



Community Family Centred Care for Children with Complex Medical Needs and Developmental Disabilities

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Innovative Practice

- Integration of two teams (CSS and WRHA Pediatric Home Care) who both provide support for families parenting a child with complex medical and developmental needs.
- Blending of the Medical Model with Family Centred Practice
- Community based with strong linkages to medical and social systems
- Social Workers and Nurses are part of the same team. Families access both Social Work and Nursing support through one system.



Definitions

- Children with complex needs include those who require a network of health, education, social and other services in their homes and communities. The children in this population have a wide range of physical/medical and developmental needs. These children are often chronically ill, medically fragile and dependent on technology.



Considerations for determining eligibility for Pediatric Home Care

Pediatric Home Care

- Child would be at risk of remaining in or being admitted to hospital if service was not provided.
- Child would be at increased medical risk.
- Family would be at risk of breaking down and not able to care for the child.



CSS eligibility criteria

Provide support services for children with:

- A mental/developmental disability
- Physical disability with significant functional limitations
- Risk of developmental delay
- Autism Spectrum Disorder (ASD)
- Lifelong extreme complex medical needs

Integrated Children's Services

Home Care

- Services are centralized In Winnipeg
- Provincial responsibility Consultation and hospital Discharge planning

Integrated Children's Services (ICS)

- ## Children's Special Services (CSS) (Family Services and Housing Program)
- Provincial program delivered in 7 regions throughout Manitoba
 - In Winnipeg delivered through 7 community areas, SMD and ICS



The model of Service Delivery

- A Lead Service Coordinator (LSC) is assigned to work with the family to assist and support them in coordinating services for their family.
- The LSC is either a nurse from the WRHA or a Social Worker from CSS.
- The LSC has a “buddy” of the other discipline for each child on their caseload.
- The LSC can access services provided by both HC and CSS.
- A Family Centred Approach is used in service delivery.



Goals of the ICS Program

- To develop and provide flexible care options with the child and family that can respond to changing needs and are achievable within available resources.
- To facilitate discharge from the hospital
- To reduce frequency of hospital admissions
- To maximize the child's/family's potential and experience in the community.



Family Centred Approach in Assessment of Family Needs

- Family composition (e.g. #of children and ages, two parent/one parent)
- Family's perception of child's needs/issues
- Who will be the primary caregiver(s) within the family
- Child and/or family learning needs
- Ability to alter home environment
- Geographical barriers (e.g. distance from medical care facilities).
- Presence/inclusion of other relevant family, friends
- Family's past experience with medical and social systems
- Family's coping strategies and the burden of care (capacity).
- Family's goals and priorities.



Services are based on an assessment of each family's needs

- Respite (Nursing, non nursing)
- Provincial Outreach Therapy for Children
- Autism Outreach Services, FASD Outreach Services.
- Behavioural Services
- Consumables/supplies
- Some equipment/home and vehicle modifications
- Support staff for summer gap programming
- After school support for adolescents (employment support)
- Referrals for external supports such as Children with Disabilities (childcare), Manitoba Adolescent Treatment Centre for Psychiatry Services, Out of home respite, Family Care Program, etc.



Linkages

At times the children/families in the ICS program may require linkages to Public Health and Mental Health Programs, other Health Care and social Services such as

- Manitoba Home Nutrition Program
- Home IV antibiotic Program
- Palliative Care
- Provincial Ostomy Program
- Home Oxygen Program
- Home Ventilatory Assistive Device Service (HVADS)
- Visiting Nurse Program
- Wound Care Program
- Employment and Income Assistance
- Manitoba Childcare
- Supported Living Program and Vocational Rehabilitation Program (Transitional Planning at Age Of Majority)
- Child and Family Services



How is the ICS service delivery model different?

- The LSC becomes the family's primary contact for services from both programs and for links to other services or supports.
- The family has access to both nursing and social work support in the community. Needs vary depending on the medical stability of the child and the family's other competing needs. Joint meetings and/or home visits involving both disciplines can be arranged.
- Interface of the medical model (focus on medical stability for the child) and family centred practice model (which ensures that family is central in planning for the needs of their child and family) provides a balanced perspective for families and care providers.
- Service providers have greater confidence that the family are being addressed in a holistic manner



Transitions

Transitions are stressful events for families

Transition of settings

Transition of level of service provider

Transition to adult programs

Transition to palliative care



Transitions to Adult Programs

- Introduce eventuality of transition to adult programs early in care
- Age of transition may vary slightly. Families need to know which changes will occur at 18 years and what to expect if transition occurs earlier.
- Reassess respite, equipment and supply needs
- Explore the possible role of other programs (Self and Family managed Care, EIA, SMD, SLP)
- Family and young person may have ideas about independent living: contingency plans for placement if parents unable to provide care.



- Ensure that all partners in the child's care are aware of transfer
- Case conference with adult care coordinators
Formal transfer summaries from pediatric care providers to be sent to adult counterparts.
- Provide a list of all staff in adult programs with contact numbers to family.
- If possible arrange for a tour of adult facilities i.e.. Clinic setting, hosp unit.
- Include siblings if appropriate
- Medical stability must be considered.



Program Challenges

Demand exceeds capacity

- Managing an ongoing increase in volume and acuity
- Increasing number of children with complex needs

Differing Expectations:

- Families
- Multiple Service Providers (Human resource issues)
- Schools, childcare centres, recreation programs
- Location, location, location!

Ensuring linkages to community areas – As a centralized service the team provides services throughout Winnipeg. Need to know community resources and development for all areas of Winnipeg in order to link families to appropriate resources in their community.



Successes

- Children who previously would have to remain in a care facility are now being cared for at home, attending school and social outings.
- We are building expertise in finding “paths of service” to meet the needs of families parenting children with complex medical and developmental needs.
- Continuing to explore and develop “best practices” to better meet the needs of families. (e.g. Early Intervention Programs are developing expertise in approaches/intervention for children with complex needs.)

Case Study

WIS Integrated Model

- Our journey with one little boy





Prologue

- Little boy is a 5 year old with a life limiting metabolic disorder.
- He cannot walk , but he can hold your hand
- He cannot talk, but he can communicate, with smiles
- He has limited ability to move but loves to be played with, read to, chatted with.
- He loves his toys.
- Currently this little boy is in the care of CFS
- With the help of our integrated systems, he may come home
- Our story begins



Chapter 1

A Bumpy Start

- By one year of age he had been diagnosed with a life limiting genetic disorder
- He had been referred to and assessed by:
 - Genetics
 - Child Development clinic
 - Neurology
 - Acute care
 - Children's Special Services
 - Home Care
 - Rehabilitation Center for Children
 - MetabolicsEach system has its own plan, resources, goals and expectations



Chapter Chapter 2

Rocky Roads

- His condition was unstable for the first few years. Finally well enough for d/c home with support from multiple systems.
As mom was overwhelmed they moved in with Grandmother for a while.
Now it is time for them to move to their own place
Mom is going to have another baby
Each system continues to try to support little boy and mom
Independently
Lots of letters, emails, faxes, appointments
Assessments
Reassessments.



Chapter 3

A Place of Their Own

- Little boy and his mom settle into a large apartment. Helping them in this transition are:
 - Nursing Respite
 - POTC
 - CSS
 - Equipment/supply chains
 - EIAEach with their own plan and limited communication with each other.



Chapter 4

RED FLAGS

- New baby arrives. Healthy baby boy
Increasing maternal dissatisfaction with staff
Nursing reporting some concerns regarding the care of both children through nursing channels
CSS noting concerns through CSS channels
POTC concerns
Mom inconsistent historian. Increasing manipulation/misrepresentation of events.
Information conflicting, all systems escalating services
All systems reporting concerns for both children and the mom through separate channels.



Chapter 5

The Systems Connect

- As these events are developing in his life ICS team (WIS prototype) is developed Pediatric Home Care CC's/CSS Tech Dependant Service Co-ordinators co locate
Weekly review of new intakes and high profile clients commence
This family is immediately identified as a prime concern for both systems



Chapter 6

Bridging the Gap

- Team selects one service lead co-ordinator. Co-ordinator follows up with mother and other systems. Collects information, confirms concerns, organizes follow up with HC, CSS, EIA, Education system
Co-develop one integrated plan. Systems all aware of plan expectations, service plans, anticipated outcomes. Plan reviewed and amended with input from mother and grandmother.
Continued concern with care situation in the home, plan revisited with mother, with little successful outcome.

Lead Service co-ordinator contacts CFS



Chapter 7

The Bridge Collapses

- CFS joins the care team
Revisits parental concerns, systems concerns, and child care needs(for both children).
Provides input to the team who again, develops care plans with parent.
Revised specific goals, activities, care expectations are clarified and shared with staff.
Goals unmet, children are removed from the home



Chapter 8

FALL OUT

- Sadness and Anger from the parent
Lost of trust in care providers

Discouragement and Sadness in the team

Loss of confidence in effectiveness



Chapter 9

Picking up the Pieces

- Request from CFS to assist and focus on reintegrating family
Team reconvenes, Team now includes

Family
CSS
CFS
EIA
EDUCATION
ST.AMANT
CHILD ADVOCACY
HOMECARE
PEDIATRICIAN



Chapter 10

Questions

- How much support can be offered ?
What is the minimum standard of care?
Who should take the lead now ?
What will be done differently?
What/who is missing from this picture
to make it successful



Chapter 11

More Partners Needed

Need one more key member from the health care community

Adult Mental Health

At issue

not for our client

for the parent

may not be prepared to accept



EPILOGUE

- TO BE CONTINUED



Future Directions

ICS Team Membership

Under consideration to expand and include
CFS, Mental Health, Education

SCCY Initiative

Funding received to co-locate community
services in one central location and to
develop a central intake process for
access to assessment and interventions.