THE UNIVERSITY of York

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The Children's Community Nursing Development Tool

CCN practice for children with long-term, complex health care needs

An adaptation of the Medical Home Index (Pediatric)

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Where does this tool come from?

- The Medical Home Index (Pediatric) was developed by the Center for Medical Home Improvement in the USA (funded by the US Maternal and Child Health Bureau).

- Originally, it was a questionnaire designed to capture and quantify the activities of primary care practice for children and young people with chronic and complex health care needs.

- As part of the TraCCS project, we have adapted this questionnaire so that it is a development tool that reflects the organisation and delivery of Children's Community Nursing (CCN) services.

- We have developed this tool in partnership with NHS commissioners, managers and practitioners.

How to use this tool

- This tool has **six** domains representing areas of service organisation and delivery of CCN teams.
- Each domain has a number of items describing aspects of practice.
- Each *item* contains **four levels** of practice.
- This tool can be used to facilitate discussions about what your *current* team practice looks like, and how you would *like* it to look. For each item across the six domains, you can choose which level best describes your current practice, and which level you want it to be.
- There are various ways to use the tool (e.g. within teams, as peer assessment across teams), and it is up to you how much of the tool is used at any one time. For example, you may choose to focus on one particular domain that is of particular interest to your current practice, and revisit the remainder of the tool at another time.
- There is space under each item, and each item level, to write notes, for example, about team development plans, or if you think the item is currently irrelevant to your team's practice. It may help to think about, and make a note of, current barriers you face as a team to achieving the different levels of practice.
- This workbook is about practice for children with long-term, complex health care needs only.

Abbreviations:

CCNT: Children's Community Nursing Team

PPI: Patient & Public Involvement

CC: Care coordinator

Note about terminology

Throughout this tool, we use the term 'family' to refer to: children and young people with complex health care needs using your service, their families (e.g. parents, siblings), and for those children and young people in care, their carers.

DOMAIN 1: ORGANISATIONAL CAPACITY

1. The aims of the team

LEVEL 1
Nurses in the CCNT have individual ways of delivering care; their own education, experience and interests drive care quality.

LEVEL 2
Approaches to the care of children in the CCNT are child rather than family centred; the team's needs drive the implementation of care.

LEVEL 3
The CCNT uses a family-centred approach to care, they assess children and the needs of their families in accordance with its aims; feedback is solicited from families and influences the team's policies.

LEVEL 4
In addition to level 3, PPI groups are used to inform and develop family centred strategies, practices and policies; a written, visible mission statement reflects the CCNT's commitment to quality care for children and their families.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 1: ORGANISATIONAL CAPACITY

2. Communication & Access

LEVEL 1
Communication between the family and the CCNT occurs as a result of family inquiry; contacts with the family are for test result delivery or planned follow up by the service.

LEVEL 2
In addition to level 1, standardised communication methods are identified to the family by the CCNT.

LEVEL 3
The CCNT and family communicate at agreed upon intervals and both agree on “best time and way to contact me”; individual needs prompt weekend or other special appointments.

LEVEL 4
In addition to level 3, the CCNT’s activities encourage individual requests for flexible access; access and communication preferences are documented in the care plan and used by other team staff.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 1: ORGANISATIONAL CAPACITY

3. Access to care plan

LEVEL 1
A policy of access to care plans is not routinely discussed with families; plans are provided only upon request.

LEVEL 2
In addition to level 1, it is established among team staff that families can review their child's care plan (but this fact is not explicitly shared with families).

LEVEL 3
All families are informed that they have access to their child's care plan; staff facilitate access within 24-48 hours.

LEVEL 4
Families hold their child's care plan and staff make themselves available to answer questions. Team orientation and training materials include information about this.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 1: ORGANISATIONAL CAPACITY

4. Family feedback and audit

LEVEL 1

Family feedback to the CCNT occurs through external mechanisms, such as, satisfaction surveys issued by commissioners /managers; this information is not always shared with team staff.

LEVEL 2

Feedback from families is elicited sporadically by individual CCNT staff or by a suggestion box; this feedback is shared informally with other providers and staff.

LEVEL 3

Feedback from families regarding their perception of care is gathered through systematic methods; there is a process for staff to review this feedback and to begin problem solving.

LEVEL 4

In addition to level 3, an advisory process is in place with families, which helps to identify needs and implement creative solutions; there are tangible supports to enable families to participate in these activities. Solutions and changes are demonstrated to families.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 1: ORGANISATIONAL CAPACITY

5. Equality, diversity and inclusion

LEVEL 1

The CCNT attempts to overcome obstacles to diversity (e.g. communication needs) on a case by case basis when confronted with barriers to care.

LEVEL 2

In addition to level 1, resources and information are available for families of the most common diverse backgrounds and circumstances; others are assisted individually.

LEVEL 3

Materials are available and appropriate for a range of diverse backgrounds and circumstances; these materials are appropriate to the developmental level of the child/young adult.

LEVEL 4

In addition to level 3, family assessments include pertinent information about their diverse circumstances and needs to facilitate inclusion. This information is incorporated into care plans.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 1: ORGANISATIONAL CAPACITY

6. Staff education

LEVEL 1
For all CCNT staff, an orientation to internal team practices, procedures and policies is provided.

LEVEL 2
In addition to level 1, the NHS trust supports (paid time, tuition support) continuing education for all CCNT staff in the care of children with complex health care needs.

LEVEL 3
In addition to level 2, educational information on community-based resources for children with complex health care needs, including condition specific resource information, is available for all staff.

LEVEL 4
In addition to level 3, families are integrated into CCNT staff orientations and educational opportunities as teachers or 'family experts'; support for families to take this role is provided.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 2: LONG-TERM CONDITION MANAGEMENT

1. Care planning (Visits)

LEVEL 1

Home visits by the CCNT occur as a result of acute problems or well child schedules; the family determines follow up.

LEVEL 2

Planned visits occur with families to address long-term condition care; the CCNT determines appropriate visit intervals; follow up includes communication of tasks to staff and of test results to the family.

LEVEL 3

The CCNT and the family develop a care plan, which details visit schedules, communication strategies, and addresses home, school and community concerns. Other providers' practice is informed by this plan.

LEVEL 4

In addition to level 3, the CCNT uses condition protocols. A designated CC uses these tools and other standardised office procedures, which support children and families.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 2: LONG-TERM CONDITION MANAGEMENT

2. Continuity of information and communication across settings

LEVEL 1
Communication among the CCNT, specialists, therapists and school happens as needs arise for children.

LEVEL 2
A CCN makes requests and/or responds to requests from agencies or schools on behalf of children; all communication is documented.

LEVEL 3
Systematic practice activities foster communication among the CCNT, family, other providers. These methods are documented and may include information exchange forms or ad hoc meetings with external providers.

LEVEL 4
In addition to level 3, a method is used to convene the family and key professionals on behalf of children; specific issues are brought to this group and they all share and use a written plan of care.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 2: LONG-TERM CONDITION MANAGEMENT

3. Collaborative management between the CCNT and specialist

LEVEL 1

Specialty referrals occur in response to specific diagnostic and therapeutic needs; families are the main initiators of communication between specialists and their CCNT.

LEVEL 2

In addition to level 1, specialty referrals use phone, written and/or electronic communications; the CCNT waits for or relies upon the specialists to communicate back their recommendations.

LEVEL 3

The CCNT and family set goals for referrals and communicate these to specialists; together they clarify co-management roles, and determine how specialty feedback to the family and CCNT is expressed, used, and shared.

LEVEL 4

In addition to level 3, the family has the option of using the CCNT in a coordinating role; parents and the team manage the child's care using specialists for consultations and information (unless they prefer specialists to manage the majority of their child's care).

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 2: LONG-TERM CONDITION MANAGEMENT

4. Family support

LEVEL 1
Families are responsible for carrying out recommendations made to them by their CCN when they specifically ask for family support or help.

LEVEL 2
The CCNT responds to clinical needs; broader social and family needs are addressed and referrals to support services facilitated.

LEVEL 3
The CCNT actively takes into account the overall family impact when a child has a long-term condition by considering all family members in care; when families request it, staff will assist them to set up family support connections.

LEVEL 4
In addition to level 3, the CCNT facilitates family support activities; they have current knowledge of community support organisations and connect families to them.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 2: LONG TERM CONDITION MANAGEMENT

5. Identifying and anticipating need

LEVEL 1
Presentation of children with acute problems determines how needs are addressed.

LEVEL 2
The CCNT identifies specific needs of children; follow-up tasks are arranged for, or are assigned to families and/or available staff.

LEVEL 3
The child, family, and the CCNT review current child health status and anticipated problems or needs; they create/revise action plans and allocate responsibilities at least 2 times per year or at individualised intervals.

LEVEL 4
In addition to level 3, the CCNT and families create a written plan of care that is monitored at every visit; the office CC is available to the child and family to implement, update and evaluate the care plan.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 3: CARE COORDINATION

1. Care coordination/role definition

LEVEL 1

The family coordinates care across agencies without specific support; they integrate the CCNT's recommendations into their child's care.

LEVEL 2

A CCN or other team member engages in care coordination activities as needed; involvement with the family is variable.

LEVEL 3

Care coordination activities are based upon ongoing assessments of child and family needs; the CCNT partners with the family (and older child) to accomplish care coordination goals.

LEVEL 4

CCNT staff offer a set of care coordination activities, their level of involvement fluctuates according to family needs/wishes. A designated CC ensures the availability of these activities including written care plans with ongoing monitoring.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 3: CARE COORDINATION

2. Family involvement

LEVEL 1

The CCNT makes care recommendations and defines care coordination needs, the family carries these out.

LEVEL 2

Families and children are regularly asked what care supports they need; care decisions are made jointly with the CCNT.

LEVEL 3

In addition to level 2, families and children are given the option of having a CC in the CCNT.

LEVEL 4

In addition to level 3, children and families help describe care coordination activities; a CC develops and implements these, which are then evaluated by families and designated supervisors.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 3: CARE COORDINATION

3. Child & family education

LEVEL 1

Generic and specific reading materials and brochures are available from the CCNT upon request.

LEVEL 2

Basic relevant information is offered in one-on-one interactions with children and families; these encounters use supportive written leaflets with resource information.

LEVEL 3

General information and condition specific information, is offered by the CCNT in a standardized manner; information and advice anticipates potential issues and problems and refers families to other resources.

LEVEL 4

In addition to level 3, diverse materials and teaching methods are used to address individual learning styles and needs; information and advice is broad in scope and learning outcomes are examined.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 3: CARE COORDINATION

4. Resource information and referrals

LEVEL 1

Information about resource needs is gathered during initial assessment; the CCNT addresses immediate family information and resource needs.

LEVEL 2

Using a listing of local and national resources, covering physical, developmental, social and financial needs, the CCNT responds to family information requests.

LEVEL 3

Significant team knowledge about family and health resources is available; assessment of family needs leads to supported use of resources and information to solve specific problems.

LEVEL 4

In addition to level 3, CCNT staff work with families to solve resource problems; a designated CC provides follow up, researches additional information, seeks and provides feedback and assists with the family to integrate new information into the care plan.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 3: CARE COORDINATION

5. Advocacy

LEVEL 1
The CCN suggests that the family find support services and resources outside of the team when specific needs arise.

LEVEL 2
All families are routinely provided with basic information about parent groups, family support, and advocacy resources during scheduled home visits.

LEVEL 3
The team identifies resources to the family for support and advocacy, facilitates the connections and advocates on a family's behalf to solve specific problems.

LEVEL 4
In addition to level 3, the team advocates on behalf of children and their families as a population and helps to create opportunities for community forums, discussions or support groups which address specific concerns.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 4: COMMUNITY OUTREACH

1. Community needs assessment

LEVEL 1
The CCNT's awareness of the population of children with complex health care needs in their community is directly related to the number of children for whom they provide care.

LEVEL 2
The CCNT make an informal assessment of the needs of children with complex health care needs in their community, based on known issues and personal observations.

LEVEL 3
In addition to level 2, the CCNT raise their own questions about children with nursing needs in their community; they seek pertinent data and information from families and local sources and use data to inform practice care activities.

LEVEL 4
In addition to level 3, at least one CCN participates in a community-based public health need assessment, integrates results into practice policies, and shares conclusions with relevant agencies.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 4: COMMUNITY OUTREACH

2. Community outreach

LEVEL 1

When the family, school or another agency requests interactions with the CCNT on behalf of a child's community needs, the team responds, thereby establishing itself as a resource.

LEVEL 2

In addition to level 1, when another agency or school requests technical assistance or education from the CCNT a child, the team communicates, collaborates, and educates based upon availability and interest.

LEVEL 3

The CCNT initiates outreach to other agencies and schools that directly involved with the child; they advocate for improved community services and inter-organisational collaboration and communication.

LEVEL 4

In addition to level 3, the CCNT work with families to facilitate activities that raise community awareness of resource and support needs.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 5: DATA MANAGEMENT

1. Electronic data systems

LEVEL 1
CCNs retrieve information/data by individual record review; electronic data are available and retrievable from commissioners only.

LEVEL 2
Electronic recording of data is limited to scheduling; data are retrieved according to diagnostic code in relation to scheduling; these data are used to identify specific patient groupings.

LEVEL 3
An electronic data system includes identifiers and utilisation data about children on the caseload; these data are used for monitoring, tracking, and for indicating levels of care complexity.

LEVEL 4
In addition to level 3, an electronic data system is used to support the documentation of need, monitoring of clinical care, care plan and related coordination, and the determination of outcomes.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 5: DATA MANAGEMENT

2. Data use

LEVEL 1
CCNs retrieve patient data from paper records in response to outside agency requirements.

LEVEL 2
The CCNT retrieves data from paper records and electronic scheduling for the support of significant team changes.

LEVEL 3
Data are retrieved from electronic records to identify and quantify the caseload and to track selected health indicators & outcomes.

LEVEL 4
In addition to the previous, electronic data are produced and used to drive practice improvements and to measure *quality* against benchmarks.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 6: QUALITY IMPROVEMENT/CHANGE

1. Quality standards

LEVEL 1

Quality standards are imposed upon the CCNT by internal or external organisations.

LEVEL 2

In addition to level 2, an individual staff member participates on a committee for improving processes of care within the CCNT. This person communicates and promotes improvement goals to the whole team.

LEVEL 3

The CCNT has its own systematic quality improvement mechanism; regular team meetings are used for input and discussions on how to improve care and treatment.

LEVEL 4

In addition to level 3, the CCNT actively utilises quality improvement processes; staff and families are supported to participate in these activities; resulting quality standards are integrated into the operations of the CCNT.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

DOMAIN 6: QUALITY IMPROVEMENT/CHANGE

2. Quality activities

LEVEL 1

CCNs have completed courses or have had an adequate orientation to continuous quality improvement methods.

LEVEL 2

Commissioners identify gaps in the team and their practice, and set goals for improvements; team staff are identified to fix problems with limited participation in the process.

LEVEL 3

Periodic formal and informal quality improvement activities gather staff input about team improvement ideas and opportunities; efforts are made toward related changes and improvements.

LEVEL 4

In addition to level 3, the CCNT systematically learns about the needs of children on their caseload. The team and families design and implement team changes that address needs and gaps; they then study their outcomes and act accordingly.

GAPS IN PRACTICE:

ACTIONS:

PERSON TO LEAD:

******* END OF TOOL *******

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