

Table 1a. Details of characteristics of studies, outcomes, and interventions

Study (Author year)	Beyene et.al. 2013 ²⁰	Braga et.al. 2005 ³³	Bruns et.al. 2015 ²⁶	Cady et.al. 2015 ²¹	Carcone et.al. 2015 ³⁰	Caskey et.al. 2019 ²⁷	Cohen et.al. 2023 ²⁵	Coller et.al. 2018 ²²	Farmer et.al. 2011 ²³	Frakking et.al. 2021 ²⁸	Gillette et.al. 1991 ³¹	Jessop et.al. 1994 ²⁴	Kolko et.al. 2020 ³²	Simon et.al. 2017 ²⁹
Setting	USA	Brazil	USA	USA	USA	USA	Canada	USA	USA	Australia	USA	USA	USA	USA
Participants (N): Age range (years)	445 0-19y	72 5-12y	93 6-17y	163 2-15y	146 10-17y	6259 0-25y	139 0-9y	147 0-8y	70 0-17y	81 0-16y	38 0-1y	174 0-11y	206 5-12y	331 0-18y
INT CON	148M, 81F 149M, 67F	20M, 18F 19M, 15F	26M, 21F 27M, 19F	INT 1: 33M, 21F INT 2: 26M, 28F CON: 31M, 24F	32M, 42F 32M, 40F	1670M, 1456F 1456M, 1663F	45M, 32F 38M, 24F	43M, 34F 44M, 26F	23M, 13F 23M, 11F	28M, 14F 27M, 12F	15M, 4F 15M, 4F	NR NR	72M, 28F 70M, 36F	89M, 70F 79M, 55F
Chronic and complex condition(s) included in study	Multiple disorders: Cerebral palsy, Brain injury, developmental difficulties, Down syndrome, Spina bifida, Autism, Physical disability, Developmental disability, Pervasive developmental disorder, or a chronic medical condition	Traumatic brain injury (TBI)	Multiple disorders: mental, behavioural or emotional disorder	Multiple disorders: Single complex chronic condition, Multiple complex chronic conditions, Neurologic impairment, Need for life-sustaining technology assistance	Type 1 diabetes (T1D) and Type 2 diabetes (T2D)	Multiple disorders: Asthma, diabetes (type 1 or 2), prematurity, seizure disorder, or sickle cell disease	Multiple disorders Children with Medical complexity (CMC)	Multiple disorders Children with Medical complexity (CMC)	Multiple disorders: Mental disorders, Disease of nervous system/sense organs; Congenital anomalies, Perinatal conditions, Organ specific conditions	Multiple disorders: Attention-deficit/hyperactivity Disorder (ADHD), autism spectrum disorder, global developmental delay, oppositional defiant disorder, adjustment disorder, and generalized anxiety disorder	Medically Fragile Infants	Multiple disorders: Children had >100 different conditions, including sickle cell anaemia, asthma, diabetes, leukemia, juvenile rheumatoid arthritis, and congenital conditions such as meningomyelocoele and biliary atresia	Behavior problems with comorbid ADHD	Multiple disorders Children with Medical complexity (CMC)
Risk of bias (ROB) score	Moderate	High	High	Low	High	Low	Low	Moderate	Moderate	Low	High	Moderate	Moderate	Moderate


OUTCOMES														
1. Child health and functioning														
1.1 Physical (motor) functioning		↑ (p=0.018) ^a									↔ (p=0.5) ^b			
GRADE score		Low									Low			
1.2 Cognitive functioning		↑ (p=0.05) ^c									↔ (p=0.24) ^d			
GRADE score		Very low									Very low			
1.3 Behavioural functioning			↔ (p=.078) ^e											
GRADE score			Very low											
1.4 Youth functioning			↔ (p=0.710) ^f											
GRADE score			Very low											
1.5 Child's functional status								↔ (p=0.06) ^{g1}					↔ (T1 & T2; p>0.05) ^{g2}	
GRADE score								Very low					Very low	

1.6 Physical pain							↔ (T1 - p = 0.86) ^h (T2 - p = 0.87) Very low							
2. Parent/carer perception on child health & family wellbeing														
2.1 Quality of Life	↔ (p = 0.32) ⁱ						↔ (T1- p=0.03) ^{fl} (T2- p=0.28) Very low		↔ (T1-p=0.06) ⁱ (T2-p=0.04) Very low			↑ (T1-p=0.03) ⁱ (T2-p=0.02) Very low		
2.2 Family functioning	↔ (p=0.97) ⁱ							↔ (p=0.69) ^k	↔ (T1-p=0.09) ⁱ (T2- p=0.004) Very low					
2.3 Parental distress	↔ (p=0.09) ^m						↔ (T1-p =0.03) ⁿ (T2- p=0.14) Very low	↔ (p=0.07) ^o	↔ (T1 & T2; p>0.05) ^p					
GRADE score	Very low						Very low	Very low	Very low					

2.4 Social support	↔ (p=0.86) ^q								↔ (p=0.75) ^r					
GRADE score	Very low								Very low					
2.5 Satisfaction with life							↔ (T1- p=0.04) ^s (T2- p=0.29)							
GRADE score							Very low							
2.6 Fatigue							↔ (T1-p =0.05) ^t (T2-p =0.09)							
GRADE score							Very low							
2.7 Sleep disturbance							↔ (T1- p=0.08) ^u (T2- p=0.003)							
GRADE score							Very low							
2.8 Physical health							↔ (T1- p=0.16) ^v (T2- p=0.01)							
GRADE score							Very low							
3. Healthcare use & spend						↔ (p=0.85) ^w	↔ (T1- p=0.82) ^w (T2-	↑ (p=0.04) ^w						↓ (T1 & T2; p>0.05) ^w
Hospitalization														

<i>Total charges</i>						(p=0.99) ^x	p=0.73) (T1- p=0.90) ^x (T2- p=0.01)	(p=0.02) ^x						(T1-p=0.09) ^x (T2-p=0.01) ^x
<i>GRADE score</i>						<i>Very low</i>	<i>Very low</i>	<i>Very low</i>						<i>Very low</i>
4. Care coordination	NR	NR	NR	↑ (p<0.05) ^y	↑ (p<0.05) ^z		↔ HCP ^s (T1- p=0.44), (T2- p=0.55)	NR	↔ (T1- p=0.058) ^e		↑ (p<0.001) ^s	↑ (p<0.05) ^e		↑ (T1-p=0.05) (T2-p=0.004) ^g
<i>GRADE score</i>				<i>Very low</i>	<i>Very low</i>		HCP&F ^x (T1- p=0.08) (T2- p=0.46)		<i>Very low</i>		<i>Very low</i>	<i>Very low</i>		<i>Very low</i>

INTERVENTION														
Description of integrated care/care-coordination	Children's Treatment Network: an integrative health team together with family members develop a tailored single plan of care for the child, through a service coordinator .	Indirect, family-supported treatment (IFS): to provide families the skills to deliver home based care through 2 case managers with appropriate specializations to train families and acting as service navigators .	Wraparound service of individualized, team-based holistic care planning through wraparound facilitators acting as service navigators .	A single clinic-based Advanced Practice Registered Nurse (APRN) care coordinator	Multisystemic Therapy (MST): an intensive, home and community-based family treatment (psychotherapy approach), delivered by a psychotherapist functioning as a care coordinator	CHECK (Coordinated Healthcare for Complex Kids): quality improvement project of comprehensive community-based care for children and young adults with care coordination delivered by community health workers .	Complex Care for Kids Ontario (CCKO): Assignment of a nurse practitioner-paediatrician dyad partnering with families in a structured complex care clinic to provide intensive care coordination and comprehensive plans of care.	Plans for Action and Care Transitions (PACT), delivered by multidisciplinary team, created by a medical home physician or nurse practitioner .	Family Support Specialist (FSS): liaising with primary care, specialty health care providers and community service agencies to improve access to and coordination of comprehensive care.	Care coordination delivered by an Allied Health Liaison Officer (AHLO) .	CATCH: A Collaborative Kids Approach to the Transition from the Hospital to the Community and Home through a collaboration of family and the community professional .	Paediatric Home Care (PHC): a comprehensive outreach program in which a multidisciplinary team of paediatricians, paediatric nurse practitioners, and a social worker deliver comprehensive services, including case management.	Doctor Office Collaborative Care (DOCC) - Children and parents received on-site services in coordination with the Primary Care Providers (PCP) through care managers .	Seattle Children's Hospital (SCH) developed a comprehensive case management service (CCMS), a multidisciplinary, hospital-based service focused on improving care coordination for CMC.
WHO integrated care model category	Managed clinical network	Case-management	Care planning	Care planning	Care planning	Disease-specific integrated care model	Managed clinical network	Care planning	Care planning	Care planning	Case-management	Patient-centered medical home	Case-management	Case-management

Note:

 ←→ = no difference; ↑ = improvement in outcome; ↓ = decline in outcome.

- ^a = SARAH Scale of Motor Development: 12 months follow-up
- ^b = Bayley Psychomotor Index (PDI): 6 months follow-up
- ^c = Weschsler Intelligence Scale for Children (WISC-III): 12 months follow-up
- ^d = Bayley Mental Developmental Index (MDI): 6 months follow-up
- ^e = Strengths and Difficulties Questionnaire (SDQ): 6-12 months follow-up
- ^f = The Child and Adolescent Functional Assessment Scale (CAFAS): 6-12 months follow-up

^{g1&2} = Child functional status (FS II-R) follow-up: 6 months ^{g1} and 12-18 months ^{g2}

^h = A 10-cm linear visual analog scale at 12 months (T1) and 24 months (T2) after intervention

ⁱ = Pediatric Quality of Life Inventory (PedsQL): follow-up time points: 6, 12, 18 and 24 months.

^j = KIDSCREEN-52: follow-up at 12 months (T1) and 24 months (T2)

^j = Byles J, Byrne C, Boyle MH, Offord DR. Ontario Child Health Study: reliability and validity of the general functioning subscale of the McMaster Family Assessment Device. *Fam Process*. 1988;27(1):97–104.

^k = Bailey, D. B., & Simeonsson, R. J. (1988). Assessing needs of families with handicapped infants. *Journal of Special Education*, 22, 117–126.

^l = Family functioning subscale from the PedsQL Family Impact Module, version 2.0 at 12 months (T1) and 24 months (T2) after intervention

^m = Kessler RC, McGonagle KA, Zhao S, et al. Lifetime and 12-month prevalence of DSM-III-R psychiatric disorders in the United States: results from the National Comorbidity Survey. *Arch Gen Psychiatry*. 1994;51(1):8–19.

ⁿ = Patient Reported Outcomes Measurement Information System at 12 months (T1) and 24 months (T2) after intervention

^o = Beck Depression Inventory-II (BDI-II) : follow-up: range 6 to 24 months

^p = Subjective Units of Distress Scale (SUDS) at 6 months (T1) and 12 months (T2) after intervention

^q = Cutrona CE, Russell DW. The provisions of social relationships and adaptation to stress. *Advances in Personal Relationships*. 1987;1(1): 37–67.

^r = Dunst, C. J., Trivette, C. M., & Hamby, D. W. (1994). Measuring social support in families with young children with disabilities. In C. J. Dunst, C. M. Trivette, & A. J. Deal (Eds.), *Supporting and strengthening families: Methods, strategies, and practices*. Cambridge, MA: Brookline Books

^s = Satisfaction With Life Scale at 12 months (T1) and 24 months (T2) after intervention

^t = Patient Reported Outcomes Measurement Information System at 12 months (T1) and 24 months (T2) after intervention

^u = Patient Reported Outcomes Measurement Information System at 12 months (T1) and 24 months (T2) after intervention

^w = Rate of hospitalization

^x = Total patient charges

^y = Survey question US Department of Health and Human Services (USDHHS). (2008). Health Resources and Services Administration, Maternal and Child Health Bureau. National Survey of Children with Special Health Care Needs 2005–2006

^z = King S, King G, Rosenbaum P. Evaluating health service delivery to children with chronic conditions and their families: Development of a refined measure of processes of care (MPOC-20). *Children's Health Care*. 2004; 33:35–57.

⁵ = Coordination of care among health care professionals (HCP) using Family Experience With Care Coordination (FECC) scores (FECC 8a & 8b) at 12 months (T1) and 24 months (T2) after intervention

^y = Coordination of care among HCP & Family (F) using Family Experience With Care Coordination (FECC) scores (FECC 5) at 12 months (T1) and 24 months (T2) after intervention

^ε = Epstein, S. G., Taylor, A. B., Halberg, A. S., Gardner, J. D., Walker, D. K., & Crocker, A. C. (1998). *Shared responsibilities: Ensuring quality managed care for children with special health care needs*. Took kit: Version 1.0. Boston, MA: New England.

^{§&ε} = Structured interview questions

^φ = Consumer Assessment of Healthcare Providers and Systems (CAHPS) version 4.0 Child Health Plan Survey