
NAVIGATOR R

Program

ENVIRONMENTAL SCAN/LITERATURE SEARCH

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*Edelstein H, Schippke J, Sheffe S, Kingsnorth S. Children with medical complexity: a scoping review of interventions to support caregiver stress. Child Care Health Dev [Internet]. 2016 Nov 29 [cited 2016 Dec 5]; Available from: <http://onlinelibrary.wiley.com/doi/10.1111/cch.12430/abstract>

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Current State / Practice (n=11)					
Agrawal R 2015 United States	Journal Article – Expert Opinion	Children with medical complexity (CMC)	Describe recent growth and Key Challenges for the field.	Editorial of issue dedicated to Complex Care. Presents a range of original research with areas of investigation including quality of life, caregiver challenges, health care utilization, technology assistance and residency education.	(1)
Berry 2015 United States	Report	Families/CMC	Describe what all those involved in the care of CMC deserve from the healthcare system and how to achieve an ideal health system of care	Work needed in a variety of areas, including care management, care coordination, care planning, financing, payment, risk assessment, and the treatment and management of specific healthcare problems	(2)
Bye A, Aston M 2015 Canada Nova Scotia	Journal Article - Qualitative Study	Caregivers of children with intellectual disabilities	Describe and reflect one mother’s experience navigating the medical system with a child with intellectual disability		(3)
Canadian Home Care Association 2016 Canada	Report	Families/Children with Complex Health needs	Describe the findings of a pan-Canadian scan undertaken by the Canadian Home Care Association, in collaboration with key informants and subject matter experts, to gain an understanding of the current programs available through provincial and territorial governments for children with complex care needs	Scope included: <ul style="list-style-type: none"> • Identification of existing home- based programs • description of the availability of programs and services, accessibility, eligibility, limitations or restrictions, funding eligibility and caregiver supports • Understanding of the issues, challenges and opportunities for home- based services • Listening to the perspective and advice of parents 	(4,5)

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
				<ul style="list-style-type: none"> • Identification of services available through provincial and territorial funding to Aboriginal children 	
Change Foundation 2013 Canada Ontario	Report	Ontario healthcare community	Review Benefits and challenges of Health System Navigator Model	Shared results from PANORAMA , a standing panel of 31 Ontario residents exchanging views, experiences and advice. Implementation must haves can be found on page 12	(6)
Glader et al. 2016 United States	Journal Article – Non Systemic Review	Families/CMC	Propose a new framework for analysis and discussion based on the components of the International Classification of Function, Disability and Health	Family-oriented recommendations can be found in Table IV on page 7	(7)
Keilty K, Cohen E 2015 Canada	Journal Article – Expert Opinion	Children, youth and young adults with conditions and/or disabilities that manifest themselves during early life	Commentary paper endorsing comprehensive and coordinated caregiver policy across the life span	Discusses Family-centered care, Life course approach, Medical home, Human resources in homecare, caregiver perspectives	(8)
Kuo et al. 2011 United States	Journal Article – Observational Study	Families/Children with special health care needs (CSHCN)	To profile the national prevalence of more-complex children with special health care needs (CSHCN) and the diversity of caregiver challenges that their families confront	<ul style="list-style-type: none"> • Families of more-complex CSHCN face exceptionally high care demands, high unemployment and underemployment, and large financial burden, and that many more-complex CSHCN have unmet medical needs • Over half of families of more-complex CSHCN in our study 	(9)

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
				<p>report financial difficulties and employment loss</p> <ul style="list-style-type: none"> • Most of the families reported having at least ten physician visits and out-of-pocket health care costs of more than \$1,000 annually. 	
<p>Kuo et al. 2014 United States</p>	<p>Journal Article – Observational Study</p>	<p>Families/Children with special health care needs (CSHCN)</p>	<p>Determine the association between variables known to be associated with inequities in health care needs and the medical complexity status of children and youth with special health care needs</p>	<ul style="list-style-type: none"> • At least one unmet need was reported by 44.2 percent of families of children with medical complexity, compared to 19.1 percent of those without medical complexity. • Overall, children with medical complexity had a higher percentage of unmet health care needs than children without medical complexity, regardless of race/ethnicity, insurance coverage, and household income in relation to poverty level. • For uninsured children, the number of unmet needs was higher across both children with medical complexity and children without medical complexity, which suggests that a lack of insurance is a major driver of unmet needs. 	<p>(10)</p>

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Kuo et al 2016 United States	Journal Article – Observational Study	Families/CMC	Describe family-reported health service needs of children with medical complexity (CMC) and to assess which needs are more often addressed tertiary care center	Many families reported not receiving adequate chronic care management or assistance with referral to specialists, family support services, or community services from the primary care setting, despite receiving preventive care checkup.	(11)
Ontario Association of Community Care Access Centres 2013 Canada	Report	Families/Children with Complex Health needs	Part of series of papers that present viewpoints regarding the future of Ontario's society and health care system	Includes what's working well in Ontario, Alberta, Holland, Austria, UK	(12)
Provincial Advocate for Children & Youth 2016 Canada Ontario	Report	Young people with special needs and their families	Provide perspectives, challenges and recommendations on different aspects in the lives of young people with special needs	Topics include: <ul style="list-style-type: none"> • Family and Home • School & Education • Supports & Services • Transitions 	(13)
Siddiq et al 2016 Canada					(14)
Thomson et al. 2016 United States	Journal Article – Observational Study	Families/Children with medical Complexity (CMC)	To describe hardships experienced by families of children with medical complexity (CMC) and compare them with those experienced by families of children with asthma.	<ul style="list-style-type: none"> • Although 44% of families of CMC reported out-of-pocket medical costs of <\$250 in the last year, nearly one-half reported financial problems resulting from their child's health. • Changes to employment were frequent, with 60% reporting that 	(15)

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
				<p>a family member stopped working and nearly 66% reporting that a family member cut back on work to care for their child</p> <ul style="list-style-type: none"> • Approximately 68% reported a financial hardship and >50% a social hardship; ~80% reported ≥1 experienced hardship • The most common financial hardship reported by families of CMC was the expressed need to borrow money in the past 12 months (46%) • Nearly one half of families expected little to no help from family/friends when needed, and 33% could not count on family/friends for a \$1000 loan. 	
<p>Turcotte M 2013 Canada</p>	<p>Report</p>	<p>Family Caregivers</p>	<p>Provide insight on family caregivers, resources available</p>	<p>Also highlights the difficult situation of family caregivers who care for a sick child</p>	<p>(16)</p>

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Woolf-King et al 2017 United States					(17)
Health and related supports (n=23)					
About Kids Health – Complex Care 2016 Canada	Website	Families/Children with Complex Health needs	Resource centre to inform and help parents cope	Provided by Hospital for Sick Children	(18)
Axelsson 2015 Sweden	Journal Article – Observational Study	Families/CMC	To understand the role of external personal assistants in relation to the child and family	<ul style="list-style-type: none"> Assistant role included substituting basic functions, supporting child in everyday life, and giving relationship support, while balancing and showing sensitivity to family life and privacy External assistants were more often found to assist in activities away from home, while parents tended to assist within home External assistants fulfilled a function as they reduced parental burdens freeing them to engage in other activities or rest 	(19)*

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Brookman et al. 2011 Canada Ontario	Report	Caregivers	Determine the current promising practice education and support programs for family members and friends who care for others and to create recommendations for cost-effective education and support priorities for a range of people across Ontario	Identified 5 promising practices and 20 indicators of effective caregiver education and supports programs.	(20)
Coquillet et al. 2015 United States	Journal Article – Observational Study	Families/CMC	Quantify hospital-wide social work services utilization by CMC compared to non-medically-complex children (non-CMC) to inform the development of family-centered care models that support these vulnerable patients and families.	<ul style="list-style-type: none"> • CMC were more than six times as likely to use Social work services. Additionally, on average, social workers spent more than eight times as many hours per child with CMC than they did with non-CMC. • Understanding the specific SWS needs in this population will allow practices to tailor their care team appropriately. • It may be appropriate for non-licensed support staff such as patient navigators or resource specialists to fill a subset of these roles 	(21)
Carter et al. 2007 United Kingdom	Journal Article – Qualitative Study	Caregivers of Children with Complex Health Needs	Explore examples of best multi-agency working practice with families/workers	Identified 10 best practice statements about “things work well when...” – Table 2, page 532	(22)

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Chigamik Community Health Centre - French Health Care System Navigation Initiative 2015 Canada Ontario	Website - Pilot Project	Francophone clients in North Simcoe Muskoka LHIN	Guide Francophone clients towards French language health services that are adapted to meet their specific needs.		(23)
Duffy L, Vessey J 2014 United States Massachusetts	Journal Article - Randomized Controlled Trial	Parents of children with epilepsy and other chronic conditions – 46 enrolled, 21 completed all phases	Tested the efficacy of COPE (Creating Opportunities for Parent Empowerment) intervention	Focused on challenges parents face during their child's intervention, 3 days after discharge and 4-6 weeks after discharge	(24)
Edelstein et al. 2016	Journal Article – Systematic Review	Families/CMC	Describe the current range of caregiver- focused interventions, identify promising approaches, discuss gaps for future research	<ul style="list-style-type: none"> • Positive findings of reductions in caregiver stress were noted within an emerging body of evidence on effective interventions • Significant focus on streamlining services and reducing the burden of care related to carried pressures. • Non-conclusive evidence around which of the six identified intervention domains or combination are most effective for reducing stress 	(25)
Family to Family 2016 United States	Website	Individuals with disabilities and/or special health care needs, their families, and professionals who support them.	Address the need for individuals with disabilities, their families, and others in the field to receive family-friendly information on best-		(26,27)

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
			practices and disability topics, peer support, and leadership opportunities		
Family Voices 2016 United States	Website/Resources	Families/Children with Special Health Care Needs	Assist families and children, improve hospital/state/federal policies, train leaders		(28)
Johnson C, Kastner T 2005 United States	Journal Article – Expert Opinion	Families/Children with Special Health Care Needs	Educate physicians on the philosophy of providing a permanent family environment for children, special health care needs, and the importance of adequate and accessible community services to support and maintain the well-being of all family members	Recommendations on page 510	(29)
Knafl et al. 2016 United States North Carolina	Journal Article – Systematic Review	Families of children with chronic conditions	Examine the focus, structure, and level of family engagement in interventions	<ul style="list-style-type: none"> • Synthesizes 70 intervention studies • Investigators most often sought to improve condition control or management, with parent engagement in the intervention focused on enhancing capacity to manage the treatment regimen 	(30)

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
National Consensus Framework for Systems of Care for Children and Youth with Special Health Care Needs Project 2014 United States	Report	Children and Youth with Special Health Care Needs	Describe Standards for Systems of Care	Includes Community based services, Respite Care, Palliative Care, Transition. Describes case studies across U.S states	(31,32)
Peckham et al. 2014 Canada Ontario	Journal Article – Observational Study	Caregivers of Children with Medical Complexity	Present insights of the Caregiver Framework for Children with Medical Complexity Series of Publications	Key workers accessed supports in four categories: <ul style="list-style-type: none"> • Family Care (e.g. respite) • Household expenses • Unfunded equipment/services/supplies • Recreation/health promotion 	(33)
Pelentsov et al. 2015 Australia	Journal Article – Qualitative Study	Parents of children with rare diseases	Better understand the experiences and supportive care needs of parents caring for a child with a rare disease.	Main identified themes: <ul style="list-style-type: none"> • Feeling boxed-in outside the box • Practicalities of care • Relationships 	(34)
Ranaghan et al. 2016 United States	Journal Article – Systematic Review	Adult patients	Synthesize the best available evidence on the effectiveness of a patient navigator on patient satisfaction in adult patients 18 years and older in ambulatory care settings.	<ul style="list-style-type: none"> • The literature supports improved satisfaction with an educated and trained navigator that is knowledgeable about healthcare practices and who is familiar with the healthcare system • Some studies supported care coordination with a volunteer or lay navigator who may be capable of providing emotional support, guidance, encouragement and assistance during the treatment 	(35)

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				process	
Rocque et al. 2016 United States Alabama	Journal Article – Observational Study	Geriatric patients with cancer	Describe a lay patient navigation program, training navigators in evidence-based strategies to activate and engage patients in health care	<ul style="list-style-type: none"> • High patient satisfaction with the program: 83% (n = 336) are satisfied or very satisfied, 14% are neutral or uncertain, and 3% are unsatisfied or very satisfied • Emphasis on empowering patients is essential to the function of this navigation program 	(36)
Shepherd et al. 2007 Australia	Journal Article – Observational Study	Mothers of Children with Medical Complexity	To examine parental perceptions on introduction of a mobile hoist	<ul style="list-style-type: none"> • Introduction of assistive technology requires compromises by families and can generate emotions related to acceptance of the child's disability • Early introduction in anticipation of future needs was viewed positively • Positive impact on families' quality of life with increased flexibility in timing of care management and reduced physical strain 	(37)*
Trowbridge K, Mische- Lawson L 2015 United States	Journal Article – Systematic Review	Families/Children with Medical Complexity	Analyze the quantitative literature on children with medical complexity	Focuses on Pediatric Self- Management Model, Social work model	(38)

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University of Minnesota - LEND Program 2016 United States Minnesota	Website	Neurodevelopmental and related intellectual and developmental disabilities	Facilitates development of health care and allied health care leaders with the knowledge, skills and attitudes to allow them to take committed action		(39)
Wiersma et al. 2015 United States Washington DC	Conference Abstract	Family of Children with Special Health Care needs	Measure impact of navigation services on healthcare utilization or family satisfaction	No significant difference for ED, medical home, or subspecialty visits in the six months before and six months after enrollment. More than 95% of parents were satisfied with their PNP experience, felt it was helpful, and would recommend it to other families	(40)
Williams et al. 2011-2014 Canada Ontario	Report	Caregivers of Children with Medical Complexity	Provide a flexible mix of health and social supports, as well as ongoing counselling and care management, to family caregivers of CMC judged to be “at risk” as a result of their caregiving activities	Part of Caregiver Framework for Children with Medical Complexity Series of Publications Highlights: <ul style="list-style-type: none"> • “Joint working”/ “Key Worker” Models • Children’s Treatment Network (CTN) of Simcoe York model 	(41)

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Williams et al. 2014 Canada Ontario	Journal Article – Expert Opinion	Caregivers of high-needs older persons and children with complex medical needs in Toronto	Introductory paper for two longer papers detailing Toronto initiatives for “at risk” caregivers	Part of Caregiver Framework for Children with Medical Complexity Series of Publications	(42)
Home Care (n=6)					
Canadian Healthcare Association 2009 Canada	Report	Caregivers	Review Home Care in Canada	Recommendations: <ul style="list-style-type: none"> • Ensure integration and expansion of home care within the continuum of care. • Ensure predictable and sustainable funding in home care. • Introduce appropriate and relevant pan-Canadian principles to address a greater integration of home/community care. • Provide appropriate supports to 	(43)

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				<p>both formal and informal (usually family) caregivers.</p> <ul style="list-style-type: none"> • Address the public/private split in terms of access to and quality of services, as well as transparency and accountability. • Invest in health human resources. • Make greater use of information and communications technology. • Share leading practices and experiences from both within and outside Canada. 	
Desai et al. 2016 United States Washington	Journal Article – Qualitative Study	Caregivers of Children with Medical Complexity	Explore caregiver needs and preferences for achievement of high-quality pediatric hospital to home transitions	<p>Three main themes:</p> <ul style="list-style-type: none"> • Adequate support and resources • Caregiver Self-efficacy for Home Care Management • Comprehensive Knowledge of Care Plans 	(44)
Elias E et al. 2012 United States	Report	Families/Children with Complex Health needs	Present an approach to discharging the child with complex medical needs with technology dependencies from hospital to home and then continually addressing the needs of the child and family in the home environment	Family need are discussed in pages 1002-1003	(45)
Pediatric Home Service 2016 United States Minnesota	Website/Service	Families/CMC in Minnesota, western Wisconsin, northern Iowa, and eastern North and South Dakota	Provide comprehensive pediatric home care services to help children with medical complexities		(46)

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Pediatric Practice Enhancement Project 2016 United States Rhode Island	Website	Children with special needs and their families	Provide a coordinated system of care and medical home enhancement for children and youth with special healthcare needs	Also trains and places parent consultants into pediatric primary and specialty care practices to help families coordinate and access the health system, as well as other services (e.g., social services, education, housing)	(47)
Tsao H 2015 United States Massachusetts	Thesis	Families/Children with special healthcare needs	Describe how Rainbow Medical Home Initiative (RMHI) targets the medical and social care coordination needs of this population	Developed a tool to screen unmet needs	(48)
Insurance and employment benefits (n=4)					
Chen AY, Newacheck PW 2006 United States	Journal Article – Observational Study	Children with Special Health Care Needs and families	To understand the effects of health insurance on financial burden and work loss incurred by families	<ul style="list-style-type: none"> Regardless of income, health insurance is a key component of financial safety and should be considered part of a multifaceted national strategy Near-poor and low-income families not eligible for federal assistance were more vulnerable than qualifying poor families As income increases, the proportion of parents cutting back or stopping work decreases but many low-income families continue to experience loss despite insurance coverage 	(49)*
Earle A, Heymann J 2011 United States	Journal Article – Observational Study	Children with Special Health Care Needs and families	To examine the association between caregiver burden and supportive working	<ul style="list-style-type: none"> Access to different types of paid leave buffered the strains of caregiving affecting physical and mental health 	(50)*

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
			conditions	<ul style="list-style-type: none"> • Access to ‘paid sick leave’ mattered most for physical health status while ‘paid family health leave’ moderated mental health status as they afforded different opportunities for self-care • Inflexible work cultures (i.e. difficult to take time off) were associated with lower mental health scores • Universal access to paid leave was recommended to protect caregiver health 	
Schuster et al. 2009 United States	Journal Article – Observational Study	Children with Special Health Care Needs and families	To examine the perceived effects of leave from work varied outcomes among employed parents	<ul style="list-style-type: none"> • 57% of parents reported that leave had positive effects on their emotional health, but a substantial minority of 42% reported neutral or negative effects. • Leave-taking, even with full pay, was shown to strain some parents’ finances. • Overall, longer leaves were associated with a greater number of positive perceived effects on child physical and emotional health but a more negative perceived effect on parental job performance, and a greater number of reported financial problems, particularly when unpaid. 	(51)*

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Yu et al. 2008 United States	Journal Article – Observational Study	Children with Special Health Care Needs and families	To understand the impact of health insurance coverage and how it protects the out of pocket medical expenditures by families	<ul style="list-style-type: none"> Public rather than private coverage provided better financial protection if catastrophic medical costs exceeded 10% of family income; no difference in coverage type was noted when costs exceeded 20% of family income Individual families' financial burdens positively associated with growth of economy-wide health costs over time; unless controlled, families will continue to experience significant financial stressors 	(52)*
Peer Support (n=11)					
Arens 2006 United Kingdom	Journal Article – Observational Study	Families/CMC	To identify service provision needs for siblings with a life- limited brother or sister using hospice service	<ul style="list-style-type: none"> Many families struggled with communication, requiring safe and supportive environments for expression. Observations by program leaders regarding participating youth included decreased isolation, enhanced friendship-building and reduced need for intense bereavement therapy 	(53)*
Baum 2004 United States	Journal Article – Observational Study	Children with Special Health Care Needs and primary caregivers	To understand the effect of internet peer support groups on sense of well- being among primary caregivers	<ul style="list-style-type: none"> Overall high satisfaction with internet peer support options Themes related to getting usable ideas and information, improved caregiver-CSHCN relationship, and finding people to trust Overall, participants felt better as a result of participating, were able to come to terms with their caregiving role, and 	(54)*

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				recommended accessing as soon as possible after diagnosis	
Giallo R, Gavinia-Payen S	Journal Article – Experimental, Randomized, Controlled Trial	Families of Children with Special Health Care Needs	<i>Sibstars</i> is a 6 week family-based psychoeducational intervention; key aspects include 20-30 minute face-to-face sessions, completion of a practice booklet and telephone support provided by a clinician with postgraduate psychology training	<ul style="list-style-type: none"> • High ratings of satisfaction, with majority of mothers and siblings agreeing that <i>Sibstars</i> helped them • Improved sibling outcomes, with significantly lower emotional symptoms, perceived intensity of daily hassles stress and less use of distancing coping post-intervention 	(55)*
Hammarberg et al. 2014 Australia	Journal Article – Qualitative Study	Caregivers of care for children with chronic illness or disability in Australia	Investigate barriers and promoters of participation in a government funded peer support group program (MyTime)	<ul style="list-style-type: none"> • The previously reported benefits of peer support for those who care for children with disabilities in reducing isolation, improving psychological well-being and increasing knowledge were evident • With very few exceptions, participants affirmed that being a group member provided much valued social support, a sense of belonging, and helped them learn about and navigate the disability funding and allowance systems and available disability services. • It seems that the MyTime program was highly effective in Australia and might be a model for other nations to consider in 	(56)

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
				their strategies to improve services for carers of children with special needs.	
Holland Bloorview Rehabilitation Hospital - Peer Support Kit 2015 Canada	Reports	Individuals developing and providing peer support programs for families of children with medical complexity and other lifelong disabilities	Provide practical information summarizing: <ul style="list-style-type: none"> • Peer support models • Research evidence on best practices in peer support • Case studies, templates, and links to helpful resources 		(57–60)
Kingsnorth et al. 2011	Journal Article – Qualitative Study	Families/CMC	To assess impact of a parent-led transition peer group	<ul style="list-style-type: none"> • Group led to increased awareness related to personal planning challenges; increased active planning; and enhanced valuing of experiential knowledge • Participation helped parents envision a future for their child and identify their family and personal needs • Much support noted for the ‘family facilitator’ role and mutual opportunities to share common experiences during this stressful period. 	(61)*

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Mahoney K, Reynolds M 2011-2014 United States	Poster Presentation	Urban families with children and youth with special healthcare needs (CYSHCN)	Enhance care coordination through integration of a parent- to-parent model of peer support within pediatric care clinics	Part of Missouri Family to Family Program	(62)
Nicholas D, Keilty K 2007 Canada	Journal Article – Quasi- Experimental	Families/CMC	To evaluate a dyadic peer support intervention for families	<ul style="list-style-type: none"> • No significant changes over time on measures; limited instrument sensitivity an issue • Parents reported sharing their experiences and emotions and benefited from sustained communication with someone who could understand what they were going through • Participants generally appreciated peer support received through the matched model, with experiences enhanced through face-to-face contact 	(63)*
Parent to Parent USA 2016 United States	Website	Families of Children with Special Needs	National non-profit organization committed to providing emotional and informational support to families of children who have special needs most notably by matching parents seeking support with an experienced, trained 'Support Parent'		(64)

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Toly et al. 2014 United States	Journal Article - Randomized Controlled Trial	Families/CMC	To determine feasibility, acceptability, and efficacy of resourcefulness training (RT) on mental health outcomes among mothers	<ul style="list-style-type: none"> • The RT intervention is acceptable and feasible and can be used by pediatric nurses to assist mother in home management care • Mothers reported RT intervention helped them work through challenges by raising awareness for strategies • Promising effect size noted in reducing negative emotions and depressive cognitions for RT group 	(65)*
Wynter et al. 2014 Australia	Journal Article – Observational Study	Caregivers of care for children with chronic illness or disability in Australia	Evaluate if online surveys can be used for monitoring and evaluating peer support groups for caregivers of children with special needs	<ul style="list-style-type: none"> • Evaluated same peer support group as in Hammarberg et al. • In spite of being likely to have limited discretionary time, parents and other caregivers of young children with special needs were willing and able to complete the brief, online surveys about their experiences of participating in peer-support groups • Consistent with Hammarberg et al. , most caregivers who responded to the online survey reported significant benefit from participation, including social support from people in similar situations, access to relevant information and ideas and having “time out”. Negative experiences were also similar 	(66)

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Resources/Training (n=11)					
Canadian Association of Pediatric Health Centres 2016 Canada	Website	Families/Children and Youth with Medical Complexity	Catalogue of Canadian Complex Care Programs and/or Organizations Providing Services	Part of Knowledge Exchange Network	(67)
Centers for Disease Control and Prevention 2016 United States	Website	Family Caregivers of adults or children	Provide information and resources to caregivers of children or adults with disabilities		(68)
CanChild 1989 -2016 Canada	Website/Research Centre/Reports	Children and youth with developmental conditions and their families	Maximize the quality of life and participation of children and youth with a variety of developmental conditions, along with their families, through evidence-based clinical and health services research.	Relevant research and resources for parents include a Parent Information Kit, Parenting Matters project	(69–72)
Caregivers Alberta 2016 Canada Alberta	Website/Workshop	Health professionals, service providers and community agency staff	One-day workshop Training to better support caregivers		(73)

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Caregivers Nova Scotia Association - The Caregiver's Handbook 2014 Canada Nova Scotia	Book	Caregivers in Nova Scotia	Providing recognition and practical supports to friends and family giving unpaid care		(74)
Complex Child Magazine 2016 United States	Online Magazine	Caregivers of children with special healthcare needs and disabilities	Provide medical information, along with personal experiences, in simple language that other parents can understand		(75,76)
Children and Youth with Special Health Care Needs (CYSHCN) Program 2016 United States Wisconsin	Website/Resources	Families who have children with special health care needs	Promotes family/provider partnerships and collaborates with parent-led organizations in the state	Funds Family Voices and Parent to Parent of Wisconsin	(77,78)
Giosa J, Holyoke P 2014 Canada	Journal Article – Mixed Methods	Family Caregivers across the Healthcare System	Promote a culture Shift towards Proactive and Preventative Caregiver Education and Support	<ul style="list-style-type: none"> After direct and indirect input from caregivers, the promising practice indicators were more oriented to making proactive, preventative and practical supports available to caregivers to support them and help them avoid crises and burdens 	(79)

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Jackson et al. 2016 Australia	Journal Article – Systematic Review	Families of Children with Complex Health Care needs	Examine the design, implementation and evaluation of parent education programs for families with CSHCN, to better design interventions that focus on the psychosocial aspects of living with a chronic condition, for both the child and the family.	Identified several successful elements of effective parenting or family support programmes for children with special health needs: <ul style="list-style-type: none"> • Provision of opportunities for parents/families to tell and share their unique stories • Support for the well-being and strengths of the family as a unit (e.g. strengthening relationships between parents, the CSHCN and siblings) • Focus on generic skills in relation to parenting (e.g. problem- solving, stress management) • Having input from trained professional staff (e.g. expert on chronic illness management) 	(80)
Seattle Children’s Center for Children with Special Needs 2016 United States	Website	Families and Professionals of children and youth with special health needs	Information source for families and professionals. Also provides program evaluation/needs assessment and Health education/training		(81)
St. Mary’s Healthcare System Resource Directory 2016 United States New York	Website	Families/caregivers of children who have medically complex needs	Provide resources to assist with finding help		(82)

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Respite Care (n=11)					
Canadian Healthcare Association 2012 Canada	Report	Caregivers	Review Respite Care in Canada and compare with international efforts	<ul style="list-style-type: none"> Recommendations for action on page 46 	(83)
Carter et al. 2012 United Kingdom	Journal Article – Observational Study	Families/Children with Special Healthcare Needs	To evaluate a homecare program to enhance best practices	<ul style="list-style-type: none"> Care at home was seen as ‘more normal’ and parents experiences positive changes in managing care, reducing hospital admissions Services worked well when integrated flexibly into families’ lives and where a partnership perspective was developed Care delivered in standard working hours (8 hours/day 5 days/week) did not always fit with family needs Having inadequate coverage and untrained HCPs added to parents’ physical and emotional stress 	(84)*
Davies et al. 2004 Canada	Journal Article – Observational Study	Families of Children with Special Healthcare Needs	To identify perceptions related to program benefits, and considerations related to use and timing of respite care over its first 2.5 years of operation	<ul style="list-style-type: none"> Majority of parents reported positive child benefits and viewed the hospice as safe, happy and fun place Respite provided parents with a break from the routine, with sleep, comfort, and freedom, time for themselves, a sense of privacy and ‘normalcy’ and learning opportunities with peers 	(85)*

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Dunbrack 2003 Canada	Report	Caregivers	Provide an Environmental Scan of Publicly-funded Respite Programs in Canada	<ul style="list-style-type: none"> • The availability of respite across Canada varies widely depending on provincial/territorial financial resources and the availability of qualified workers. • Respite availability also varies within jurisdictions when low-income families may be unable to afford the cost, even though they receive some public assistance. • Demand is high for respite, especially for in-home respite and day programs • Gaps appear to exist in respite for family caregivers of those living with mental health conditions 	(86)
Eaton 2008 United Kingdom	Journal Article – Observational Study	Families of CMC	To understand parents' perceptions of two types of respite services	<ul style="list-style-type: none"> • Families reported that they 'did not know how they coped' before receiving respite services • Irrespective of type, consistency in providers enhanced trust and feeling of happiness among parents • Concerns around privacy for home provision and potential conflicts over who held the power in the parent-provider relationship were noted • Hospice care created challenges related to ensuring equipment needs were met 	(87)*

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Forde et al. 2004 Ireland	Journal Article – Quasi- Experimental	Families of Children with Special Healthcare Needs	To evaluate a pilot in-home respite care program by assessing degree of stress experienced and impact of service	<ul style="list-style-type: none"> • Prior to participation, majority of parents reported that caring for a child with a disability placed extra stress on themselves with clinically significant stress scores; after, all 16 parents qualitatively reported reduced stress but frequency of clinically significant stress scores remained • Overall parents reported that respite allowed them to do things that they normally couldn't do, such as varied social and recreational activities 	(88)*
MacDonald & Callery 2004 United Kingdom	Journal Article – Observational Study	Families of CMC	To understand parent perceptions of the meaning of respite to inform service development and acknowledge differences between services and parents' expectations	<ul style="list-style-type: none"> • Parents identified 3 broad respite types: short breaks by extended family/friends (often seen as babysitting); 3-4 hour breaks by an agency (allowing parents to attend to day-to-day responsibilities); and overnight stays at a facility (allowing for holidays or time with other children) • Some parents valued out of home respite because it allowed time 'to be a normal family'; long overnight stays were identified as essential to 'alleviate total exhaustion' and sustain themselves in a caring role 	(89)*

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Meltzer et al. 2010 United States	Journal Article – Quasi- Experimental	Families of CMC	A home-care program that provides case management, advocacy, education, counseling, and respite nursing care with a specific focus on night time provision	<ul style="list-style-type: none"> • Overall, less night support was associated with shorter sleep and more negative moods with implications for daytime caregiving capacities • It was clinically notable that families who received more than 48 hours of night nursing per week slept on average almost 1 hour more than other families. • Problems related to night coverage were identified, with frequent cancellations or no show among issues causing disturbances to parents' sleep patterns 	(90)*
Nova Scotia Partnership on Respite, Family Health and Well-being 2009/2014 Canada Nova Scotia	Reports	Families of Children and Youth with Chronically High Needs in Nova Scotia	Develop solution-focused strategies that promote a proactive system of care for children and adults with disabilities and respite for caregivers and families		(91–94)

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
<p>Swallow et al. 2011 United Kingdom</p>	<p>Journal Article – Qualitative Study</p>	<p>Families of CMC</p>	<p>To understand parent and teenager views of a particular respite service</p>	<ul style="list-style-type: none"> • Parents valued meeting other families using the service and opportunities for rest and leisure, they otherwise could not achieve while their child was at home • Parents’ perceptions focused on service atmosphere, the trust between staff and children, staff-parent communication, stages of need and level of professionalism displayed; reflecting a partnered approach to care • Teenage clients valued choice equipment access, quality of staff interpersonal skills and opportunities for ‘typical’ leisure activities 	<p>(95)*</p>

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Thomas & Price 2012 United Kingdom	Journal Article – Qualitative Study	Families of CMC	To evaluate whether the Community Children’s Nursing (CCN) respite service met parent’s needs	<ul style="list-style-type: none"> Mothers’ valued the respite care, were reliant on the service and felt a reduction would be devastating They were satisfied and confident with staff competence, noted positive parent-professional relationships; and identified consistent and familiar carers as important Recommended greater access during periods of crisis and more involvement of families in carer recruitment processes 	(96)*
Telemedicine (n=5)					
Clawson et al. 2008 United States	Journal Article – Quasi-Experimental	Families of CMC	To assess the value of a teleconferencing system on parent burden of care experience	<ul style="list-style-type: none"> High satisfaction with enhanced access to specialty physicians For most families, this model made the difference between access vs. ‘no access’ Dramatic reduction in family-incurred costs and related burden of care through elimination of extensive travel needs (e.g. work loss decreased from 2 full days to 1 half day) 	(97)*
Haney T, Tufts KA 2012 United States	Journal Article – Quasi-Experimental	Families of CMC	To examine impact of nurse-established and managed electronic communication on well-being and satisfaction among parents	<ul style="list-style-type: none"> Overall satisfaction scores increased but change was not significant; limited power was noted No significant changes in pre- and post-intervention well-being were noted 	(98)*

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
				<ul style="list-style-type: none"> Anecdotal qualitative comments within emails indicated that parents found the intervention helpful and informative, with 12/19 requesting continued support post-study 	
Marcin et al. 2004 United States	Journal Article – Quasi- Experimental	Families of Children with Special Healthcare Needs	To identify parent- identified barriers and perceptions as well as parent/provider satisfaction	<ul style="list-style-type: none"> Prior barriers to subspecialty care included lengthy travel, missed work and increased reliance on emergency dept. Model supported child in the medical home allowing for increased care coordination between primary care provider and subspecialists and addressed parental travel and work-loss burdens Very high satisfaction with majority of families and HCPs wanting continued telemedicine services 	(99)*

Source Year Region	Type	Target Population	Objective	Key Findings/Notes	Citations
Young et al. 2006a Canada	Journal Article – Quasi- Experimental	Families/CMC	To understand children’s and parents’ experiences of a telehealth model to support hospital-to- home transition	<ul style="list-style-type: none"> • With little experience caring for complex health conditions, The Tele-HomeCare (THC) alleviated feelings of being overwhelmed and helped parents become more proficient carers • Families were satisfied and felt THC allowed for rapid access to and continuity of specialty care • Access rather than actual use contributed to an increased sense of confidence and security around the child’s care needs 	(100)*
Young et al. 2006b Canada	Journal Article – Quasi- Experimental	Families of CMC	To assess quality of life and impact on family over the initial period of discharge among families receiving telehealth supports as compared to standard care	<ul style="list-style-type: none"> • All groups experienced a significant improvement in quality of life around discharge, with slower gains during the remaining time at home • Families reported THC support was crucial as an adjunct to other services during the initial period of discharge and enabled them to develop care competencies at home 	(101)*

*Extracted, with permission, from Table S1 in supplement of Edelstein et al., 2016 (25)

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