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

ROBERT NICKEL, MD
MAY 19, 2012

ORPRN

OPIP

OCCYSHN

Kim Miller – the Violinist

Art by People with Autism –
Part of your world

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.

2nd Disclosure

- 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

- National Initiative for Children's Healthcare Quality (NICHQ)

  Powerful Partnerships: A Handbook for Families and Providers Working Together to Improve Care, http://www.nichq.org/resources/powerful_partnerships.html

- National Center for Medical Home Implementation (NCMHI)

  Interactive toolkit, Building Your Medical Home, http://www.pediatricmedhome.org

- Center for Medical Home Improvement (CMHI)

  Medical Home Practice-Based Care Coordination Workbook, http://www.medicalhomeimprovement.org/pdf/MHPracticeBasedCC-Workbook 7-16-07.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

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)
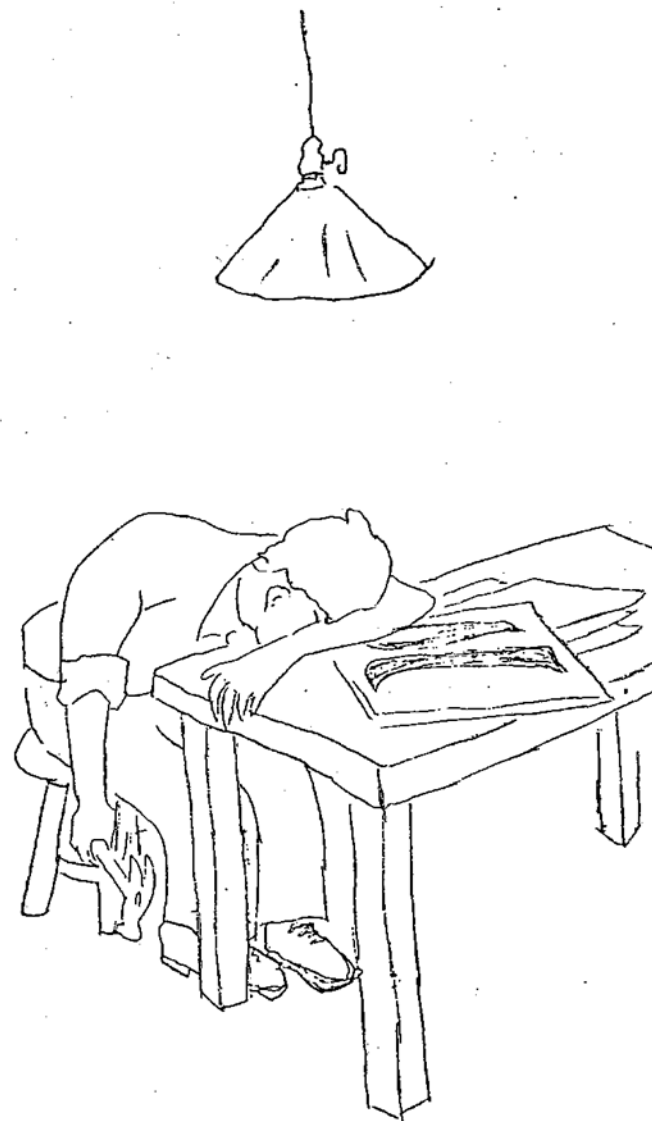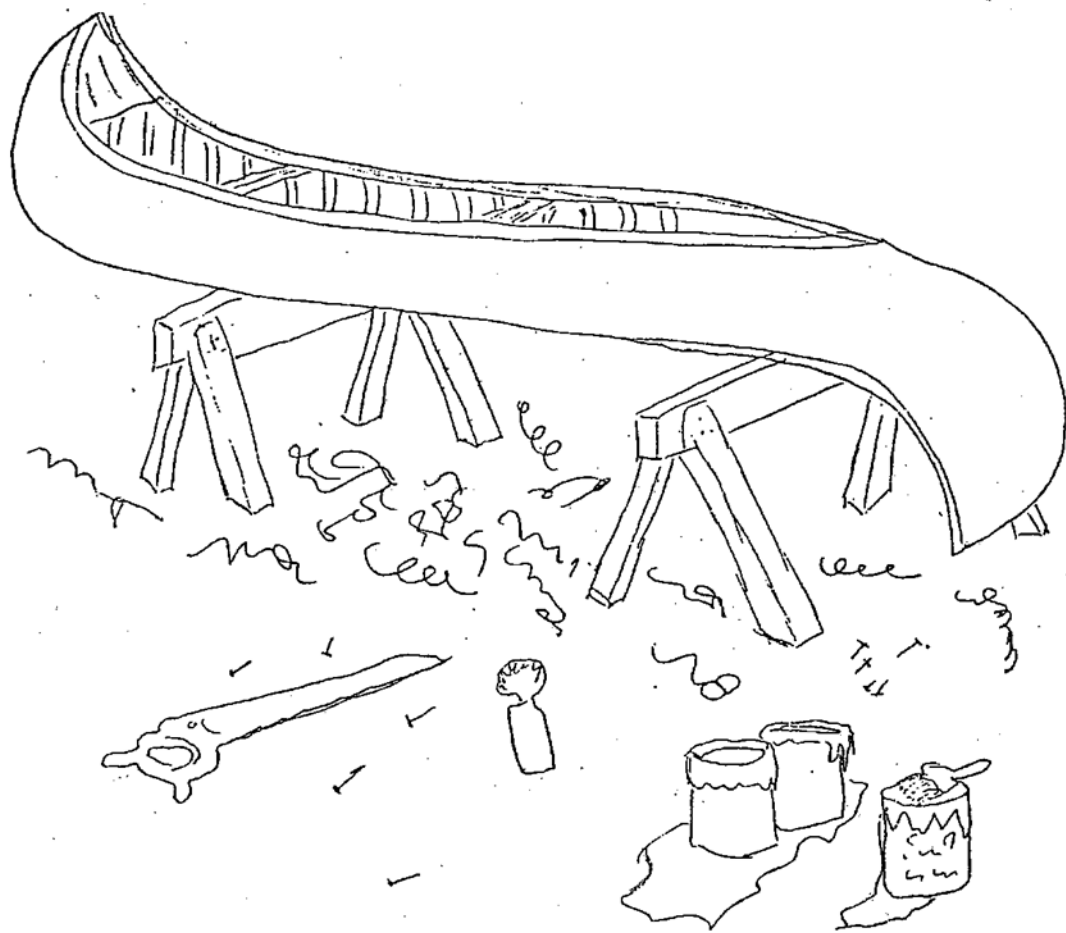
Leslie

- 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^{TM} 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

www.mysharedcareplan

http://www.improvingchroniccare.org/downloads/3.3_3.4_shared_care_plan.pdf

- 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

    http://www.innovations.ahrq.gov/innovations_qualitytools.aspx?categoryID=54554&taxonomyID=54603
- 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/occyshn/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 and Parent Help Line at http://www.birthto3.org/parents

- Identify external care coordination supports (health)

  - CaCoon/Public Health Nurses http://www.ohsu.edu/xd/outreach/occyshn/programs-projects/cacoon.cfm

  - Exceptional Needs Care Coordinators and other care coordinators of health plans

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,
  - http://www.ncbi.nlm.nih.gov/sites/GeneTests/?db=GeneTests
- National Organization for Rare Disorders (NORD),
  - http://www.rarediseases.org
- NIH Office for Rare Diseases Research, information on current NIH-funded research studies,
  - http://rarediseases.info.nih.gov

Other Resources for Providers and Parents

- National organizations and advocacy groups on specific conditions. For example,
  - National Down Syndrome Society, www.ndss.org
  - Children and Adults with Attention Deficit/Hyperactivity Disorders, www.chadd.org
  - LD Online, website on learning disabilities and ADHD, www.ldonline.org
  - Autism Speaks, national advocacy group on Autism Spectrum Disorder, www.autismspeaks.org
  - The Arc, for people with developmental disabilities, 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

<u>Dreams</u>, 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
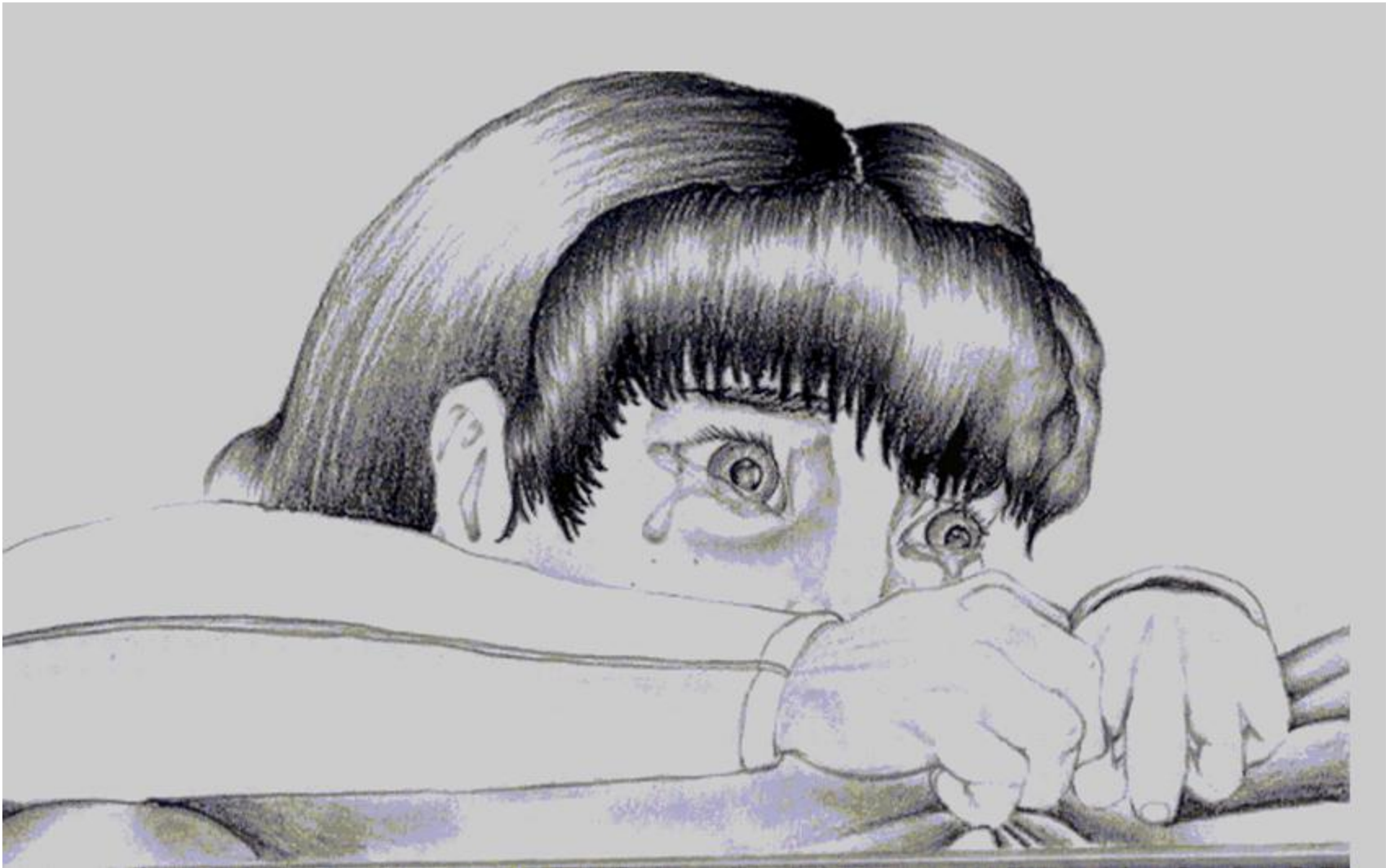
Kim

- 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, <u>Better: A Surgeon's Notes on Performance</u>

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

How to cite this presentation:

Nickel, R. (2012, May). *The what, why, who and how of care coordination: A symphony in B Flat major* [PowerPoint Slides]. Retrieved from the Oregon Pediatric Improvement Partnership website: http://www.oregon-pip.org/resources/presentations.html