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

Presenters:

Maria Steeds, Team Leader – WRHA (Pediatric Home Care)

Irma Nadeau, Program Manager, Children's Special Services, Winnipeg

Co-managers for the Integrated Children's Services Team, Winnipeg

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.

- 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.

Background

- Children’s Special Services in Winnipeg and Pediatric Home Care have worked together co-operatively for many years to provide services for children with complex medical and developmental needs.
- Medical advances and legislative changes have created opportunities for children with special health care needs to participate in the community.
- Staff in community programs have become responsible for ensuring the safety and well being of these children while in their care.

URIS (Unified Referral and Intake System

- In 1995 URIS was created to provide a standard means of classifying the complexity of health care procedures and to establish the level of qualification required by staff to support each child.
- URIS is a joint strategy developed by the departments of Family Services, Health and Education and Training.
- URIS provides funding for schools to hire nurses and to community programs to provide for training of health care procedures.
- Medical Needs are classified into two categories:

Child requires a nurse to provide care when parents are not present. Care needs include:

- Ventilator care
- Tracheostomy care
- Nasogastric tube feeding
- Suctioning

Group A may also include a child who requires a complex regimen of care with clinical instability and unpredictability

Caregivers (non nursing) require Specialized training to carry out procedures such as:

- Gastrostomy tube feeding
- Intermittent catheterization
- Preset oxygen
- Medication administration
- Seizure management.

- As the number of children with complex needs who were eligible for CSS support increased in Winnipeg, a specialized case load was created. The specialized case managers worked closely with the Pediatric Home Care case co-coordinators at Children’s Hospital.

Health Coordination Project

Integrated Children's Services was one of the Health Coordination Projects (2004/05) undertaken by the WRHA as part of the Winnipeg Integrated Services Initiative (WISI).

WISI (now WIS – Winnipeg Integrated Services) is a major government initiative to integrate health and social services (WRHA and FSH) in Winnipeg

- Services delivered by FSH and WRHA are organized into community areas. (Co-location into community areas occurred in 2004)
- Some specialized services remain centralized (e.g. Integrated Children's Services)

Specialized Services for Children and Youth (SSCY)

At the same time that WIS was being implemented, a parallel initiative was developing. This initiative brought together a wide range of government and community agencies that provide services for children with special needs.

Integrated Children's Services (ICS)

- Work continued after the completion of the Health Coordination Project which wrapped up in 2005 and the Integrated Children's Services Team was born.
- Over the next year the team met on a weekly basis to learn each other's program and philosophy, to integrate forms and paperwork.
- Families were invited to forums at which the initiative was discussed.
- Team co-located in February 2006 (this involved moving two of the HC case coordinators from the hospital to the community. One HC case coordinator remains at the hospital as a liaison between the hospital and community team.
- Lead Service Coordinators were identified for each family.
- Each family was notified by letter of the introduction of ICS. An agency letter and information sheet was also sent to relevant agencies.
- Manitoba Home Nutrition Program has also been added to the team.

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 6 community areas, SMD and ICS

Community Areas
-Access River East/Transcona
-River Heights/Fort Garry
-St. James/Assiniboia
-St. Boniface/St. Vital
-Downtown/Point Douglas
-Seven Oaks/Inkster

- 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.

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 (URIS Group A, high needs Group B in combination with one of the above).

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.

- We meet families at different points along their journey…we need to know where they have come from to know how to help them “now”
- Providing resources is a very complex process
- The presence of caregivers in the home can be stressful for children and families.
- Families, children move through developmental stages and the care needs change over time.

How do we assess needs?

- Upon receipt of a consult (referral), information is obtained from the referral source (most often from Children's Hospital).
- Contact is made with the family to listen to their concerns and explore needs.
- Current information about the child is maintained with the inpatient unit through rounds and the family.
- Consult with other community programs if involved

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.

Principles of Family Centred Practice

- Parents are involved in all aspects of planning for the needs of their child.
- Recognition of family as the primary caregiver and source of information about their child.
- Recognition of family strengths
- Providing support to maintain and build on family strength.
- Relationship building/developing partnerships with families to meet family needs.
- Helping families to recognize and build informal support systems (extended family, friends, community organizations).
- Working collaboratively with other service providers/agencies in developing a support plan that meets the needs of the family.
- Sharing information with families so that they can make choices about how best to meet the needs of their family.
- Cultural sensitivity

Services may include:

- Service Coordination (case management)
- Early Intervention Services (Child Development Services, Provincial Outreach Therapy for Children (POTC), Autism Outreach Services, FASD Outreach Services).
- Respite (Nursing, non nursing)
- 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 (MATC) for Psychiatry Services, St. Amant respite, Family Care Program, etc.

Links to other WRHA Health Programs

- Manitoba Home Nutrition Program
- Home IV antibiotic Program
- Palliative Care
- Provincial Ostomy Program
- WRHA Specialty teams (e.g. wound care)
- Home Oxygen Program
- Home Ventilatory Assistive Device Service (HVADS)
- Visiting Nurse Program
- Wound Care Program

At various times the children/families in the ICS program may require linkages to any of the above as well as to Public Health and Mental Health Programs

Linkages to other FSH Programs

- Employment and Income Assistance
- Manitoba Childcare
- Supported Living Program and Vocational Rehabilitation Program (Transitional Planning at Age Of Majority)
- Child and Family Services

How do we determine what type and amount of service?

- What are the needs of the child/family in a 24 hour period?
- What specific procedures are required?
- How often does the child need intervention and how much can the family provide?
- Identify need for human resources
- In consultation with the family, determine the amount of service based on identified needs, program guidelines and resources available at the time of referral
- What does the family think they need?

Teaching Role in the hospital and in the community

- Hospital team does majority of teaching for families
- Hospital Coordinator ensures all teaching is complete.
- Family learns how to use/trouble shoot equipment
- Family learns how to maintain/clean equipment and how to order supplies.
- Ensure all care providers for the child have adequate training.

Discharge Planning Process

Role of Hospital based Home Care Case Coordinator

- Receives consults from the various sources, gathers information from hospital staff, reviews chart, speaks to family to assess needs and determine eligibility
- Follows child's progress throughout hospitalization
- Attends weekly rounds, discharge planning meetings
- Links to community team in anticipation of discharge from hospital
- Ensures resources are in place prior to discharge (supplies, equipment, human resources).

- Assessment is ongoing with adjustments in care plans or level of service provider, reflecting changing needs
- As medical needs stabilize, attention can be given to other areas of the child’s development as well as the well being of all family members
- Hospital admissions, clinic appointments can be monitored and care plans changed as needs change.

Goals for hospital discharge

- Optimize child's stability
- Ensure the plan of care is reasonable for the family to manage
- Ensure resources are set up and ready once the child is home
- "Normalize" the child's and family's experiences to the extent possible

- Reliable Service
- Continuity of Care
- Qualified Care Providers
- Responsiveness to Change in Need
- Respectful Service
- Flexibility and Informed Choice

Schools Child Care Facilities Expect

- Reliable Service
- Continuity of Care
- Qualified Care Providers
- Responsiveness to Change in Need

How is the ICS service delivery model different?

- The LSC becomes the family's primary contact for services from both programs as well as for links to other services and supports. The LSC has a direct link to other discipline for each child.
- The family has immediate access to both nursing and social work support in the community. Needs often go back and forth 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 easily arranged.
- Interface of the medical model (which focus on achieving medical stability for the child) and family centred practice model (which ensures that family is central in all planning that occurs regarding the needs of their child and family) provides a balanced perspective for families and care providers.
- Service providers have greater confidence that needs of the family are being addressed in more holistic manner
- There are few if any other jurisdictions that have adopted an integrated community based, family centred model of care for children with complex needs.

Community 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

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.

- Transitions are stressful events for families
- Transition of settings
- Transition of level of service provider
- Transition to adult programs

For families it can mean the loss of familiar:

- Caregivers
- Established hours of service
- Transportation plans
- Routine for other children

Transition Between Group A &B

- Needs may dictate a move from non-nursing to RN or vice versa
- Families may be very anxious, especially when moving from RN service
- Families and other health care team members must be involved in the process

Transition to Adult Program Process

- 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 ie.St.Amant, Self and Family managed Care, EIA,SMD
- Family and young person may have ideas about independent living: contingency plans for placement if parents unable to provide care.

Transition Considerations

- 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.

- 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.)

- The ICS Program continues to evolve as the needs of the children and families we serve change.
- We are committed to a process which allows for families/community to participate in current and future development.
- To be successful, communication and partnership with families and the community is key.