THE WHAT, WHY, WHO AND HOW OF CARE COORDINATION: A SYMPHONY IN B FLAT MAJOR

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Art by People with Autism - Part of your world

Kim Miller - the Violinist
Magnum Opus

- Each symphony usually contains 4 movements
- Each movement will have a musical motif or phrase which is repeated or shared across different sections of the orchestra
- Some movements will be more technically challenging
- The end product depends on the team of players.
- Today I am providing the musical notes and musical notations
- You and families will be the conductors. You add your interpretation and passion to the music.
- You begin to learn a new piece by focusing on one movement at a time, similarly you and your team will start to learn or implement a care coordination program one step at a time.
1st Disclosure

☐ I’m a co-author of the Ages and Stages Questionnaires and do receive royalties.
I’m learning to “walk the talk” at CDRC just as you are learning to walk the talk in your office.

These are activities you are all doing in part with some and at times with many of your families.

My intent is to provide you recommendations for specific activities, representative tools and ways to invite families as full participant.

Care coordination is not something you do for someone but something you do with someone.
3rd Disclosure

☐ I’m technologically impaired
Objectives

- By the end of the morning, participants will be able to:
  - Describe the contents of an office-based care coordination toolkit and steps for implementation
  - Conduct an assessment of child and family strengths, needs and goals including health literacy skills
  - Discuss the process and representative tools for pre-visit planning
  - Describe the development and use of shared care plans which include self-management supports and collaborative goal-setting
  - Link families to needed services
  - Develop a formal office-based program to support the transition of youth to adult services
General Resources for this Talk

- The OCCYSHN Care Coordination Toolkit, [http://www.ohsu.edu/xd/outreach/occyshn/programs-projects/providers.cfm](http://www.ohsu.edu/xd/outreach/occyshn/programs-projects/providers.cfm)
- National Initiative for Children’s Healthcare Quality (NICHQ)
- National Center for Medical Home Implementation (NCMHI)
  Interactive toolkit, Building Your Medical Home, [http://www.pediatricmedhome.org](http://www.pediatricmedhome.org)
- Center for Medical Home Improvement (CMHI)
  Medical Home Practice-Based Care Coordination Workbook, [http://www.medicalhomeimprovement.org/pdf/MHPracticeBasedCC-Workbook7-16-07.pdf](http://www.medicalhomeimprovement.org/pdf/MHPracticeBasedCC-Workbook7-16-07.pdf)
- Jennifer Lail, MD, Practical Approaches to Enhance Communication and Care Coordination in the PCMH, [http://www.pcpcc.net/files/webinar/jennifer_lail_presentation.pdf](http://www.pcpcc.net/files/webinar/jennifer_lail_presentation.pdf)
Definition of Care Coordination

Patient and family centered, assessment driven, team based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational and financial needs to achieve optimal health and wellness outcomes. (Antonelli, et al., 2009)

“…not fixed or determined by a defined set of tasks… a dynamic process… driven by the needs of the child and family.” (Cooley & McAllister, 2010)
Leslie

- 32 year old woman with Spina Bifida and hydrocephalus
- Graduate of U of O, working as research assistant
- Thoracic motor level, wheelchair ambulator, regular stretching and exercise program
- Bowel and bladder continence programs
- Skin checks and regular pressure relief, use of compression stockings
- Other required knowledge – latex products; signs and symptoms of UTI and neurosurgical complications; basic wheelchair/cushion adjustment/repair; who to call when....?
Critical Concepts

- planned (proactive) care
- self-management
- self-advocacy (speaking up)
- self-determination (informed decision making)
- health literacy
- goal-setting
Why? Patient and Family Experience of Care

- From National Survey of Families of CYSHCN (OCCYSHN, 2010)
  - 50% needed health care they could not get for their child
  - 64% reported difficulty getting needed care
  - 30% went without health care due to cost
  - 22% were unable to pay bills
  - 28% have more than one CYSHCN in family
Why? The Cost of Care

- CYSHCN utilize disproportionate amount of health care $
  - Children with chronic conditions expected to be lifelong, progressive and will require extensive care
    - <1% of all children
    - 24% of hospital charges (Neff, 2004)
  - Children with chronic condition which lasts >12 months, involves several organ systems and requires pediatric specialty care
    - 26% of pediatric hospital days
    - 40% of hospital charges (Simon, 2010)
Benefits of Office-Based Care Coordination

- Increased child and family satisfaction with care
- Increased provider satisfaction with care
- Improved access to care and health care quality
- Decreased duplication of services
- Decreased ER visits and hospital days
- Decreased costs
- Improved health
What’s the Evidence?

- A Critical Analysis of Care Coordination Strategies for CSHCN (Wise, Lynne & Brat, 2007)
  - Paucity of empirical data (7 studies in past 15 years)
  - For example, Pediatric Alliance for Coordinated Care
    - Designated pediatric nurse practitioner
    - Consultation from local parent of CSHCN
    - Modification of office routines
    - Development of individualized health plan
- Recommendations
  - Expand evaluation of care coordination programs
  - Conduct replications of promising practices
Today We Will Discuss...

- Implementation of a formal office-based care coordination program
- Pre-visit planning
- Assessment of Child and family strengths, needs and goals
- Development of a shared care plan which includes self-management goals (coaching patients/families) and as action plan
- Linking families to needed services (coordination of care with community providers)
- Supporting families and youth in the transition to adult services

We will not discuss...

- Identification of CYSHCN/creation of registry
- Monitoring/tracking of tests, referrals and outcomes
- Coding and billing appropriately
- Measuring success
Implementation of a Formal Office-Based Care Coordination Program

- Identify a quality improvement team, include family members, conduct self-assessment, build on current QI initiatives
- Identify and train an office care coordinator
- Develop a list of important community resources
- Identify external care coordination support
- Promote and market your care coordination services, adapt *Medical Home Practice Brochure for Parents*
- Identify CYSHCN, create a registry, decide where to start
- Schedule regular well child (chronic condition management) appointments for CYSHCN
- Code and bill appropriately
- Create a mechanism to monitor and track tests, referrals and outcomes
- Measure success
Big Goals, Little Steps

- Family satisfaction
- Adequate time for care
- Planned visits
- Better co-management with specialists
- Help with referrals and resources
- Avoid duplications, errors
- Fiscal Viability
- Caution—Don’t wait for consensus

Lail, 2011
Parents as Team Members

- Improves the planning process
- Helps you carry out your mission
- Increases your knowledge and skills
- Helps you do a better job
- Brings fresh perspective to problems
- Provides an ally to advocate for better services for children and families
- Increases your empathy and understanding for families
- Brings about better consumer satisfaction

Powerful Partnerships, NICHQ
The Growth and Development of Care Coordinators by PDSA Cycles

- Staff volunteer attended MHLC-1
- BCBS Foundation funded 3 hours/week
- 3 hr/week, 40 in registry in 2004
- Title V grant as Demo. Project
- 20 hr/wk, 540 in registry in 2006
- CC supported entirely by CHPA
- 72 hr/wk, 1645 in registry in 2011
- Practice supports CC services – better efficiency, coding, reimbursement, referral support and tracking

Lail, 2011
Pre-Visit Contacts: Imagine

- Care coordinator screens schedule for upcoming CYSHCN well child (chronic condition management) appointments
- The child’s MD assesses child’s complexity and requests pre-visit contact (PVC)
- Care Coordinator makes call to parent.
- Parent concerns are identified
- Labs (and pain control!) are anticipated and scheduled for
- Consultant notes are available
- ED and specialty visits are noted
- New issues/special needs are anticipated and addressed
- Adequate appointment time is scheduled

Lail, 2011
Pre-Visit Planning Tools

- (Bright Futures)
- Family-Centered Care Coordination Tool (new patient)
- Pre-Visit Contact Form (return patient)
- CAHMI CSHCN Screener, complexity tool
- Tips for a Successful Visit (new patient)
Tips for a Successful Visit - 1

- Mention any special needs for the appointment and mention strategies that work
  - a longer appointment
  - a special time of day, e.g., at the end of the morning or first thing in the afternoon
  - limited time in waiting room (e.g., a child with autism who cannot tolerate long waits in unfamiliar places)
  - a time when few children or parents are present in the office
  - any sensitivities to light, sound or touch
Tips for a Successful Visit - 2

- Prepare for the visit:
  - do pre-visit to the office or virtual visit online
  - create a picture schedule or social story for the visit
  - bring toys, visual supports from home as needed
  - list the one or two important questions you would like answered
  - think of 2 goals (e.g., functional skills) you would like your child to develop over the next 6 months or so.
  - make sure you bring your child’s care notebook
  - bring copies of reports from specialists as well as any recent test results
  - bring copies of school records and be prepared to discuss any school issues
Colin

- 30 year old young man with Autism and Intellectual Disability
- Non-verbal, limited functional communication
- Lives in group home
- Marked difficulty finding adult health care provider
- History of agitation, SIB, aggressive behavior
Assessment of Child and Family Strengths, Needs and Health Care Goals

- First step in building a relationship and in building the family’s capacity to manage their child’s care
- Components:
  - Child and Family strengths – “what would you like us to know about your child, what he does well/likes/dislikes, about you and your family?”
  - Child and Family Needs – “do you have any concerns or worries? can we help you with the following…?”
  - Child and Family goals – “what do you want to accomplish…?”
  - Cultural issues
  - Health literacy
  - How best to communicate with the family
Child and Family Strengths and Needs Assessment Tools

- Cultural issues,
  - Website on cultural issues and health, U of W, http://ethnomed.org
  - Other tools, *Brief Interview to Elicit Health Care Beliefs* and *Brief Assessment of the Family’s Cultural and Religious Practices*

- Supplement *Family Centered Care Coordination Tool* with *Family Needs Survey* or *Family Concerns Checklist*

- Health Literacy tools— *Teach Back*, *Ask Me 3*, *Checklist for Caregiver Understanding*
Brief Interview to Elicit Health Care Beliefs (adapted from CaCoon Manual)

- What do you think has caused your child’s condition?
- What do you fear (worry about) most about your child’s condition?
- What have you done to treat your child’s condition so far?
- Are there any other treatments you think your child should receive?
- (Ask specifically about traditional and complementary treatments)
- What do you hope treatment will accomplish? (goals)
Assessment of Cultural and Religious Traditions (adapted from CaCoon Manual)

- Does your family identify with a particular religious or ethnic group?
- Are both you and your spouse/husband/wife from that group?
- What special religious or cultural traditions are practiced in your home?
- How does your family know when a health problem needs medical attention?
- Who is the person your family contacts when a member is ill?
- Who does your family go to for support (clergy, medical healer, relatives etc.)?
Family-Centered Care Coordination Tool

- What would you like us to know about your child/youth?
- What would you like us to know about your family?
- Do you have any concerns/worries for your child/youth?
- Have there been any recent changes in your family (changes since we saw you last) such as...?
- Can we help with any of the following needs?
Family Needs Survey (Bailey & Simeonsson)

- Family & Social Support
  - Talking with someone in my family about concerns
  - Having friends to talk to
  - Finding time for myself
  - Helping my spouse accept any condition our child might have
  - Helping our family discuss problems and reach solutions
  - Helping our family support each other during difficult times
  - Deciding who will do household chores, child care and other family tasks
Definition of Health Literacy

- Obtain, process, understand basic health information and services
- Make appropriate healthcare decisions (act on information)
- Access/navigate healthcare system

From Putting Health Literacy into Practice: A Pediatric AAP Community Pediatrics Webinar, May 2007
IOM Report on Health Literacy

- 90 million adults have trouble understanding and acting on health information
- Complex text must be simplified and attention paid to culture and language
- Providers need health literacy training
- Healthy People 2010
  - Improve health communication/health literacy
Limited Health Literacy: the Problem

- A mismatch between patients’ capacities and demands placed on them by
  - the nature of their illness
  - health care providers or systems
  - self-management expectations
- For example, compared to children with asthma of parents with high health literacy, children of parents with low health literacy have:
  - Hospitalizations: 4.6 X
  - Emergency room visits: 1.4 X
  - Missed days of school: 2.8 X

DeWalt et.al., 2007
Print Materials

- Simplify and avoid duplicative paperwork
- Offer to read aloud and explain
- Check reading levels of materials (5-6th grade)
- Plain language principles
- Show or draw simple pictures
- Focus only on key points
- Emphasize what the patient should do
- Minimize information about anatomy/physiology
- Underline or circle key points
Interpersonal

- Plain “living room” language
- Slow Down
- Break it down, short statements
- Organize into 2-3 concepts & check for understanding (“chunk and check”)
- Teach Back
- Ask Me Three
“Teach Back”

- Ask patients to demonstrate understanding using their own words:
  - What will you tell your husband about what to do when Erin’s asthma gets worse?
  - I want to be sure I explained everything clearly, so can you please explain it back to me so I can be sure I did?
  - We’ve gone over a lot of things you can do to..... Can you go over what we talked about? How will you make that work at home?

- Do not ask:
  - Do you understand? Do you have any questions?
Ask Me Three

☐ Ask Me 3™ is a patient education program designed to promote communication between health care providers and patients,
http://www.npsf.org/for-healthcare-professionals/programs/ask-me-3/

☐ What is my main problem?

☐ What do I need to do?

☐ Why is it important for me to do this?
Checklist for Caregiver Understanding

☐ I can tell someone about my child’s diagnosis, disability or health condition.
☐ I can describe how my child’s disability or health condition affects daily life.
☐ I can list my child’s allergies and know what to do if he has an allergic reaction.
☐ I am comfortable asking questions if I don’t understand the doctor’s directions.
☐ I know how to reach the on-call doctor or nurse when the office is closed if I need to.
☐ I know who to call in an emergency.
☐ I can list my child’s medications and tell you why he takes them, how much he takes of each one and any possible side effects.
☐ I keep a health notebook or medical journal for my child.
☐ I carry my child’s care plan or medical summary with me.
☐ I have a computer at home, use email and use the Internet to obtain health information.
☐ I know how to judge the quality of health information on the Internet.

I prefer to communicate with the primary care office by (phone, email, in writing).
Shared Care Plans for CYSHCN

- Developed collaboratively with child and family, incorporates child and family goals
- Effective way to support self-advocacy and self-determination

Types of care plans
- medical summary/transition summary
- emergency care plan
- working care plan or action plan
- (IHCP for educational setting)
Shared Care Plans: Examples

- Issues - who’s in control of the information, how is it updated and how portable/accessible is it?
- Care Notebook (written care plan)
- OHSU EPIC My Chart
  - Send a message
  - View health summary
  - View test results
  - Schedule an appointment
  - Pay OHSU bill online
- My Shared Care Plan
About Me

- I want the person working with me to know
- The most important information you need to know about me
- I have a challenge with
- My religion/spirituality does not impact my health care
- I learn best by
- Where I am (concerns)
- Where I want to be (goals)
Action Plan

- Name, DOB
- Parents/Guardians
- Primary Diagnosis
- Secondary diagnosis(es)
- Original Date of Plan, Updated last
- Main concerns/goals
  - Current plans/actions
  - Person(s) responsible
  - Date to be completed
- Signatures
Goal-Setting

- Specific goals may address
  - Health literacy
    - Understanding health care information
    - Making informed decisions
    - Using the Internet to obtain health care information
  - Self-management goals
    - General goals, knowing how to reach the on-call doctor
    - Condition specific goals, e.g., asthma self-management
  - Adaptive skills, social skills and independence, e.g.,
    - Knowing the basics of good nutrition, planning and preparing meals
    - Using community transportation
    - Participating in community recreational and leisure activities of their choice
Guidelines for Goal-Setting

- Work collaboratively with the child and family
- Identify goals that are specific and short-term
- Choose goals that are reasonable and achievable
- Start small and build on success
- Provide regular feedback: phone follow-up, email and face-to-face
- Use salient and frequent external rewards
- Goal-setting discussions and follow-up can be conducted by allied office staff
- Identify external supports as needed, e.g., public health nurses, school staff
- Use the Plan-Do-Study-Act or PDSA cycle
Navigating the System: Community Resource Directory

- Partial list at [http://www.ohsu.edu/xd/outreach/occysnh/programs-projects/providers.cfm](http://www.ohsu.edu/xd/outreach/occysnh/programs-projects/providers.cfm)
- Ask MD’s in office to submit their favorites from all disciplines
- Parent Partner and office Care Coordinator add Local Resources (Lail, 2011)
- Use community resource guides, 211 at [http://www.211info.org](http://www.211info.org) and Parent Help Line at [http://www.birthto3.org/parents](http://www.birthto3.org/parents)
- Identify external care coordination supports (health)
  - CaCoon/Public Health Nurses
    - [http://www.ohsu.edu/xd/outreach/occysnh/programs-projects/cacoon.cfm](http://www.ohsu.edu/xd/outreach/occysnh/programs-projects/cacoon.cfm)
  - Exceptional Needs Care Coordinators and other care coordinators of health plans

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Navigating the System: Parents/Families as Resources

- Family Navigators (contact barnessh@ohsu.edu)
  - Parent-to-Parent collaboration and support
  - Personal knowledge of
    - Advocacy Groups
    - Providers and Services
    - Other resources and information, e.g., making visual schedules
  - Physical Plant walk-through Lail, 2011

- Remember Oregon Family 2 Family Resource Center, www.oregonfamily2family.korg
Navigating the System: the Internet

- “Need to Know” information
- Internet searches by office staff for services
- Supporting families in accessing and understanding info from the Internet

www.trustortrash.org
Need to Know Information for Health Care Providers

- Information on specific conditions:
  - http://www.medicalhomeportal.org
  - http://depts.washington.edu/healthtr/hcp/diag.html

- Gene Tests,

- National Organization for Rare Disorders (NORD),
  - http://www.rarediseases.org

- NIH Office for Rare Diseases Research, information on current NIH-funded research studies,
Other Resources for Providers and Parents

- National organizations and advocacy groups on specific conditions. For example,
  - National Down Syndrome Society, [www.ndss.org](http://www.ndss.org)
  - Children and Adults with Attention Deficit/Hyperactivity Disorders, [www.chadd.org](http://www.chadd.org)
  - LD Online, website on learning disabilities and ADHD, [www.ldonline.org](http://www.ldonline.org)
  - Autism Speaks, national advocacy group on Autism Spectrum Disorder, [www.autismspeaks.org](http://www.autismspeaks.org)
  - The Arc, for people with developmental disabilities, [www.thearc.org](http://www.thearc.org)
- Other national parent associations and advocacy groups can often be found by conducting a “Google search” for that condition, for example, Williams Syndrome Association, [www.williams-syndrome.org](http://www.williams-syndrome.org)
Dreams, Langston Hughes

Hold fast to dreams
For if dreams die
Life is a broken-winged bird
That cannot fly
Hold fast to dreams
For if dreams go
Life is a barren field
All covered with snow
Jeff

- 22 yr old young man
- Graduated from high school on IEP
- Transition planning started in 7th grade
- Started working on transportation in high school but few vocational skills
- VR supported job development and job coach at 19 years
- Actively involved in person centered planning, IEP meetings
- Now partially employed at Walmart, living independently
Goals of Youth Transition

- Optimal health, wellness and function of the individual
- Self-determination of the individual to the greatest extent possible
- Maximum independence and inclusion based on his or her choices
Critical Concepts

- Self-determination, important skills that contribute to self-determination are:
  - Speaking up or self-advocacy
  - Goal setting
  - Solving problems
  - Making informed decisions

- Person-Centered Planning
  - Ongoing process with youth and family at the center
  - Based on respect for youth’s rights to set their own goals, their vision (what’s important to the person) and their needs (what’s important for the person)
  - Involves a committed circle of people
  - Results in an action plan
Important Community Resources

- **Schools**
  - Transition services must be included in the youth’s IEP by 16 years of age

- **Department of Vocational Rehabilitation**
  - Federally funded program to assist individuals with disabilities to find a job

- **Developmental Disability services**
  - Assists youth with ID and ASD and families transition to adult services
  - Brokerage system

- **Social Security Administration**
  - Supplemental social security income
  - Ticket to Work program
Health Care Provider “To-Do List”

- Develop a formal youth transition policy for the office
- Adapt Medical Home Practice Brochure for Parents
- Initiate a conversation about transition at 12-13 years of age
- Develop an initial transition plan at 14-15 years of age
- Provide on-going self-management supports and encourage speaking up, self-determination, self-care and independence as all visits (see resources)
- Identify external care coordination/care management supports as needed
- Assist youth and family identify needed supports for independent living and work, collaborate with community providers, e.g., Brokerage system
- Assist youth and family identify an adult health care provider
- Formulate a medical summary (transition summary) for adult health care provider, consider initial co-management of youth with adult health care provider
- Introduce adult health care provider to pediatric specialists as needed, e.g., child psychiatry and developmental pediatrics
- Assist youth and family identify on-going health insurance
- Advocate with youth and family for needed services
- Monitor for mental health co-morbidities
Kim

- 22 year old young woman with High Functioning Autism
- A’s and B’s in high school, attended Community College
- Living at home, unemployed
- Has been successful with her artwork, recent period of limited interest
- Anxiety and depression
So How Do We Get There?

- Identification of problem areas
- Establish explicit goal to address
- Break process into tiny steps
- Create tools to support weak spots
- Try ONE SMALL change
- Measurement of improvement (or failure!)
- Try another test of change and see if you’re ready to grow that change

Lail, 2011
Atul Gawande, Better: A Surgeon’s Notes on Performance

Better is possible. It does not take genius. It takes diligence. It takes ingenuity. And above all, it takes a willingness to try.