities	9	5	17	3
Speakers	5	6	23	2
Workshops	3	3	6	0
Programs	9	1	6	0
Other	8	4	3	1
Total	34	19	55	6

Table 4. Numbers of Parent-to-Parent and Professional Events in RCP and Non-RCP Chapters

	Jan.–Dec. 2006		Jan.–Mar. 2007	
	RCP	Non-RCP	RCP	Non-RCP
Parent-to-Parent	10	39	15	6
Parent-to-Professional	13	16	6	2

Table 5. Activity Feedback-Events of Future Interest to Families

Type of Event	% of Parents
Behaviour	58
Social Skills	56
Communication	49
Education	42
Parent Support	37

RCP Log (Form A)

On average, each chapter recorded 38 contacts per month. Initial analyses of the RCP Log data indicate that most families were contacting Autism Ontario chapters via email (63% of contacts), followed by phone (27%), and in person visits (10%). The length of time spent on contact was recorded for 59% of contacts (N = 5200). The mean lengths of contact by contact type were: 9 minutes (email), 15 minutes (phone), and 15 minutes (in-person contacts), yielding an overall average of 13.9 minutes. Most contacts were brief, with 13% of contacts being under 5 minutes, 66% lasting from 5–15 minutes, 10% from 16–30 minutes, 9% from 31–60 minutes, and 1% over 60 minutes. Frequency counts for reasons for contact are summarized in Table 6. The most commonly cited reasons for contacting the RCP coordinator were to find out about Social Learning Opportunities (44%), events and workshops (23%), Autism Ontario (13%), school-related issues (13%), and community services (12%). Families contacting the RCP program because of crises accounted for a small percentage of overall contacts (1%); however the mean length of time that these families spent in contact with coordinators (mean = 48.6 minutes) was substantially longer than the mean time for other types of contacts.

Family Intake (Form C)

Form C has been completed for a total of 816 families, representing a total of 845 children with ASD, with 688 boys, 128 girls, and 29 not reporting gender. A total of 28 multiplex families were documented, of which 25 families had two children with ASD (50 children in total), and two families had three children with ASD (six children in total). Date of birth was reported for 290 families; the average age reported was 9.7 years and the range was from four months to 59 years.

Discussion

This paper summarizes some of the key findings in the preliminary evaluation of the RCP program, Autism Ontario. Data reviewed in this paper were used to evaluate the degree to which the RCP program is achieving several of the program goals, including: building sustainable capacity within local Autism Ontario chapters, increasing resource networks within communities, increasing social opportunities for families of children with ASD, and increasing opportunities for contact with other parents and professionals.

Table 6. Reasons for Contacting the RCP

Reason for Contact	# of Contacts	% of Contacts
Event/Workshop	2030	23
Social Learning Opportunity	3868	44
Autism Ontario Information	1118	13
Autism Ontario Information Total	*7016*	*80*
School	1099	13
Support	519	6
Respite	240	3
Community Services	1015	12
Medical/Diagnosis	231	3
Funding	371	4
ASD Info	592	7
General Information Total	*4133*	*47*
Crisis	*91*	*1*
Other	*408*	*5*

A substantial increase in chapter activity was observed in RCP chapters relative to non-RCP chapters. RCP chapters averaged 68 contacts per month, 15 months after program inception, relative to 28 contacts at baseline. The majority of non-RCP chapters were unable to report on chapter activity because they lacked the infrastructure required to do so. In the one chapter that was able to report number of contacts, an increase from 35 to 37 contacts was observed. These data indicate that the RCP is fulfilling an important need within the local communities for families of children with ASD, evidenced by increased community engagement with their local chapters with the inception of RCP. It is likely that other communities would similarly benefit if the program were expanded. Moreover, these data demonstrate the important role that the RCP coordinators had in stimulating and supporting chapter activity, as well as tracking it using the data collection tools developed by the evaluation team. The RCP appears to be a sustainable and economical program as it had a large impact on chapter activity with local leadership from a single hire plus volunteer support, and provincial leadership through a small team for overall program supervision and ongoing evaluation. Implementation of the data collection tool set is only the first step in tracking chapter activity, although it is paramount in being able to evaluate more in depth whether the RCP is meeting the needs of the community. Moreover, this relatively straightforward data collection tool set has potential to be shared with and assist other provincial and community agencies in tracking their own activity and evaluating program effectiveness.

An increase in the number of chapter events, including parent-to-parent, and parent-to-professional events, was observed in the RCP chapters at three-month follow-up. A similar trend was not found in the four non-RCP chapters. These data indicate the success of the RCP in increasing community and resource networks, as events provide an important avenue for parents to meet other families and professionals dedicated to the field of ASD. In the future, it will be interesting to evaluate whether access to and attendance at these events does in fact relate to parents' *perceptions* of increased community support.

Surprisingly, an increase in the number of chapter members was not found in RCP chapters. This may be due to the fact that strong membership numbers may have been considered when selecting which Autism Ontario chapters would initiate the RCP program. It may also be that families are contacting chapters and attending events without actually becoming chapter members. The role of membership should be explored in terms of the added benefits to the individual families (e.g., monthly news letters, email updates on events, scholarships).

Based on parent reports from the Activity Feedback form, parents expressed the most interest in events related to understanding behaviour, social skills development, and communication. Not surprisingly, these are congruent with the three major diagnostic criteria for autism (i.e., impairment in social interaction and communication, and restricted and stereotyped behaviours or interests; APA, 1994). Of note, events that focus on behaviour were ranked as being of most relevance to the parents who attended workshops, while those who were surveyed after attending a social learning opportunity event ranked social skills development activities as being of most relevance to them. These data suggest that parents are self-selecting those events most relevant to their child or most salient to their current situation. For example, it may be that parents who are in current need of, or anticipate need of behaviour management strategies are more likely to attend a workshop on that topic. Similarly, parents for whom social skills development is salient may be more likely to attend social learning opportunity events. Whatever the rationale, activities that focus on the three diagnostic criteria were ranked as being of greatest interest to families. These goals should be kept in mind when developing future events. It may also be interesting to evaluate in the future the changing and evolving needs of families whose children are at different developmental stages. Few workshops to date have focused on transition to adulthood, employment, daily living skills, and post-secondary education.

In terms of how families are engaging with RCP, the majority of families contacted their chapter via email. This finding may reflect a more global change in the dynamics of how families are communicating with professionals. As a result, the evaluation team is working towards developing a means for evaluating the emotional content in this form of communication, and how to foster a therapeutic alliance via textual communication. Future research might also evaluate whether families use different modalities of communication for different needs. For example, do they utilize email for information gathering purposes; or, however, do they still prefer in-person or telephone communication when in crisis or for problem solving services needs?

In terms of planning and developing resources, the most common reasons for contacting chapters (Table 6) indicate that knowledge of Autism Ontario activities and resources, school-related issues, and community services should be central for staff training. Support for crisis situations is also needed. Although crisis contacts are less frequent, staff spend approximately 50 minutes with individual families contacting RCP in crisis. It will be important for future research to better understand the nature of these contacts, whether RCP staff adequately address the needs of families, and whether families perceive having received support under duress. One initiative currently underway is to train staff in rating perceived levels of stress at the outset of contact with families and upon completion, in order to determine whether contact with RCP may have an impact on family stress levels short term. Changes in longer-term stress for families is also being examined, but that is beyond the scope of the present paper. Finally, knowledge of life-span needs is also important, as the children of the families contacting RCP coordinators ranged in age from infancy to nearly 60 years. A target for the RCP program is that more families with younger children will contact the RCP program, as soon as their child receives a diagnosis. Towards that end, one initiative being implemented to encourage early family engagement with RCP is distributing take-home flyers announcing the program in physician offices.

Limitations

Research within the community context is characterized by less control over a variety of variables and environments than is the case in more laboratory-like settings. The benefit is the ability to focus on efficiency and clinical or

program utility in the real world. At the same time, that approach brings with it inherent limitations, as was the case in this project. First, it was difficult to collect data in non-RCP comparison groups due to lack of staff and infrastructure to do so. Further, questionnaires were completed by different raters within both RCP and non-RCP chapters (e.g., chapter presidents, volunteers, RCP coordinators). As a result, there were inconsistencies in the quantity and completeness of the data collected on baseline and follow-up questionnaires. Future data collection may need to operationalize how and by whom the questionnaires are completed. Second, data were primarily descriptive in nature, comprised of frequency counts and means. Future research may want to examine how data are related to other client variables using correlational analyses (e.g., length of client contact or method of contact with the reason for contact). Third, the responses from the Activity Feedback survey regarding events of interest are likely to show bias towards the activities that respondents attended; thus, events that attracted a large number of participants (such as a movie night) were likely to have yielded many completed forms, which may result in the interests of these participants being over-represented within the sample. However, few differences were noted in terms of interests between those who attended a speaker event, and those who attended a social event, indicating that the interests of the participants does not seem to have had a significant impact on the validity of the data. Finally, some of the measures required that the RCP Coordinators receive some training in order to use them, so there may be small differences in how data was being collected at the start of the program, and with the addition of new staff to the team. However, the training required was straightforward and well integrated into clinical practice to ensure that the data collection tools were meaningful to the staff using them.

Summary

Since the inception of the RCP program, the Permanent Knowledge Project has developed a series of tools to help organize and monitor the activities of chapters involved in the program in a standardized way across Ontario. The result has been a wealth of explicit data detailing the frequency and nature of contacts by families to RCP chapter coordinators and the issues that lead to these contacts, as well as enabling continuous monitoring of services provided to families (e.g., McFee et al., 2009; Schroeder, 2011. Over time, these data-collection tools will enhance the capacity and continuity of care provided by RCP chapters, and Autism Ontario as a whole. The data from these tools, in turn, provide the means to evaluate services (i.e., what parts of the program have the greatest impact on families) and will enable the continual development of programs that best support the needs of families of children and youth with an ASD. Ongoing projects are evaluating the impact of the RCP program on helping to reduce the short and long-term stress of families affected by ASDs. Finally, by identifying the effective components of the RCP program, these and other chapters will be able to continue or begin to implement these components in order to offer a sustainable support system for families.

Key Messages From This Article

People with disabilities: The Realize Community Potential Program provides important support for families and facilitates activities for children and teens with autism spectrum disorders.

Professionals: The Realize Community Potential Program is able to provide improved support to families of individuals with autism spectrum disorders by offering direct contact between parents and Autism Ontario chapters, greater access to information and experts within local communities, and community-based learning opportunities for children with ASD.

Policymakers: Intrinsic program funding for program evaluation provides critical data to inform decisions to identify, maintain or expand effective program components.

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