# THE SPACES BETWEEN…

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## What's the Problem?

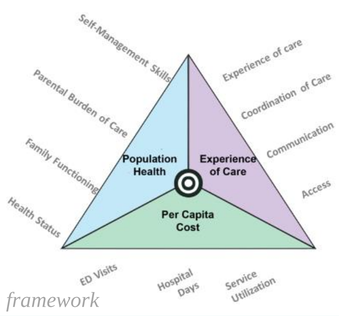
- Children with complex neurodevelopmental disorders (NDD) experience fragmented service delivery, resulting in:
  - poor outcomes
  - family functioning difficulties
  - reduced quality of life
  - inappropriate and inefficient health care utilization

## What Does Success Look Like?

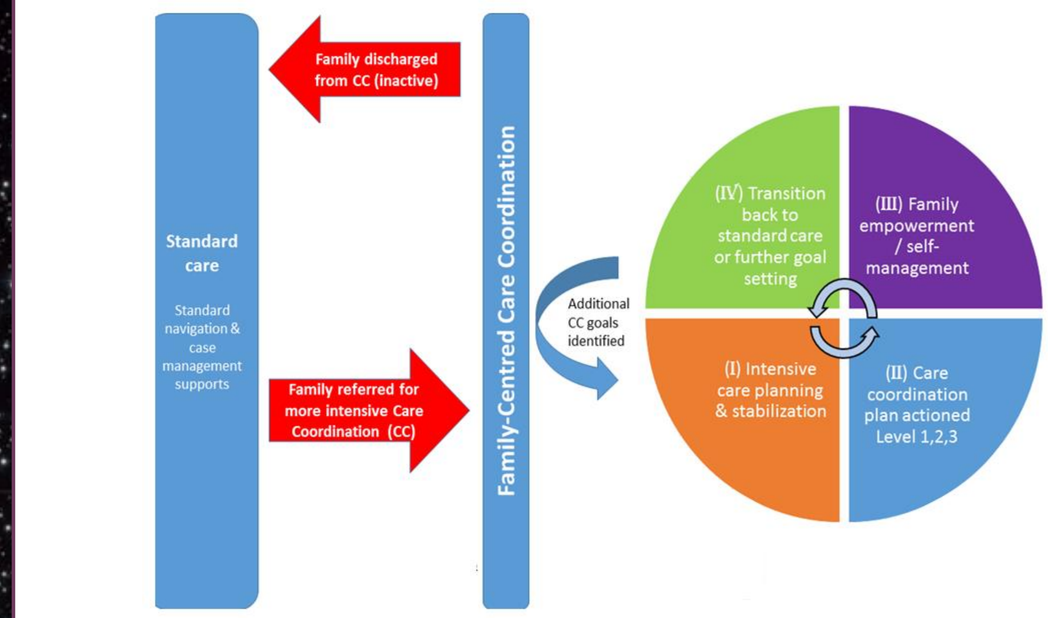
Enhanced family supports and innovative Care Coordination will improve service delivery for children with concurrent complex neurodevelopmental, neurological and mental health needs.

## How Will We Do This?

- Innovative Care Coordination designed and researched by Boston Children's Hospital
- Care Coordination is the set of activities which occurs in "the spaces between" visits, providers, hospital stays, agency contacts
- Pilot project to adapt and test this model in Alberta with a defined NDD complex needs population
- Outcomes measures:
  1) Patient/family/care team experience of care
  2) Coordinated delivery across services/ sectors. Examples: coordinated same-day specialty clinic visits, enhanced communication, joint care planning
  3) Change in health system performance. Examples: avoiding duplication of tests and/or Services, reduced hospitalizations/ ED visits




*Adapted from the IHI Triple Aim framework*




*The Family Liaison has been exceptional helping me access programs that I did not know existed… The Care Coordinator, in only one day, had all of my son's specialists call me and appointments were made that I had been waiting weeks for.*

*Our family has not yet benefitted wholly from the program, but now doors have been opened that I didn't even know existed and we are excited for the future!*

*Dayna, mom to Connor (14)*

*"As a mom of two special needs kids with multiple diagnoses, who see multiple clinics and Doctors, I wear many hats. Sometimes what gets lost in all the therapies, appointments, tests and paperwork is the joy of just being 'mom'.*

*Trying to organize communication between departments and Doctors is a huge job. I hope this will be available to other families in the future because I know there is a great need for it."*

*Christin, mom to Delaney (6)*

*"I have had to be a strong advocate for Julian for so long that it's hard to let go and ask for – or accept – help. It was the small things about Care Coordination that had a huge impact.*

*My stress was reduced considerably by having one person to talk to, someone I didn't have to repeat Julian's story to. And the Care Coordinator's focus was on solutions – how to make things better for me and for Julian."*

*Jeannine, mom to Julian (8)*

## How is the Project Helping Families?

**24** Families enrolled in the pilot

Reduced parental stress

Access to community resources

Timely information to families and the care team

Streamlined services

Improved communication across the care team

Develop an action plan with the care team

Attend appointments to provide real time knowledge sharing

Wait times for tests and services

## References

Antonelli R, McAllister J and Popp J (2009). Making care coordination a critical component of the pediatric health system: A multidisciplinary framework. May 2009 – supported by The Commonwealth Fund pub. no. 1277 www.commonwealthfund.org

Craig C., Eby D. and Whittington J. (2011). Care Coordination Model: Better Care at Lower Cost for People with Multiple Health and Social Needs. Institute for Healthcare Improvement - Innovation Series 2011. www.IHI.org

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