

**Table S1. Identifying questions for evidence review from patient journey mapping, focus group discussion and study team meetings**

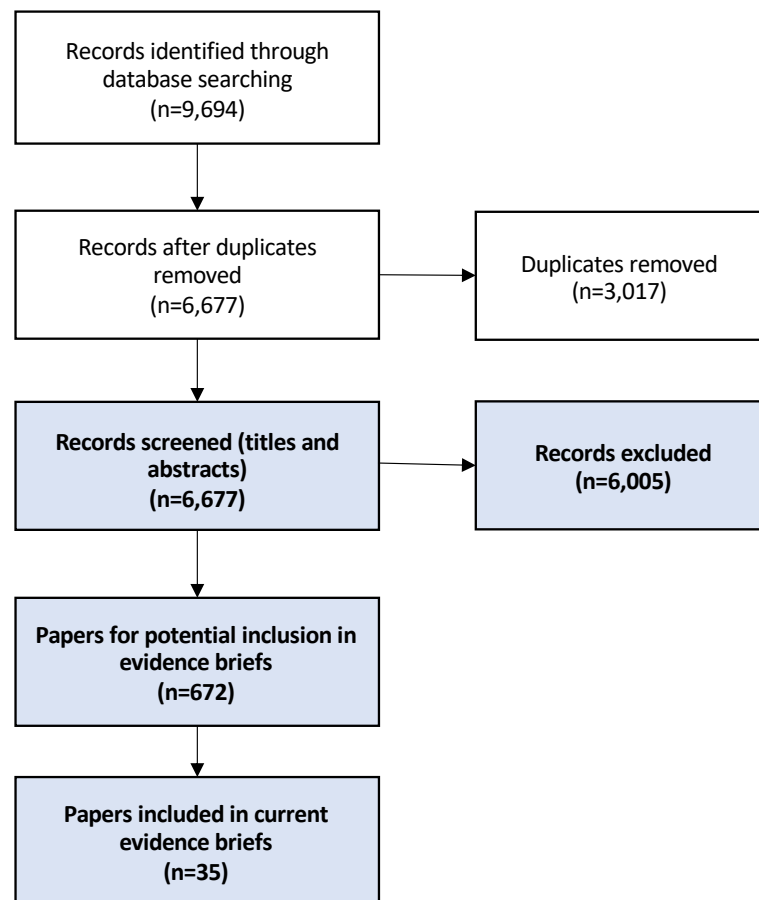
	Context	Themes converted to statements or symptoms	Underlying problem of the statement or symptoms
1	NICU stay	Families during NICU stay, cannot expect how a day in the life of a parent looks like after going home	Inconsistent or inadequate understanding of parent roles in home prevents them from being prepared to deal with stress
2	NICU stay	Families during NICU stay do not know what the commonly expected IMC care problems are and how to respond e.g. When, and Whom to call, or “what if this happens”?	Inadequate preparedness and hesitation prevent timely access to an appropriate level of care and resulting suboptimal outcomes
3	Post NICU discharge encounters	NICU discharge summary or other essential reports are not accessible by parents readily during subsequent clinic or hospital visits	Lack of timely access to patient details (history, meds and preferences) negatively affects informational continuity of care
4	NICU stay	Most families are unaware about availability of psychosocial support under one umbrella of family health teams in the community	Lack of awareness prevents family to seek adequate, timely help and promotes suffering in silence
5	NICU stay	Most families at transition from acute care mixed acuity pods in NICU to Neonatal complex care team are in denial and have difficulty in accepting the situation	Lack of acceptance is a barrier (i)in effective transition from curative to rehabilitative care, (ii) parental involvement in learning technical, coping and navigational skills
6	First 3 months post NICU discharge	100% of parents report challenges in identifying whom to call for help for various issues especially during first 3 months of going home e.g. trouble shooting device, supplies, emotional resilience, self-care, medications, appointments, illness, appointments, etc.	Lack of clarity on whom to contact or their inability to connect with a nurse liaison at all times, potentially aggravates parental stress, and potential delay in recognising patient illness
7	NICU and Post NICU	Most families lack information or have partial information on community-based resources to care for IMC. e.g. hours of home nursing support, hours of	Lack of information, variation in community supports and allocation prevent effective

		respite, disability Tax Benefit, etc. This problem is further compounded by high variability in services offered in a particular health authority, decision on allocation, and on the care providers who connect families with community resources..	rehabilitation and creates mistrust and negative family experience
8	NICU stay or during rehospitalizations	During NICU stay or any rehospitalization episode, a serious illness conversation opportunity using a structured template does not occur on most occasions	Every deterioration episode is an opportunity to re-elicite goals of care and tailor care according to parents' values and preferences. Lack of serious illness conversation might cause under or over medicalization of care.
9	Rehospitalization	During every rehospitalization episode or a deterioration, a review for modifiable factors and mitigation strategy to prevent reoccurrence is not a standard practice	Failure to implement mitigation strategies result in frequent rehospitalizations and negative family experience
10	NICU stay and post NICU encounters	Before discharge from the hospital care providers do not consistently check parents understanding of what health care system can do and what it cannot do.	Lack of understanding of the boundaries and limitations of health care system result in undue expectations, frustration and disappointments among parents
11	NICU stay	Most NICU discharge summaries do not include details on what kind of support are available for primary care providers in the community	Primary care providers hesitate to accept these patients as they have to spend a lot of time coordinating the services in the community. The system is inefficient and taxing for community care providers.
12	Emergency visit	When an infant with medical complexity arrives in the emergency room, but not attached to the pediatric complex care team, emergency room care providers cannot readily gather infant/family care needs and preferences.	Lack of infant/family care needs and preferences result in delays, inconsistency in care, and latent safety threats
13	At home, acute deterioration	When 911 is called, a patient is taken to the geographically closest hospital rather than the right hospital where IMC/ families care needs could be met	The closest hospital care providers' often unfamiliar with patient/ care needs, hesitate

			to contact specialists at BCCH and this delays access to right care
14	During NICU and Post NICU discharge encounters	Parents find care providers do not have access to or have not reviewed medical records. Thus, families repeatedly have to communicate medical information.	Lack of medic alert decreases informational continuity and confidence in care provider, while increasing storytelling fatigue and latent safety threats associated with inaccurate information
15	During NICU and Post NICU discharge encounters	Most families are unaware about community services' eligibility requirements and changing eligibility status overtime at discharge from the hospital or after discharge, when a new medical diagnosis is made.	Not having a reliable way of knowing whether they are eligible for community services prevents or delays access to scarce community services.
16	At home	Families availing home nursing support face adjustment challenges resulting from changing personnel, different routines, and variation in support received	Variation in nursing support services negatively impact relational continuity of care

**Figure S1: Details of rapid review**

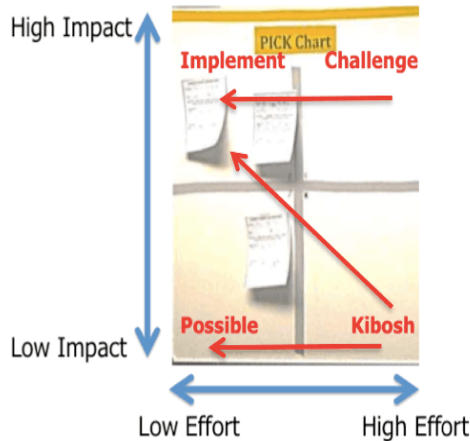
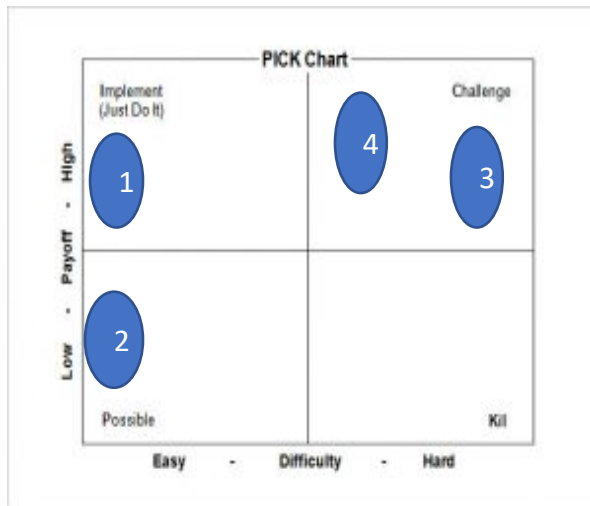
- Rapid review of the literature
- Multiple databases searched to ensure comprehensiveness
  - MEDLINE
  - Embase
  - CINAHL
  - Web of Science
- Flexible search strategies to ensure literature found for all issues
  - Broader search of NICU discharge
  - 9 targeted searches with each issue and complex populations
- First screening to exclude off-topic papers and non-complex populations
- Criteria for selection for evidence briefs
  - Study population
    - NICU infants with medical complexity
    - Other NICU infants
    - Other complex populations
  - Level of evidence
    - Systematic / scoping reviews
    - RCTs
    - Other studies
    - Commentaries, narrative reviews, editorials
  - Prioritize articles with applicable / plausible interventions



**Table S2a: Evidence brief on neonatal to pediatric complex care team transition**

Problem statement	Impact of not addressing this issue (Patient/family, care providers, hospital, system)	Validation of problem & its impacts (Stakeholder, Family, Evidence briefs validation)	EVIDENCE BRIEF DETAILS: Neonatal to Pediatric complex care transition							PICK Chart & Key implementation considerations
			Research Purpose/aim	Design	Description of intervention	Outcome measures	Results/Findings	Limitations	Policy or Programmatic options	
50% or more neonates with CMNs, though eligible for Pediatrics complex care team are not referred at discharge from NCCT	<p>Benefits of Peds CCT are denied (Inequity, lack of access)</p> <ul style="list-style-type: none"> <li>Ambulatory clinic services: Link to various Peds Dept services, Telephone support to community Pediatricians, Annual review, care planning &amp; anticipatory guidance</li> <li>Inpatient services: Consistent, coordinated, efficient, patient and family centred safe care by a limited number of consistent care providers (co-management)</li> <li>Perception of neonatal team not</li> </ul>	Stakeholder meetings +, Family meetings +, Evidence briefs +	5 studies Evaluate the impact of a tertiary care complex program on kids, families, & health care systems	Prospective or retrospective cohort studies with mixed qualitative and quantitative analysis	Care coordination by a complex care program (i)staffed by a minimum of nurse, or nurse practitioner and a Pediatrician (ii)Coordinator being a primary advocate and contact person, (iii) Liaise with primary care practitioner and community services, (iv)Create and maintain comprehensive care plan for patients, (v) Schedule ambulatory clinic visits and consult when the kids get admitted to the hospital	Resource utilization, Parent experience, Parent stress, Process of care, unmet needs of parents,	<p><b>Patient/Family</b></p> <p>↑ health related quality of life, satisfaction, continuity of care, family centredness of care, measures of process of care, out of pocket expenses, ↓ parent need for care coordination, help with school care coordination, mean number of unmet needs</p> <p><b>Care providers</b></p> <p>Coordinator is helpful and in enhancing work life, engagement of key workers is essential</p> <p><b>Hospital</b></p> <p>↓ hospitalization, hospital days, emergency visits</p> <p>↑ scheduled outpatient visits</p> <p>↓ annual inpatient and emergency visit costs</p> <p>↑ outpatient costs</p> <p>28% reduction in per-member-per-month healthcare costs and reduced</p>	Recall bias, single centre, no controls or before and after design No community data Small sample size Variable referral patterns	<ol style="list-style-type: none"> <li><b>PROVIDER &amp; HOSPITAL LEVEL</b> At discharge from NICU, refer neonates with CMNs to Pediatrics complex care team who meet the Pediatrics complex care team referral criteria at discharge (1-9).</li> <li><b>PROVIDER LEVEL</b> Maintain a list of patients who are eligible but couldn't be accepted by Peds complex care team (waitlist)</li> <li><b>HOSPITAL LEVEL</b> Strategic approach to build skillset among all professional</li> </ol>	

	<p>advocating enough at the crucial point of transition</p> <ul style="list-style-type: none"> <li>Hospital vision is not met "Province-wide solutions for excellence in health, every time"</li> </ul>						<p>hospitalizations/ED visits (Coller) 2-5 days median hospitalization days</p>		<p>s in taking care of this population in the community; training curriculum, mandatory rotations in complex care team, training workshops for existing practitioners (Breneol 2017)</p> <p>4. <b><u>PROVINCIAL LEVEL</u></b> Billing codes based on complexity to recruit/retain professionals</p>
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### Deliberation triggers

1. Feasibility of implementing in next 12 months
2. Potential barriers influencing successful implementation
3. Creatively shift things from right to left, finding ideas that are easier to implement
4. Other options

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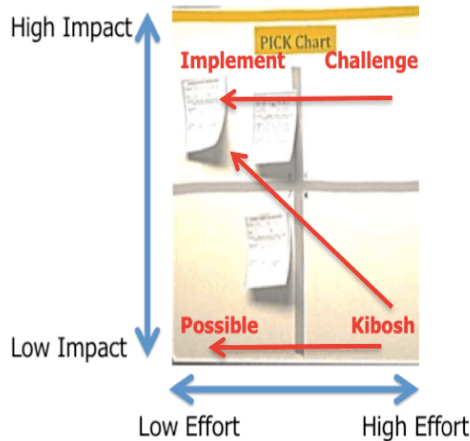
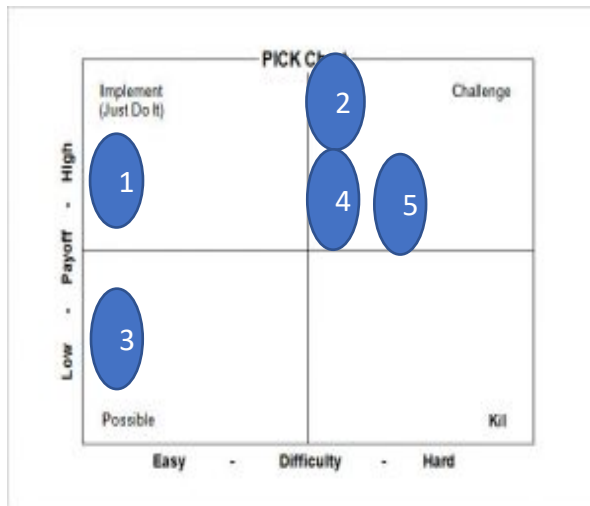
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Table S2b: Evidence brief on Mental health issues among caregivers of infants with medical complexity

Problem statement	Impact of not addressing this issue (Patient/family, care providers, hospital, system)	Validation of problem & its impacts (Stakeholder, Family, Evidence briefs validation)	EVIDENCE BRIEF DETAILS: Mental Health issues among caregivers							PICK Chart & Key implementation considerations
			Research Purpose/aim	Design	Description of intervention	Outcome measures	Results/Findings	Limitations	Policy or Programmatic options	
<p>Access to relevant mental health support is not routinely initiated during NICU stay or during post discharge period (low barrier access)</p> <p>Parents feel unprepared not knowing: what to expect at home"</p> <p>Medical psychology services are available for parents with kids in BC Children'</p>	<p>Parents struggle to manage their child's health and neglect their own emotion and self-care contributing to poorer health outcomes for the family</p> <p>The spectrum of mental health issues reported in literature continue to be pervasive Disruption to family life, reactions and feeling of loss, guilt, fear and shame, sleep deprivation, social isolation, chronic distress, withdrawal from paid work, higher</p>	S+, F+, E+	<p>Describe the interventions and their effectiveness aimed at improving wellbeing and parenting skills for parents of children with special care needs</p> <p>Included interventions that could be used in community by existing personnel with training. Excluded those psychiatrist or psychologist delivered psychotherapy sessions.</p>	<p>65 studies- scoping review RCT, Observational, qualitative, mixed method studies</p>	<p>Under 5 categories  <b>1.Parenting Programs</b>                      e.g. Triple P program  <b>2.Targeted parent behavioral change</b>                      e.g. Acceptance and commitment therapy (ACT), Cognitive behavioral therapy (CBT), Problem solving skills therapy, coping skills, multifamily treatment  <b>3.Peer support development</b>                      In-person, online, email list serves, telephone, one-one peer support</p>	<p>Anxiety, Stress, Depression, Coping, Family functioning, Quality of life, Mood, Post-traumatic stress, psychological flexibility, wellbeing, adjustment, family conflict, perceived social support, problem solving skills.</p>	<p><b>Evidence of effectiveness</b>                      Half of the studies were in favor of using interventions , 42% had mixed results                      Having a repertoire of intervention options, selecting ones according to the context and family needs, is a key success factor</p> <p>Theory based interventions were associated with positive results e.g. Cognitive behavioral therapy, Triple P program</p> <p><b>Evidence of harm</b>                      None reported serious harm</p>	<p>Lack of consistency in subject selection, interventions, tools, quality of evidence and measures, across child's illness trajectory                      Lack of parental involvement and input on identifying measures that are meaningful to parents</p>	<ol style="list-style-type: none"> <li>1. Offer every family an opportunity to explore a list of interventions available for improving parental wellbeing on admission to lady bug pod offered by discharge coordinator, social worker or medical Psychologist or a counsellor.</li> <li>2. Routine medical psychologist consultation, therapeutic conversation and creating a parental wellness care plan/pathway in collaboration with parents On admission to ladybug pod [BCCH psychologist, Reproductive mental health program, or other]</li> <li>3. Share low cost community mental health support (e.g. <a href="https://willowtreecounseling.ca/wp-content/themes/willowtree/reduced-cost-counselling.pdf">https://willowtreecounseling.ca/wp-content/themes/willowtree/reduced-cost-counselling.pdf</a> (Recommend but not endorse)</li> <li>4. Provide a booklet of parent stories along with the discharge booklet</li> <li>5. Others Group sessions on Mindfulness, relaxation, narrative treatment, therapeutic conversations,</li> </ol>	

<p>s hospital, but not in NICU (BCWH)</p>	<p>risk of poverty and intensifying cycle of caregiver stress, mental health problems like anxiety, depression, post-traumatic stress, mood disorders</p> <p><b>SYSTEM</b>  <b>High cost of care, poor family experience arising out of unmet needs, secondary victim</b></p>				<p><b>4. Preparation and support for hospital admission and discharge</b>  <b>5. Others</b>  e.g. Mindfulness , relaxation, narrative treatment, therapeutic conversations, wish granting, communication skills, financial counselling</p>	<p>to participants  Common themes included lack of time, incompatible peer relationships, repetitive group discussions, too early exposure and parents being not ready, didn't fulfil expectations, disappointment about size and composition of support groups, poor attendance, no meaningful connection, high dropout rates, feeling overwhelmed after enrolling in an intervention, negative feelings on exposure to others' problems, feeling of being left alone and "cut off" after the intervention</p>	<p>wish granting, communication skills, financial counselling</p>	
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**Deliberation triggers**

- 5. Feasibility of implementing in next 12 months
- 6. Potential barriers influencing successful implementation
- 7. Creatively shift things from right to left, finding ideas that are easier to implement
- 8. Other options

**References**

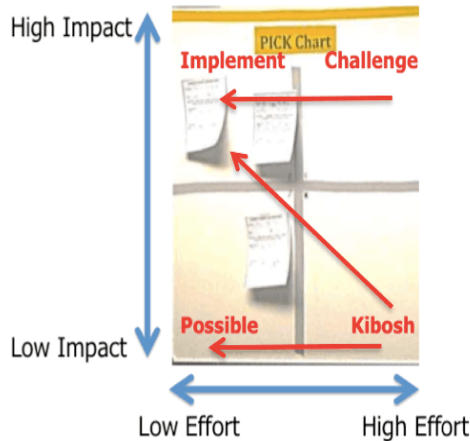
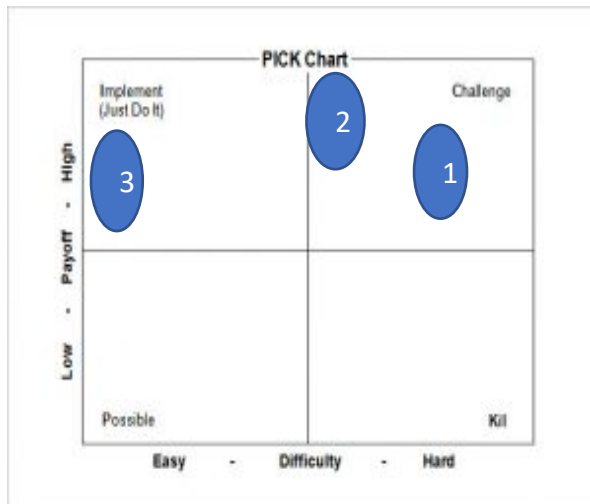
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Table S2c: Evidence briefs on peer support and self-help groups for caregivers of infants with medical complexity

Problem statement	Impact of not addressing this issue (Patient/family, care providers, hospital, system)	Validation of problem & its impacts (Stakeholder, Family, Evidence briefs validation)	EVIDENCE BRIEF DETAILS: Peer support and self help							PICK Chart & Key implementation considerations
			Research Purpose/aim	Design	Description of intervention	Outcome measures	Results/Finding s	Limitations	Policy or Programmatic options	
<p>There is no peer support system for parents of infants with complex medical needs.</p> <p><b>Key terms</b> Social support constitutes a multidimensional concept comprising, "relational provisions in the form of attachment, social integration, opportunity for nurturance, reassurance of worth, sense of reliable alliance, and the availability of guidance". Social support offers substantial promise by buffering</p>	<p>Parents continue to feel isolated, experience support deficit, lack of understanding by others.</p>	<p>S+, F+, E+</p>	<p>Is meaningful peer support that can accommodate parental limits of time, mobility and energy for parents caring for children with special care needs beneficial?</p>	<p>2 studies <i>Prospective observational mixed method</i></p> <p>Online peer support group sessions (Parents with kids having Asthma &amp; allergy</p>	<p><b>Various types, interventions range from 3m-18months</b> <b>Except one target kids age was between 2-11y</b></p> <p><b>Dyadic (one-to-one) peer matching,</b> Peer support=empathetic listening, providing encouragement, and sharing personal experience, Peer intervention was jointly developed, pertinent issues, concerns and interests were discussed as mutually desired, augmented current health care services, once a week (telephone communication) for 4 months, single tertiary care hospital</p>	<p>social support, coping and meaning of illness, anxiety score, perceived confidence, family activities &amp; relationships, long-term negative risk of caregiving, day-to-day quality of life</p>	<p><b>Patient/individual level Evidence of benefits</b> Sense of feeling understood, decreased isolation, and enhanced learning</p> <p>Replaces self-defeating thoughts and actions with wellness promoting activities, social support, problem solving, quality of life</p> <p>Parents desire was flexibility of a peer interaction, permitting in-home access. Developing a multi-pronged and less-prescriptive approach to peer support to facilitate families being able to connect with one</p>	<p>Contrived relationships, lack of motivation and incompatibility, limited outcome measures</p> <p>Utility of peer support groups not moderated by a health care professional is unknown</p> <p>Parent led online peer support group</p>	<ol style="list-style-type: none"> <li>1. Parent mentors / parent-parent buddy system led by family advisors or Patient experience team at C&amp;W</li> <li>2. Create and share the directory of participating consented experienced parents with new parents</li> <li>3. Access to a Self-help environment (Share information but not endorse it) e.g. www.mynicufamily.com</li> </ol>	

<p><i>the strains associated with family caregiving</i></p> <p><b>Self-help and Peer support group difference</b> A self-help group may be facilitated or co-facilitated by someone with the concern and is more independent from the formal service system. In contrast, a paid person working in an agency usually facilitates a peer support group.</p>				<p>Self-help &amp; Peer support interventions (Child and Youth mental health)</p>	<p><b>Online peer support group co-led by a trained experienced parent and health professional,</b> with duration and frequency guided by parents' preferences</p> <p><b>telephone contacts, face-to-face visits, and special family events</b></p>		<p>another in the ways that work best for them</p> <p><u><b>Evidence of harms</b></u>-None</p> <p>Intense and relentless nature of parental caregiving requirements precluded parents' availability, on self-care, and wellbeing intervention participation</p> <p>Difficult to identifying matching parents</p> <p><u><b>System level</b></u> Systems managers and leaders don't give self-help/peer support the recognition it deserves as a vehicle towards achieving recovery-centred mental health</p>			
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### Deliberation triggers

9. Feasibility of implementing in next 12 months
10. Potential barriers influencing successful implementation
11. Creatively shift things from right to left, finding ideas that are easier to implement
12. Other options

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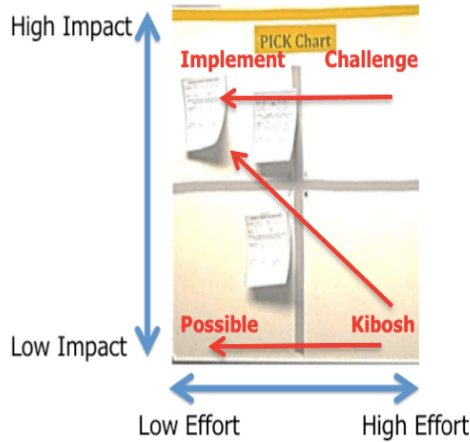
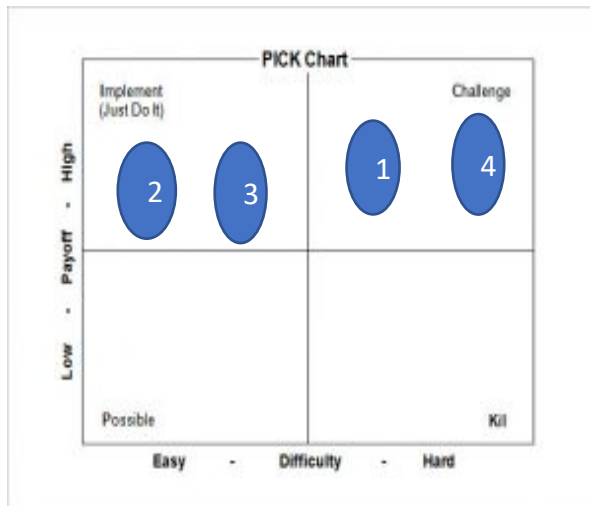
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Table S2d: Evidence brief on care coordination in the community in association with children hospitals

Problem statement	Impact of not addressing this issue (Patient/family care providers, hospital, system)	Validation of problem & its impacts (Stakeholder, Family, Evidence briefs validation)	EVIDENCE BRIEF DETAILS-CARE COORDINATION IN COMMUNITY						PICK Chart & Key implementation considerations
			Research Purpose/aim	Design	Description of intervention	Outcome measures	Results/Finding s	Limitations	
Majority of care providers caring for infants with complex medical needs do not have (i) ready access to information on geographic location-based resources, networks for ongoing care coordination, (ii) formal interprofessional training in care-coordination	Lack of awareness precludes optimal referral, care coordination and access to effective health care services Delays and frustration  <b>System</b> High cost of care secondary to inefficiency	S+, F+, E+	What are the non-hospital components of care that needs care coordination ? Home care, community-based supports, coordination with subspecialists and family physicians, social supports (poverty, housing, education, support network, ability to work), Family and caregiver health  What are the Geography based challenges? Travel, care availability and access in rural area  What interventions		Mostly Commentaries  Creation of interdisciplinary teams, System navigator, Interprofessional training curriculum, care maps created by family, dynamic care plans  Virtual clinics through telehealth, outreach clinics  Billing codes that support family health teams, individual care providers			What do primary care providers need to improve care coordination services?	<ol style="list-style-type: none"> <li>1. Introduce a system navigator or expand existing coordinator role in pediatrics complex care team</li> <li>2. Create a geographic location-based resource map and list (Name, phone number, location, referral forms) for use by all care providers. E.g. Pediatricians, Family Physicians, Child development centres, specialized services, financial funding resources, subspecialist services</li> </ol>



			have been shown to improve care coordination ?						<p>3. Care coordination competency development by introducing care coordination workshops for practicing care providers. Provide resources, templates and toolkits</p> <p>4. Introduce care coordination curriculum with resources, templates and toolkits in training programs</p>	
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**Deliberation triggers**

- 13. Feasibility of implementing in next 12 months
- 14. Potential barriers influencing successful implementation
- 15. Creatively shift things from right to left, finding ideas that are easier to implement
- 16. Other options

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