Thames Valley Children's Centre

Facts To Go …

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The Quality of Services Delivered by Ontario Children's Rehabilitation Centres

Facts To Go…Volume 1 Issue 1, May 2005 (King, G.)

Children's rehabilitation centres in Ontario (OACRS centres) are uniquely structured to provide family-centered services and, in partnership with other organizations, to provide a broad range of information, services, and support needed to meet the often complex needs of children with disabilities and their families. OACRS centres are uniquely positioned to provide services that create satisfaction on the part of clients and lead to positive outcomes for children, families, and communities. This summary outlines the aspects of service delivery that contribute to "quality," indicates how OACRS centres address these aspects, and provides evidence of the linkages between these aspects, and improved outcomes for children and families.

Much of the research summarized was conducted in Ontario children's rehabilitation centres and therefore highly pertinent to the relationships between service delivery and outcomes for children and families in the province.

The Priorities, Values, and Worldviews of Families of Children with Autism or Down Syndrome: Study 1

Facts To Go…Volume 1 Issue 2, Sept. 2005 (King, G., King, S., Zwaigenbaum, L., Baxter, D.,Rosenbaum, P., & Bates, A.)

Family priorities deal with the activities and roles families feel are most important. Family values are fundamental operating principles by which parents organize the lives of their families, such as the importance of open communication and of doing things together as a family. Worldviews are the family's assumptions about the social and cultural environment, and their family's place in the world. The priorities, values, and worldviews of families affect their adaptation and resilience. Little is known, however, about how families may adjust to raising a child with a disability by changing or adapting their priorities, values, or worldviews.

This summary reports findings from the first phase of a two-part study investigating changes in the belief systems of families of children with autism or Down syndrome. Three focus groups involving 19 knowledgeable individuals (15 parents and 4 service providers) were conducted to obtain information about the priorities, values, and worldviews of families, and how these might change over time. Four categories of themes emerged from the analysis of the focus group information: (1) initial reaction to parenting a child with a disability (a life-changing experience), (2) adapting over time (being spurred to examine beliefs, importance of hope, gaining a sense of control and empowerment), (3) changes in priorities (giving up "trying to fix the child," refocusing on the needs of other family members), and (4) changes in worldviews and values (stronger values and broader worldviews, areas of personal growth, learning what is important in life). Implications for families of children with disabilities and service providers are included.

Youth En Route: An Evaluation of a Transition Program

Facts To Go…Volume 1 Issue 3, Dec. 2005 (McDougall, J., Evans, J., & Baldwin, P.)

Youth with disabilities have the same future expectations as all adolescents: making a contribution to society through employment and creating an independent life that includes family and friends. In spite of their dreams and goals for independent living, employment, and participation in their communities, these youth, at best, take much longer to achieve successful transition into adult life and, at worst, resign themselves to less satisfying roles and lifestyles.

The purpose of this summary is to present the findings of a study that evaluated the utility of services provided by Youth En Route (YER), a flexible, multi-faceted approach transition program for youth and young adults aged 16 to 29 with multiple disabilities who have completed secondary school. YER is client-driven and family-centred and includes three components: self-discovery, skill development, and community experience. Underlying the service delivery model is a philosophy of self-determination that is facilitated through coaching and supporting youth to define, lead, and guide the services and supports they want as they learn more about themselves and their communities.

The primary aim of the YER program in to enhance community participation of youth with disabilities. The study measured the self-determination, sense of personal control, and community participation of these youth before and after their involvement in the YER program to determine if any change had occurred and to determine clients' satisfaction with the services. The study found statistically significant and clinically meaningful improvements among youth with multiple disabilities in all three of the study outcomes following involvement with YER. On average, clients were highly satisfied with services. Recommendations for service delivery are included.

An Evaluation of Developmental Resources for Infants: Collaborative Health Care Services for Infants and Their Families

Facts To Go…Volume 1 Issue 4, Dec. 2005 (Kneale Fanning, J., Legros-Kelly J., McVittie, A., Pigache P., Tucker, M., & Servais, M..)

The provision of a coordinated system of services that emphasizes partnership among families, professionals, and agencies is critical in developing children and enhancing families' quality of life. In 1999, the Developmental Resources for Infants (DRI) program was initiated by 2 community agencies (Thames Valley Children's Centre, and Child and Parent Resource Institute) and 2 hospitals (St. Joseph's Health Care, and Children's Hospital of Western Ontario) to provide a collaborative approach to healthcare services for children from birth to two years of age. Prior to the implementation of the DRI program, families of children at risk for developmental delays or with established physical, cognitive, and/or multiple disabilities were often referred to or received services from one or more of these agencies. This meant that services such as intake, assessment, and intervention were duplicated, resulting in system inefficiencies. DRI was implemented with a common referral form, a central phone line, a coordinated intake, and a shared database. Through this collaboration, families with young, at-risk children could access the most appropriate and timely services to meet their needs through one point access. The collaboration provided an opportunity to increase communication among agencies and ensure services were not duplicated.

In 2002, a research task force was formed to evaluate the DRI program. The study evaluated the DRI tools and processes, the staff and leaderships' perception of system collaboration, and the families' and community members' satisfaction with DRI services. The study found that DRI had achieved an identity and operating procedure that were unique and separate from any of the four partner agencies.

An Evaluation of the Pediatric Acquired Brain Injury Community Outreach Program (PABICOP)

Facts To Go…Volume 2 Issue 1, July 2006 (McDougall, J., Servais, M., Sommerfreund, J., Rosen, E., Gray, J., Somers, S., Gillet, J., & Frid, P.)

Acquired brain injury (ABI) is a leading cause of death and disability among children and adolescents in Canada. Children and youth often have medical, physical, cognitive, behavioural, and social problems that arise from their injuries. Families also experience difficulties related to their children's injuries. The Pediatric Acquired Brain Injury Community Outreach Program

(PABICOP) provides a coordinated, family/community-focused continuum of care to children and youth with acquired brain injuries (ABI) and their families. PABICOP is funded by the Ontario Ministry of Health and Long-Term Care and is implemented through a partnership between Thames Valley Children's Centre (TVCC) and Children's Hospital of Western Ontario (CHWO).PABICOP provides, among other services, help with transition from hospital to home, psychosocial support, information and education, school re-entry support, community-based clinics, and crisis intervention. The results of a five-year study was to evaluate the program indicated that children and youth with ABI and their families receiving PABICOP services fared significantly better than a comparison group receiving standard clinic-based care on two of PABICOP's program objectives: (1) to enhance caregivers' knowledge about the characteristics of ABI and about effective strategies to deal with associated problems, and (2) to increase child and youth community reintegration/ participation. Moreover, these group differences were maintained one year following initial involvement with PABICOP.

On average, caregivers perceived PABICOP services to be family-centred. That is, services were viewed as focusing on the family as a whole (rather than the child in isolation) and as seeing families as the experts on their children's abilities and needs. Moreover, on average, caregivers reported high overall satisfaction with the program. Information from this study will be useful in helping to ensure PABICOP continues to meet the needs of children and youth with ABI and their families.

An Evaluation of the School Support Program – Autism Spectrum Disorder (SSP-ASD)

Facts To Go…Volume 2 Issue 2, Dec. 2006 (McDougall, J., Servais, M., Meyer, K., Case, S., Dannenhold, K., Johnson, S., & Riggin, C.)

Increasing numbers of children are now diagnosed with an autism spectrum disorder (ASD) in the preschool years. Early intervention and preschool programs have become increasingly available, and have brought a corresponding demand for school-based services.

In March of 2004, the Ontario Ministry of Children and Youth Services introduced a new program targeting school-aged children with ASD: the School Support Program - Autism Spectrum Disorder (SSP-ASD). This program provides consultation services to enhance supports for publicly funded school board staff in the provision of educational services for students with ASD. The SSP-ASD program draws upon a whole-school approach to provide a framework for enhancing school supports for students with ASD. Services are provided at the board, school, and classroom level. The program aims to modify aspects of the environment that may result in students' challenging behaviours. The program has four components: planning, training, consultation, and resource development and sharing. ASD consultants, trained in a relevant field, provide services.

This study examined the utility of the SSP-ASD program for enhancing school-level outcomes over the period of one school year. One hundred and ninety-two educators completed study measures in late fall and late spring. Seventy of those educators who reported receiving no services from the program were compared to 45 educators who had one to four contacts with the program and 77 educators who had five or more contacts with the program. Statistically significant main effects of program condition in favor of beneficial effects of the school support program were found for two school-level outcomes: 'supports' and 'teaming and collaboration.' Receiving services from the school support program over a period of one school year was indicated to be more useful for enhancing: (1) supports to educators to accommodate the needs of students, and (2) teaming and collaboration among relevant parties, than not receiving services from the program. Amount of service received appeared to influence outcomes. On average, educators were mostly to highly satisfied with the consultation process and the overall program. Educators reported all aspects of the program were useful, particularly professional development day sessions, and individual consultation and support. Study findings will be useful for enhancing services provided by the SSP-ASD program.

Team Decision-Making in AAC: Examining Clinical Perceptions

Facts To Go…Volume 3 Issue 1, Jan. 2007 (Batorowicz, B., & Shepherd, T.)

Augmentative and Alternative Communication (AAC) are strategies to assist people whose speech is difficult to understand to communicate more effectively. People who use AAC effectively are viewed as more cognitively competent and engage in more social interaction. Funding is available for communication aids through the Assistive Devices Program (ADP) of the Ontario Ministry of Health and Long Term Care. In order to access this funding, an individual participates in a clinical team assessment at one of 21 AAC centres. If it is agreed that the child or adult would benefit from having communication equipment, AAC clinicians help families access ADP funding. Before funding is approved clinicians must make a presentation of recommendations at a Prescription Review (PR) meeting to fellow clinicians and AAC support staff.

PR is a model of team decision-making which includes: (a) clinical case presentation providing rationale for recommending AAC equipment for children or adults, (b) clinical discussion within a transdisciplinary team setting regarding this equipment prescription, and (c) team decision on the final recommendation. PR aims to ensure clinical effectiveness, and that ADP funding is applied appropriately and consistently. This process strives to maintain a standard of quality service in AAC centres. This study evaluated clinical staff's perceptions of PR and examined the relationships between perceptions of PR and the following variables: professional background, years of practice, size of the team, range of experience of the team, and team processes.

This study found that the transdisciplinary team decision-making model in AAC has many benefits. Furthermore, team processes seem to be crucial to the success of models such as PR. It is therefore important to foster healthy team dynamics on transdisciplinary teams to ensure successful outcomes of intervention.

Evaluation of Two Treatments for Toe-Walking for Children with Cerebral Palsy

Facts To Go…Volume 3 Issue 2, Sept. 2007 (Stephenson, F., Scholtes, C., Carey, T., & Leitch, K.)

Children with cerebral palsy often have overactive calf muscles that result in the appearance of "toe-walk." As a result, the calf muscles do not get stretched during walking activities, and lead to restriction in the range of motion at the ankle. This study examined two treatments to stretch out the calf muscles, (1) serial casting and (2) serial casting with Botulinum-toxin A (commonly known as Botox), to determine if one treatment was superior to the other. Serial casting involves casts applied to the ankle to maintain a prolonged period of stretch to the calf muscles. Botox is a chemical injected into the overactive muscles to relax the muscles. Sometimes serial casting and Botox are combined together to treat tight calf muscles.

The focus of this study was to investigate the effectiveness of serial casting treatments with and without Botox injections for tight calf muscles. Treatments that took place between 1997 and 2006 at Thames Valley Children's Centre (TVCC) were examined in this study. Ankle range of motion and observed walking characteristics were examined for serial casting and serial casting with Botox treatments. In general, both treatments were effective at stretching out the calf muscles and improving walking patterns.

Clinical implications and future research suggestions are discussed in this summary.

Enhancing Social Support for Children and Youth with Chronic Physical Health Conditions

Facts To Go…Volume 3 Issue 3, Sept. 2007 (McDougall, J., & Willoughby, C.)

Social support is considered to be one of the most important factors influencing how children and youth adjust to having a chronic physical health condition. Studies have indicated the importance of receiving social support from various sources, including support from family, close friends, classmates, teachers, and health professionals. Children and youth would benefit from initiatives aimed at enhancing social support on multiple levels (personal, interpersonal, and environmental) and in multiple environments (home, school, and community). Social support not only involves the needs, abilities, and perceptions of children and youth with health conditions, but the abilities and attitudes of those providing support.

This summary presents research that has examined the impact of various sources of social support on the adjustment of children and youth with chronic physical health conditions and presents ways that have been identified as useful for enhancing support at home, school, and in the community.

A Dynamic Wheelchair Seating System: Design and Technical Development

Facts To Go…Volume 4 Issue 1, June 2008 (Wighton, J., Smith, L., & Stephenson, F.)

Wheelchair seating systems are typically static or rigid in design. Dynamic seating systems with components that are able to move with the individual are now being recognized as an option to static wheelchair positioning. The purpose of this summary is to provide an overview of the evolution of a novel dynamic seating system (NDSS) developed at Thames Valley Children’s Centre. The NDSS uses our standard seating system along with two additional components. A newly designed sliding footplate and two-piece hinged back support (incorporating a spring-activated lever mechanism) were incorporated into our custom seating system and installed on both manual and power wheelchairs. The force absorbing quality of the lever on the back support was evaluated with the development of mathematical formulas that were then entered into a spreadsheet, creating a useful tool to predict the lever force.

Key observations are highlighted along with possible future directions in the refinement of the NDSS and the evaluation of the individual’s experience using this system.

What is “Quality of Life” and How Can Research Identify the Factors that Optimize Life Quality for Children and Youth with Chronic Conditions?

Facts To Go…Volume 5 Issue 1, May 2009 (McDougall, J., Wright, V., & Miller, L.)

Optimization of quality of life (QOL) for children and youth with chronic conditions is becoming a primary goal of pediatric rehabilitation services and a central focus of health research. However, little is yet known about which factors can best enhance QOL for this group of young people.A primary concern in the area of pediatric QOL research has been a lack of clarity about what QOL means. Although people have a general understanding of what QOL is, it is very important that this concept be accurately conceptualized and measured when conducting research so that the factors that impact it can be identified and then targeted for service.

The purpose of this summary is: 1) to briefly consider the major conceptual and methodological issues surrounding pediatric QOL research; and 2) to identify areas for future research that can help to inform policy and practice about the factors that are most important for optimizing QOL for children and youth with chronic conditions.

Relationship-Centred Practice: A Best Practice in Pediatric Rehabilitation Service Delivery

Facts To Go…Volume 5 Issue 2, May 2009 (Servais, M., Baldwin, P., & Tucker, M.)

The research literature indicates that family-centred service is considered a best practice model of service delivery for pediatric rehabilitation. The quality of the relationship between service providers and family members has been identified as a main component of family-centred service.

Relationship-centred practice involves focusing on the relationship between the service provider, the family and the child as central to delivering quality care. By reflecting on, and developing relationship-centred practices, service providers can enhance the effectiveness of their interventions and their clients’ experiences and satisfaction with service delivery.

This summary describes the specific benefits of focusing on relationship-centred care and provides key suggestions for how providers of pediatric rehabilitation services can enhance their relationship-centred practices.

Peer-Mediated School-Based Program Proves Successful in Promoting Positive Social Skills

Facts To Go…Volume 5 Issue 3, Sept. 2009 (Servais, M., Hall, C., Chadwick, C., & Lombardi, J.)

Students with Autism Spectrum Disorder (ASD) often have difficulties with social situations and peer interactions. These students need to be taught social skills directly as they do not naturally pick these skills up from their environment. Peer-mediated strategies have proven to be very effective in enhancing social skills in students with ASD.

As part of service delivery to schools, the School Support Program–Autism Spectrum Disorder, Southwest Region (Ontario, Canada) created a Program to teach social skills to students with ASD: Peers Establishing Effective Relationships (PEER Pals Program). Although the initial intent was to focus on students with ASD, the

Program was designed to benefit all students and staff. As part of the PEER Pals Program, social communication skills are taught in the classroom, student leaders run structured games at recess for trained peers to participate in, and diversity training is provided for the entire school.

This publication reports on thekey qualitative findings from the evaluation of the program; specifically, what study participants had to say about their experiences with the program. A total of 68 key informants (principals, teachers, educational assistants, and parents) participated in focus groups and 63 school staff returned mailed questionnaires on the perceived usefulness of the program, their satisfaction with the program, and the features that participants liked most and least about the program.

The Developmental Resources for Infants Partnership: Enhancing Interdisciplinary Collaboration To Improve Services for Clients and Families

Facts To Go…Volume 5 Issue 4, Sept. 2009 (Servais, M., Tucker, M., & Strachan, D.)

In an interdisciplinary collaborative approach to services, people from different professional disciplines and organizations work together to provide the best services for clients and families. The Developmental Resources for Infants (DRI) is a partnership between the Child and Parent Resource Institute, Children's Hospital–London Health Sciences Centre, St. Joseph's Health Care, and Thames Valley Children's Centre. DRI was created to provide an interdisciplinary collaborative approach across agencies to healthcare services for children from birth to two years of age. In 2004 and 2008, the DRI partnership used the Index of Interdisciplinary Collaboration Survey.(IIC; Bronstein, 2002) to examine service providers' perceived levels of interdisciplinary collaboration regarding their own, their colleagues' and their organizations' collaborative behaviours.

In this summary, the DRI partnership shares its experiences in assisting and enhancing interdisciplinary collaboration between four healthcare service organizations.

Spirituality and Pediatric Rehabilitation

Facts To Go…Volume 6 Issue 1, Jan. 2010 (Baldwin, P., McDougall, J., & Evans, J.)

This summary highlights the importance of providing holistic health care that addresses the bio-psycho-socio-spiritual needs of children and youth with disabilities and their families as an integral component of pediatric rehabilitation.

The content of this summary is based on an extensive literature review and group discussions with service providers, administrators, and parents of children with disabilities in one children's treatment centre. (see Baldwin, McDougall, & Evans, 2008 for further details. Strengths-based models of pediatric rehabilitation focus attention on the values, beliefs, strengths and needs of both the child with a disability and his/her family within the broader community (King, Tucker, Baldwin, Lowry, LaPorta & Martens, 2002). A family-centred philosophy of the child 'being at their best' as determined by child and family preferences for participation and quality of life infers a holistic approach that addresses the spiritual aspects of a child's and family's life.

"Self-Determination." Why is it Important for Youth and Young Adults with Disabilities?

Facts To Go…Volume 6 Issue 2, May 2010 (McDougall, J., Evans, J., & Baldwin, P.)

A good body of literature now exists that examines the importance of self-determination to the lives of transition-aged youth and young adults with disabilities. the purpose of this summary is to: 1) consider the meaning of self-determination, 2) present findings of studies identifying the importance of self-determination to significant outcomes for youth and young adults with disabilities; and 3) make recommendations to enhance service delivery and for future research in this area.

Wehmeyer (2006) suggests self-determination is having the power and will to make choices in one's life in order to maintain or improve one's quality of life (QOL). Evaluations of both special education and rehabilitation programs to promote self-determination skills for youth and young adults with disabilities have reported positive increases (e.g., Evans, McDougall, & Baldwin, 2006; Powers, Turner, & Ellison, 2001; Zhang, 2001).

Solution-Focused Coaching in Paediatric Rehabilitation

Facts To Go…Volume 6 Issue 3, July 2010 (Baldwin, P., Evans, J., McDougall, S., & Servais, M.)

Relationship-centred practice (i.e., focusing on the clinician-client relationship) is foundational to effective service delivery (Kalmanson & Seligman, 1992; King, 2009; Madsen, 2009) and can be considered a best practice in paediatric rehabilitation (Servais, Baldwin, & Tucker, 2009). Clinicians can use a therapeutic method called solution-focused coaching (SFC) as a tool for relationship-centred practice.

The purpose of this summary is to describe and highlight the key elements of SFC including the value, recommendations, and future directions for paediatric rehabilitation. Coaching that is solution-focused is an evidence-based method (Stober & Grant, 2006) designed to facilitate client capacity building in the management of life circumstances (Berg & Szabo, 2005). Coaching is emerging as an effective and collaborative, goal-oriented approach in paediatric rehabilitation (Graham, Rodger, & Ziviani, 2009; Hanft, Rush, & Shelden, 2004). In SFC, a movement from ‘problem’ to ‘solution’ is facilitated through the development of a therapeutic alliance and the use of strategic questions (De Jong & Berg, 2002).

This approach has been identified as helpful for children (Selekman, 1997), adolescents (Franklin, Biever, Moore, Clemons, & Scamardo, 2001), and key adults in a child’s life (Gingerich & Eisengart, 2000; Graham et al., 2009) and may be adapted for use within a variety of interactions (Warner, 2007).

A “Positive” Focus for Service Delivery and Research in Pediatric Rehabilitation

Facts To Go…Volume 7 Issue 1, May 2011 (McDougall, J., Baldwin, P., & LaPorta, J.)

Recent “Facts to Go” published by Thames Valley Children’s Centre have presented information on a variety of topics of current relevance to pediatric rehabilitation such as: spirituality, self-determination, relationship-centred care, solution-focused coaching, and quality of life. A “positive” focus in pediatric rehabilitation services and research emerges as a primary underlying theme of these summaries.

The purpose of this summary is: a) to consider how a focus on the strengths and resources of children and their families has arisen as a way to support overarching goals of meaningful participation and quality of life, and b) to briefly discuss how this focus is being incorporated into pediatric rehabilitation service delivery and research.

Using an Interactive Whiteboard to Support a Student with Autism Spectrum Disorder

Facts To Go… Volume 7 Issue 2 Sept. 2011 (Riggin, C., & Specht, J.)

Attentional issues have been identified in a number of areasfor children with ASD. Attention is important in learning because it allows individuals to determine what information they should focus on in the environment. For example, Kanner (1943) and Asperger (1991) note that children with ASD can be unresponsive to interactions initiated by adults and children, or fail to respond to an environmental stimulus like an unexpected noise. Given that children with ASD have difficulties with attention, it is important to determine strategies that can help keep them focused on appropriate environmental stimuli.

The purpose of researching this topic was to determine the effects of an interactive whiteboard as an instructional tool on student attention for a child with ASD.

Understanding Sexuality and Sex Education for Adolescents with Physical Disabilities

Facts To Go… Volume 7, Issue 3 September 2011 (East, L., & Orchard, T.)

This summary outlines findings and recommendations from a qualitative study entitled Education, Exploration and the Elephant in the Room: A Narrative Inquiry of Sexuality and Sex Education among Adolescents with Physical Disabilities. Information was collected through in-depth narrative interviews with youth who have physical disabilities, as well as parents of youth with physical disabilities. The key issues discussed with participants included experiences with sex education, barriers and challenges to receiving and delivering sexuality information, dating and sexuality, self-esteem, body image, acceptance, independence, and societal beliefs and expectations towards people with disabilities.

A Service Delivery Model for Pediatric Rehabilitation

Facts To Go… Volume 7 Issue 4 Nov. 2011 (Tucker, M., Baldwin, P., LaPorta ,J., Lowry, K., & McDougall, J.)

The purpose of this "Facts to Go"is to present in brief the Life Needs Model (LNM) of pediatric service delivery. The LNM is based on knowledge gained from collaborations with families, clinicians, and community members, and the research literature in the fields of pediatric rehabilitation and developmental disability. The model was originally developed by Dr. Gillian King, in collaboration with clinical directors, service providers, and centre administrators at Thames Valley Children's Centre in order to extend the organizational vision of the centre: "Our clients at their best", and to guide long-range planning. The types of services required to meet the needs of children and youth with disabilities, their families, and their communities, are presented in the model.

The LNM illustrates that a comprehensive, continuum of services with an emphasis on transitions is essential to address the multiple, ongoing, and interconnected needs of individuals, families, and communities.

Understanding the Impact of Fatigue on Adolescents and Young Adults with Cerebral Palsy

Facts To Go… Volume 8 Issue 1 May 2012 (Brunton, L., & Bartlett, D.)

A recent study identified fatigue, pain, and joint deformities as the top three cerebral palsy (CP)-related impairments in adulthood that can interfere with activities of daily life (Hilberink et al., 2007). Neuromuscular fatigue is a significant challenge for people with CP, but there is little consensus regarding the underlying causal factors and the impact on functioning (Brunton & Rice, 2012). There is some literature to suggest that even low levels of physical activity may adversely affect adolescents with CP as a result of higher energy costs (Maltais et al., 2005), potentially leading to fatigue.

This summary outlines findings from a qualitative study entitled Understanding the Bodily Experience of Cerebral Palsy: A Phenomenology and provides recommendations for youth and young adults with CP and service providers regarding how to manage fatigue.

Teachers' Special Education Information Needs and Source Preferences By Experience Level

Facts To Go… Volume 8 Issue 2 June 2012 (Servais, M., & Sandieson, R.)

Despite the increasing need for regular classroom teachers topractice inclusion and provide special education, teachers do not feel well prepared to do so. The research literature consistently indicates that teachers desire more information on inclusion and teaching children with exceptionalities. But, precisely, what type of special education information do teachers want? Landrum, Cook, Tankersley, and Fitzgerald (2002) noted that there is very little research describing how and from where teachers obtain information to guide their classroom practices. What are teachers' preferred sources of information? Given the proliferation of information so readily available on the Internet, including access to research information, are teachers using Internet sources? This summary focuses on the results of a study that examined teachers' special education information needs, information source preferences, and information seeking behaviours by level of teaching experience. Findings highlight how to better support and meet teachers' special education information needs.

AAC and Autism Service Providers Collaborating for Communication: An Evaluation of a Knowledge Exchange Framework

Facts To Go… Volume 8 Issue 3 Nov. 2012 (McDougall, J., & Servais, M.)

Approximately 50% of children with autism will not develop functional speech and language skills and may therefore benefit from an augmentative and alternative communication (AAC) system (Lord, Risi, & Pickles, 2005). To obtain the best outcome for these children and youth, AAC and Autism service providers can work together to achieve goals that cannot be reached when professionals are working on their own (Bronstein, 2003). Interdisciplinary collaboration may involve sharing resources, knowledge, and information across disciplines. This sharing can positively affect staff members' knowledge, skills, and attitudes.The Autism Program used an AAC specialist in the role of a Knowledge Exchange Professional to work with Autism staff to facilitate knowledge uptake and build coordinated services for clients who have Autism and require AAC.

This summary presents a knowledge exchange framework that was used to increase interdisciplinary collaboration and presents the results of a formal evaluation of the 16-month collaborative initiative.

Understanding disability and identity in Childhood: Perspectives of children and their parents

Facts To Go…Volume 10 Issue 1 May 2014 (Phelan, S., & Kinsella, E.A.)

Occupational therapists define occupations as “groups of activities and tasks of everyday life, named, organized, and given value and meaning by individuals and a culture” (Townsend & Polatajko, 2007, p. 369). Children with disabilities are at risk for limited opportunities to participate in occupations/activities (Heah, Case, McGuire, & Law, 2007). Considering that identities are shaped by what children do, limited opportunities to participate in occupations may threaten identity development.

Adults’ values and preferences, parent/caregiver vigilance, possible safety risks, lack of supportive social or environmental structures, potential for peer issues, and a history of unaccommodating or discriminatory experiences all influence opportunities for children with disabilities to participate in childhood occupations (Baker & Donnelly, 2001; Heah at al., 2007).The majority of existing research has focused on the occupations and identities of adults (Phelan & Kinsella, 2013). Few studies on the development of children’s identities exist in the occupational therapy and occupational science literature. This lack of research has left a significant gap in terms of advancing knowledge with respect to children, particularly children with disabilities, and the development of identity through participation in childhood occupations.

This summary outlines findings from a qualitative study entitled: Occupation and Identity: Perspectives of Children with Disabilities and their Parents (Phelan & Kinsella, 2013) and provides recommendations for children and their parents, health and education professionals, and policy makers.

Understanding the Mental Health Needs of Children and Youth with Chronic Conditions

Facts To Go…Volume 10 Issue 2 June 2014 (Etherington, N., & McDougall, J.)

Mental health is a critical aspect of children’s health and well-being. Children and youth with chronic conditions are at an increased risk compared to their peers without such conditions for developing mental health problems, with nearly one in three experiencing co-morbidity (Schwartz et al., 2006). Yet, physical concerns often take precedence over the mental health needs of these children and youth (Petrenchik, King, & Batorowicz, 2011). Few studies have examined the specific types of mental health problems children and adolescents with chronic conditions may have (Hunt, 2009) or the broad range of factors that may contribute to the development of these problems (Brossard-Racine et al., 2012, 2013). A view of health that recognizes the mental and physical needs of children and youth with chronic conditions is needed in both research and practice. This is particularly important given that the mental health needs of these children and adolescents often go untreated (Brossard-Racine et al., 2013; Hunt, 2009).

The purpose of this Facts to Go is to summarize recent research that has examined the presence of specific types of mental health problems among children and youth with chronic conditions and the factors related to those problems. Implications for service providers, policy makers, and future research will be discussed.

Learning about Quality of Life for Young People with Severe or Profound Disabilities

Facts To Go…Volume 11, Issue 1 March 2015 (McDougall, J.)

Increasingly, researchers are asking children, youth, and young adults with chronic conditions and disabilities to directly report on their quality of life (QOL). Evidence is emerging about what QOL means to these young people and what is important to it.

But what of those young people who have difficulty responding or who are not able to respond to questions about their QOL because they cannot communicate their thoughts, feelings, and experiences through language? How can their life quality and the various factors that contribute to it be known?

The purpose of this summary is: a) to review the possible approaches for learning about the subjective QOL of young people with severe or profound disabilities; and b) consider some of the research that has occurred in this area thus far.

Implications of Substance Use for Young People Living with Developmental Disabilities

Facts To Go…Volume 11, Issue 2 October 2015 (Turner, N., & McDougall, J.)

Being a young person in today's society is quite challenging, with many pressures to fit in, develop one's identity, and become successful. Youth living with developmental disabilities often face additional challenges, commonly experiencing oppression and marginalization. These experiences may manifest in a myriad of ways such as social exclusion, bullying, and exploitation, potentially developing into forms of physical and sexual abuse as they grow older (Taggart, McLaughlin, Quinn, & McFarlane, 2007).

This summary outlines the findings of an unpublished manuscript (Turner, 2014) on the intersectionality of oppression for people living with developmental disabilities who also misuse and abuse substances, titled Intersections of Oppression: The Implications of Substance Use for People Living with Developmental Disabilities. The results have been tailored to relate to youth who identify as members of this demographic, in order to initiate conversations on how best to support these young people in developing healthier coping techniques and lifestyles, should they wish to access help in these areas.

Quality of Life, Self-Determination, and Spirituality: What Youth with Chronic Conditions Have to Say

Facts To Go…Volume 12, Issue 1 February 2016 (Nichols, M., McDougall, J., Baldwin, P., & Wright, V.)

This summary outlines findings of a qualitative study conducted as part of a mixed-methods research project titled, The Impact of Personal, Interpersonal, and Environmental Factors on Changes in Quality of Life for Youth with Chronic Conditions. Objectives of the qualitative study were to explore what the terms ‘quality of life,’ (QOL) ‘self-determination,’ (SD) and ‘spirituality’ mean to youth with chronic health conditions. Youth were also asked to think about what factors contribute to these three concepts, and what connections might exist between QOL and SD, and QOL and spirituality. A purposive sample of 18 youth aged 11-20 years with various conditions, such as cerebral palsy, other central nervous system disorders, and Asperger’s syndrome participated in semi-structured interviews which were analyzed using a qualitative descriptive methodology (Sandelowski, 2000). Transcripts were coded line-by-line, codes were collapsed into categories, and themes were identified.

Understanding Knowledge Use in Parents of Young Children with Cerebral Palsy: An Embedded Case Study

Facts To Go…Volume 12, Issue 2 June 2016 (Lagosky, S., & Bartlett, D.)

In recent years, there has been an emphasis in the health care system for research evidence to inform decision making. This process is known as knowledge translation, and involves the synthesis, dissemination, exchange and ethically-sound application of evidence-based knowledge with the end goal of improving the health of Canadians (Canadian Institutes of Health Research, 2015).

A multitude of knowledge translation strategies exist. Examples include summaries from research, such as this Facts To Go publication. To know if knowledge translation strategies are having their desired effect (e.g., a change of awareness in a population, or a decision that is based on the information one receives) we must go beyond focusing on the dissemination of knowledge and examine how this knowledge is actually being used (Straus, Tetroe & Graham, 2009).

This summary is based on a qualitative research study entitled Understanding Knowledge Use in Parents of Young Children with Cerebral Palsy, An Embedded Case Study (Lagosky, 2012).The study was designed to understand the knowledge use processes of parents of children with CP and how one might monitor knowledge use in this population.

How Can Perceived Quality of Life be Optimized for Youth with Chronic Health Conditions throughout Adolescence?

Facts To Go…Volume 12, Issue 3 September 2016 (McDougall, J., Nichols, M., & Wright, V.)

In recent years, there has been growing interest in health and disability research to explore quality of life in terms of **individuals' own perspectives** of their life in general, and what factors or aspects of life influence those perspectives. There is increasing emphasis for public policy to be more closely aligned with **what really matters to people** as far as what they think of their life quality and what might make it better (Helliwell, Layard, & Sachs, 2011). Countries, governments, and organizations are seeing the importance of collecting information about individuals' perceptions of their own subjective well-being. Asking people if they are satisfied with their QOL and collecting information about what may be related to that satisfaction can **reveal underlying strengths** and **critical hidden issues** about individuals and the society they live in (Helliwell et al., 2011). It can suggest the **need for change**, such as the need for new or different types of supports, services, or attitudes.

This summary describes the CIHR-funded 'QOL' study and its results, and highlights key areas where service providers and policy makers can focus their efforts in order to **optimize QOL for youth with chronic health conditions** as they develop throughout adolescence.

Parents' Experiences of Classifying their Children with Cerebral Palsy & Recommendations for Family-Centered Care

Facts To Go…Volume 12, Issue 4 October 2016 (Scime, N.V., Bartlett, D.J., Brunton, L.L., & Palisano, R.J.)

Three classification systems are routinely used to provide a functional profile of children with cerebral palsy (CP). The **Gross Motor Function Classification System**[1] (GMFCS) classifies gross motor performance, the **Manual Ability Classification System**[2] (MACS) classifies hand use and object manipulation, and the **Communication Function Classification System**[3] (CFCS) classifies the receiving and sending of information. Each system has five levels of function, with level I being the highest level of function and level V being the lowest level of function. The GMFCS[4] and MACS[5] also have evidence of stability, as the classification level of most children do not change over time.

This summary outlines the findings of a published manuscript entitled *Parents' experiences and perceptions when classifying their children with cerebral palsy: Recommendations for service providers*.[9] The objectives for the qualitiative research study described in this paper were to: a) understand parents' experiences of classifying their children using the GMFCS, MACS, and CFCS, b) understand parents' perceptions regarding the usefulness of these systems relating to current and future function, and c) collate parents' recommendations for service providers on how to facilitate a family-centered approach when communicating information.

What Contributes to Multidimensional Life Satisfaction for Youth with Chronic Health Conditions?

Facts To Go…Volume 14, Issue 1 February 2018 (McDougall, J., Wright, V.)

Health is considered by the World Health Organization (1948) to be 'a complete state of physical, mental, and social *well-being* and not merely the absence of disease or infirmity' p.100). The emphasis on well-being beyond the physical signifies the importance of **psychosocial positivity** to one's health. One measure of this concept is **life satisfaction**. Life satisfaction has been considered a cognitive evaluation of the quality of one's life overall or in specific domains, such as family life or school experiences (Diener, 2000).

This *Fact To Go* summarizes longitudinal research (McDougall & Wright, 2017) that was the first to explore the personal, interpersonal, and environmental level factors related to satisfaction with specific life domains (i.e., satisfaction with self, family life, friendships, school experiences, where one lives), in addition to life overall, for youth with chronic conditions over a one-year period. It highlights **key areas** where service providers and policy makers can focus their efforts to optimize life satisfaction within and across multiple domains for these youth.