Nuts and Bolts Action Guide

Step 1: Inspiring a Vision and Mission

- Who would you bring together from your "internal" CSHCN program staff to begin the discussion on building a community-based service system? Who on your staff do you anticipate will be your supporters, and who may be skeptical?

Administration, nursing staff (public), peds/family practice, reception, IT, school, parents, youth, early child, Head Start, B & G Club, Benefits Coor, community outreach staff, med-providers, legislators, DD case managers, residential providers, ILC's (re: transition aged), community neighbors, other community providers, people with communities, people who have done it before,

- How well does your current vision (your desired, long-range outcome) reflect the outcomes for the broad population of CYSHCN? How would you change it?

Leadership, access to care, early intervention, cultural competency, sustainability, $, accountability, language needs to be the same, make one plan for child (not many-/IFSP, IEP, HC plan), EI (early & cont screening), staffing, general population, IL center goal working on, "ability to function' (IQ), chg :want adequate resources to do both well, CSHS – limited resources to accomplish goals, feds want system based & ND want direct services, have partners step up and do systems piece, CSHS – good outcomes, but would change – prefer to address systems but have someone else handle direct services

- How well does your current and mission statement reflect the role and work-scope for supporting a community-based service system? What changes would you want to make?

Skeptics – legislators, peds & family practice, schools
Supporters – administrators (Minot), parents
ACC changed to included more than just children – is community/home based (no longer center based), parents could have a 'buffet' one-stop-shop, system wide approach is needed – satisfaction with work done when I leave the office for the day, want vs need, '211', centralized list of services, 1 meeting (med & ed at the same table), eliminate attitudinal barriers, partnering (1 person, 1 family, 1 plan) dependent on age – keep family at center – child centered, think about healthy ND statements, healthy advocacy, health prevention, health services, continuity, portable plan information, portable health information, care for lifespan, *We envision a coordinated system of care for CYSHCN that provided continuity for 1 person, 1 family, 1 plan, build better communication, build professional respect, build capacity in the community, health center give info to connect dots, Headstart – do best to empower parents, 20-30% enrollment is disabled. Headstart still able to do what they want to do, advocate from federal reps, Merit Care, Chg: FVND – focus on youth in transition & youth leadership "easy' families get RT visits, but families who need it the most don't get it.

Step 2: Engage other Partners

- Is there an existing state –level team or group that you can use (also think beyond MCH) consisting of: 1st responders:law enforcement
  - Your "customers":

- Family leaders
- Youth leaders
- Those reflecting diverse cultures, esp. those under-represented

- State-level agencies (directors)
  - Who are your partners in paying for services? (i.e., Medicaid, Shriners, etc.)
  - Who are your partners in providing & coordinating services? (i.e., Vocational Rehabilitation, Education, Part C, Public Health)

- Those who can help with training or evaluation? (i.e., UCEDD's, LEND)

- Community-level providers (physicians, public health nurses, etc.)
  - What are the natural "communities" (counties? regions?) in your state to engage?

- Who will be your "champions" – those with the power and influence to support your efforts?

- Who will be your "ambassadors" – especially family ambassadors: those who can spread the vision and mission to a broader stakeholder group?

- Who will be your "reluctant" participants—those who you'll want involved in your transparent activities?

Step 3: Assess your community infrastructure

- How will you define your "communities" (i.e., by counties? Public health offices? Metropolitan areas)?

Public health, region (NWND), whole state, touchpoints of the family, employer as community, Health Referral Service area, regions, different to everyone

- What existing information do you have now about your communities/regions within your state?
  - State-wide data (i.e., surveys)

Medicaid claims, CHIP data, family survey, BRFSS, GPRA, NLTS-2, SLAITS
Kids count BR,

  - Data from your state partners

Shared work.org, trans part proj. Donene's data, personal stories

- How can you engage communities?
    - How can you identify “ambassadors” into the community?

Phys in comm.(health care providers; administrators, program/dept heads, parents, VR people, SpEd teacher, SpEd directors, workplace wellness, BC/BS medical home director, Information broker, service clubs. anybody who has interest in your projects or programs

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    - How will you bring together families, youth, and providers from the community?

Food, Health Tech and Trades Fair (hands on), organizations have contact to community (Jared), Doc talks, Doc Talks – radio show, Donene – Topical calls, learning collaborative, marketing & education

- How can you find out about the strengths and needs of your communities?
    - resources: Services, specialty care, and care coordination
    - community interagency groups
    - support services (transportation, respite, etc.)

877KIDS NOW, call someone (who?) look it, join, ask public service/county/homeless, Celebrate: family partnering, access to adequate insurance, screening, defining community & the infrastructure

- Who can assist you in gathering community assessment information and help with analysis?

UND Center for Rural Health, NDCPD, Council on Quarterly Leadership, DOH, US Census, HHS, Community Health, NDCPD, NDIS, FVND, CSHCN-ND, students (high school/college? Health Dept, Do better: Family advisory is hospitals

Step 4: Develop a Plan and Budget

- Analyze/synthesize your community-level data
    - What do you predict will be the strengths in the communities on which to build?

Each region knows what’s available, programs are already in place-functioning committees, economic advantage compared to other states, acquainted with key people, small community ask for help from neighbor, communications, resilience, apathy, small town feel, groups already working on same things, interagency meetings through the counties

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    - What do you predict may be some of the challenges?

Cultural competence, geography, resistance to change (x3), rural vs urban, access, disparity of services, time (overwhelmed), fear of change, ignorance, frustration, strapped for time, making contacts in tribal communities

- Identify implementation strategies: What are some of your potential ideas in how to promote community-level service systems:
    - Care coordination, in partnership with medical homes

- Referral and outreach Education/politics
- Inter-agency collaboration Medical work group/common goals
- Family leaders in all communities 1-800 grow systems-help to write grant,
- Pursuing financing/funding options

Get administrators from large health care involved, simplify EHR process
Make EHR systems talk the same language, Medicaid/payee access to that system, talk the same language/understand the same language, know what's available (services) & market to everyone (one-stop-shop), no competition between providers, BC/BC, employers, work place wellness, merge chronic disease management w/peds,

- Are some communities "more ready" than others? Which communities have the enthusiasm and foundation to serve as initial sites?

MH pilots, yes,

- What is your time line that is driving your systems change effort?

Kora's phone calls, Emily's emails, need is identified, keep youth here, $$, Fall budget submission for 2011 session, put in separate budget, interest in keeping youth In ND, 10 years, thought through a systematic way,

Step 5: Implementation

- How will implementing these new ideas change your state-level program structure? Everybody – translate/deliver of message to specific audience – what is the same and why is different.
  - How will this change the roles of your state level staff? Will they need to develop new skills?

  Services have to integrate training in these strategies, communication needs to be open and clear, move from being in charge to being in support

  - How will it impact your budget?

  Immediate increase w/ overall reduction due to prevention, increase for several decades - better system, less $ needed later

  - What will need to happen in terms of training/TA for communities?

- What do you think may work best for implementation "spread" in your state?
  Implement across all communities at once?
  "Pilot" in some communities, and gradually expand to new communities?

Must adapt to each community, process more than product, pilots can help 'prove' concept

Step 6: Measuring Outcomes:

- Who do you have to help you develop a measurement plan? all
    - State Statistics/Epidemiological office? Local and state
    - University-based researchers/evaluators?
    - State Family-to-Family Health Information Centers?

DHHS secretary Sebelius quality measures (federal)

- What have you used to measure process/service outcomes (i.e., services delivered, numbers served) that you can build upon?

Assessment, patience questionnaires, time studies

- What have you used to measure short-term outcomes (i.e., family ratings of how well services are meeting their needs, more children have medical homes, etc.)?

Survey, questionnaire, Survey Monkey

- What you used to measure long-term outcomes? (state survey data?)