Work Group Recommendations and Meeting Notes

Outcome 1: Families of children with special health care needs will participate in decision making at all levels and will be satisfied with the services they receive.

Problem Statement

Michigan enjoys and benefits from existing partnerships (families, hospitals, CSHCS, AAP, multiple health systems, etc.) The partners have models and tools to advance family-centered partners and awareness. The recently established National Collaborative holds promise for finding the evidence and highlighting disparities in patient and family-centered care. In order to continue to advance progress for attaining the federal 2010 goal:

1) We must define standards for:
   a. Communicating program benefits and how to access them.
   b. Engaging families as partners.
   c. Funding to support family involvement.
2) Build coalitions among stakeholders regionally and statewide.

Assure that family partnerships are equally available and supported for families, including families that are culturally, linguistically, and socio-economically diverse.

Recommendations

**Priority Recommendations
presented to large group**

Collaborate with partners and build coalitions to assure that all families have full access to consistent and complete information on program benefits, information on the benefits of family partnership; conduct outreach to fathers, grandparents, youth and diverse populations, improve shared awareness of benefits of partnering organizations, develop, translate, and communicate information in multiple formats, languages, and literacy levels

Sub priority: Send letters to families with infants on the birth defect registry (18 votes)

New regional structures are required to have family advisories that will dev guidance to prepare, recruit and engage families to become advisors. Composition of family advisory structure will be reflective of community served and inclusive of youth. Each region will have a face-to-face family liaison. Provide minimal standards for financial support for family participation.

Assure accountability of local efforts to achieve collaboration, partnership, and outreach. Use surveys and focus groups to measure and improve satisfaction levels. Require annual reporting on performance towards achieving criteria/objectives articulated in the federal goal

Implement statewide, regional, and local family leadership training

Strengths and Opportunities
- Family-centered committee work efforts at children's hospitals
- Family Voices connecting
- Good models for mothers and siblings can include fathers
- Supported well by CSHCS for conferences
- Families included at different levels
- Have data and evidence based on information to show family participation results in better services—develop a press kit
- A lot in existence regarding family centered practice how to present and share
- Inroad with Medicaid Policy

- Genetics
- Mechanism in place to outreach
- Local contracts with individuals who have/had special need and can talk with new parent to offer them a glimpse of what is possible
- Develop linkages to local CIL's
- Mi AAP—important champions Physician partners
- Compassionate—caring staff, parents are and/or affiliated with families CYSHCN
- F2FHIEC going statewide can fit into regional system—provide infrastructure—having family liaisons to connect with locals
- Doc site—include family child information, web based, family access
- Transition work—including youth in family centered discussions

Themes
1. Education Activities
2. Partners
3. Data to build upon
4. Models and Tools
5. Summit

Weaknesses and Threats
- Services dependent on where you live
- Variability at local level to include families
- Lack of standard set for delivering family centered care, and informing families
- Varying buy-in of health care providers (loss of control)
- Public Heath Code hasn't been revised—redefined terms—can create a new situation of having to examine entire code not just CSHCS
- Definition of "family"
- Not allowing for family choice—need to allow for individual family—system cannot impose
- Limited funding to support family centered care
- Lack of coalition to help implement changes statewide—vehicle for working on issues
- Connection to disability specific organizations
- Other state agencies that serve CYSHCN that have the same culture (identify link be part of coalition)
- Variability of "communication" with other programs outreach for family centeredness
- Need to update existing families of new information and policies
- Culture—socioeconomic, language diversity
- Lack of research—splitting data so we know what we are working with

Brainstorming Ideas
- All families across the state should have full participation and access to consistent and complete information
- Increase awareness of website
- Develop, translate, and communicate information in different formats, languages, and literacy levels
- Share information among partners (about multiple level or participation to promote)
- Use surveys and focus groups to measure and improve satisfaction levels
- Require annual reporting on performance towards achieve criteria/objectives

articulated in federal goal

Parking Lot
- Varying levels of family participation
- Need for parent leadership program special education
- Community-based system of care
- Alternative funding infrastructure changes to shape services

Outcome 2: All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.

Problem Statement
Michigan acknowledges national development of patient and family-centered medical home definitions in addition to various demonstration projects within the state. Michigan also has multiple programs and resources concerned with meeting the needs of CYSCHN and their families. However, there is no common statewide working definition of family-centered medical home for CYSHCN that includes specific operational criteria; nor has there been sufficient collaboration among those developing other medical home models. Increased collaboration and redirection of funding is needed to develop and support a regionalized system of care that provides a medical home for all CYSCHN.

Recommendations
Priority Recommendations **presented to large group**
Develop consensus definition for CYSCHN family-centered medical home and all subsets of medical home such as care coordination in Michigan and method to operationalize that fully involves family representation in each group and process throughout start to finish
Include full integration of all existing programs and other organizations (including community based groups) into the medical home planning and implementation process from start to finish
Address the funding and reimbursement issues allowing for multiple strategies
Develop mechanisms to educate the public, consumers, and train professionals (Training Programs, Medical community process, DME, Academic detailing (get staff and doctor) Colleges of Nursing)

Strengths and Opportunities
- MI has chronic disease clinics
- Multidisciplinary
- Telemedicine (how broadly is it used?)
- Regional Health Information exchanges
- Subspecialists in centers
- Residency programs so can train
- Should learn/collaborate with other program
- NCQA available for certification of MH
- Able to set criteria and not have to follow others
- LHDs can assist whether primary or specialty care—can fill gaps (and other entries)(required vs. what can be done)(staff who care with knowledge)
- Chance to look at best practices from other areas including international successful models in place and chance to review Grand Valley nursing project starting
- Momentum and ground swell occurring now and can build on

- BCBS giving money for practice transformation and money stay once transformed
- High interest in SP today
- National intolerance from broken health care system
- Experience with CC
- Website to find doc could be adapted to MI to make more accessible
- MICR
- Administrative support
- Coordinated funding streams
- Live "bodies" that answer the phone
- Local Agencies—committed to serve
- Agency collaboration
- Family Guide/Family Preparedness
- Dedicated Staff to LHD
- Provider network that remains in place—wont leave the families
- Plethora of services available
- Can use other programs/together/collaborate
- Point of entry: Multiple ways into program, medical from hospital, family mailed application, completed at hospital
- Parents advocate for the program (word of mouth networks)
- Diagnostics
- Database to use for variety of purposes: MICR, Oracle, Claims data
- CM/CC available to families
- Human resources
- Technology Services

Weaknesses and Threats
- Multiple groups developing own version of MH
- Was to be standardization training didn't happen
- Provider community needs to be up front about label so know what to do—what path—A comprehensive plan right away
- Process at hospital that will start correct process
- Need for neuro/psych evaluation
- Need electronic medical record
- Care plans written through other programs Doc not part of or aware of and can duplicate
- Money, Training, Education, Promotion
- Exchange of communication among all participants
- Docs don't have time to participate
- Too long a wait for reports, requests, slow turn around
- Later events often leave family on own to find help
- Need local services including for CC
- Concern of accepting money rather than based on quality could leave pediatric approach by wayside with only measurable results
- Infrastructure; money we don't have
- Need flexibility of who we include re: providers
- CSHCS limited to specific medical conditions and needs to be broader spectrum
- Need specific criteria that allows certification
- Wide variety of geography need to address regionally
- Do not have all players engaged
- Improve telemedicine section and expand knowledge base

- Lack of awareness of entry point (enrolled via hospital)
- Inability to determine if a service has been provided
- Transportation
- Fear: Loss of funds, loss of control, loss of client base
- Lack of referrals from hospitals/provider networks
- Too many forms or auth processes
- Distrust of government/Big brother in control
- Lack of understanding knowledge of what is available to assist them
- ↓ population ↓ economy
- Duplication of paperwork/effort
- Lack of collaboration PCP vs. Specialist—who is in charge?
- Electronic information sharing (privacy and security)(opportunity to increase)
- Lack of participation of private foundations
- Misinformation on financial requirements to participate in CSHCS
- No single source of into/system or person
- Lack of understanding of how parts can work together
- Maze is growing while funding declines
- Limited availability, 8am-5pm M-F
- Stigma attached to program/welfare?/family able to provide for family
- Lack of respite to support families

Brainstorming Ideas
- Full integration of all existing programs (AAFP, BCPGI, MPCC)
- Broaden stakeholder group
- Actively participate with Primary Care Coalition
- Encourage parental involvement
- Regionalize "In a perfect world" process with parents
- Keep Local Health Departments involved
- Form task force with appropriate representatives to hammer out working definition leading to certification and operationalization
- Explore barriers and solutions for electronic medical records
- Create process for inclusion of non-pediatric providers
- Create process similar to IFSP including family as partner in development per individual
- Define infrastructure of what is included in MH model
- Integrate MH training into (Residency program, Nursing, Health Professionals)
- Define who is care coordinator into definition and each plan of care
- Review historical experience and requirements MI and other states
- Allow for flexibility within model due to regional and other differences
- Create evidence-based definition
- Need flexibility and accountability for argument made from parent perspective so have record
- Parent and coordinator advocacy respected
- Coordinator with dental home activities
- MICR- Expand- vehicle to share medical information
- Development of reimbursement mechanism
- Development of funding mechanism
- Primary care added to CSHCS authorization per child
- Determine how much to cover of primary care

Questions

1. Definition of Medical Home
2. Definition of Care Coordinator
3. Primary vs. Specialist
4. Does everyone have resources to do this?
5. How to educate residence to be prepared
6. When do you need a medical home?

Issue Brief - Recommendations

- Needs reference to broaden base such as Primary Care, Family practice, ect...
- Definition need to clean about detail expectations

Outcome 3: All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.

Problem Statement
Although Michigan has one of the one of the lowest rates of uninsured children in the country and a comprehensive CSHCS medical health care program, thousands of children still remain uninsured due to the following barriers: 1) Inadequate education and awareness of the program. 2) Insufficient identification of eligible children.

Recommendations
Priority Recommendations presented to large group
Letters to Birth Defect Registry families. (integrated into family participation priority)
Pursue the Medicaid buy-in option available for children with special health care needs through the federal Family Opportunity Act (families with incomes up to 300% of poverty could buy full Medicaid coverage).
Improve communication, collaboration, and education to all stakeholders between public/private agencies, professional organizations (AMA, MDA, MAPD, etc.)
Operate as regions; improve connections between regional hospitals and local health departments and other community agencies.
Insurance premium payment program: expand/improve awareness and increase enrollment.

Strengths and Opportunities

- COBRA as insurance premium program
- CSHCS coverage
- Outreach
- Legislative support
- Local health departments
- Regional centers
- Partners
- Good financing
- Low rate of uninsured children
- High rate of employee-based insurance
- Low premium (CSHCS payment agreement fee)
- Monthly payments

- Peace of mind
- Educate congress
- Interagency infrastructure
- Take care of kids (right thing)
- Michigan Cleft Network
- Link on internet through non-profits
- Ongoing discussion
- Strategic planning
- Stakeholders, multiple
- Involve families consistently
- Staff
- Seminars – family to family education
- Informative, helpful, problem-solving Staff
- Powerful Advisory Committee
- Supplemental to insurance coverage
- Education
- Family/Provider Available Services
- Mentoring/Support
- Webpage Instruct

Weaknesses and Threats
- Medicaid public program – stigma
- Not informed about available program
- Funding limits, economy
- Concise data
- Poor outreach
- Low reimbursement rates
- Covers eligible conditions only (not comprehensive)
- Income for MI CHILD raised above 200%
- Lack of case-finding (expand partners)
- Prior authorization process too long
- Federal government unfunded mandates
- Lack of contact with registry
- No mental health coverage for CSHCS
- More collaborative efforts between service (local) programs
- Silos –separate funding programs, services
- Lack of funds for outreach
- Reduction in staff, resources
- Staff turnover: DHS, CSHCS
- Regional Center Meetings
- Excess funds returned (no carryforward)
- Provider, hospitals don't use expertise of local health departments

Brainstorming Ideas
- Use state dollars to draw down federal dollars. Advocacy.
- Support national health care with specific design for children and youth with special health care needs.
- Restructure local health departments for efficiencies in service delivery.
- PSAs
- Michigan Catastrophic Fund for CSHCS

- Revise range cells for payment agreement
- Internet link to CSHCS
- Meet with Congress members
- Create advocacy group for CSHCS
- Method of how insurance works on website.
- Create algorithm of how CSHCS program
- Report of when insurance ends
- Education providers, employers, social workers
- Educate families who do not understand program (family, privacy)
- CMS clinics

Parking Lot
- No referrals to crania-facial
- Not referring to existing resources
- Funding for providers and local health departments not adequate
- Restructure local health departments, increase funding
- Payment agreement
- Resource Bank – surplus supplies

Outcome 4: All children will be screened early and continuously for special health care needs.

Problem Statement
We recognize that Michigan has well-developed, established independent screening systems. However, the systems lack: 1) Consistency in its application, reporting, and follow-up. 2) Communication between all stakeholders. 3) Knowledge about the availability and importance of screening. 4) Resources.

Recommendations
Priority Recommendations presented to large group
Support MCIR as a single electronic record for the multiple data systems.
Develop performance standards for screening and follow-up
State-wide education of all providers to spread knowledge of screening and importance of follow-up (through MI-CHIP mechanism)
Establish partnerships among all stakeholders, (EO, Genetics, Birth Defect Registry, CSHCS, LHD) that will promote strategies to move from screening to reporting to appropriate referrals, through a work group.
Promote use of existing educational materials for parent education and networking

Strengths and Opportunities
- Unique to MI
- Blood dot, EPSDT, Hearing
- Hearing and Vision (school) preschool screening
- Birth defect registry
- Ability for collaboration—community—local physicians
- Vision and screening—LDH (Jackson) does clinic

- LDH Ages/Stages—mailed family
- ASQ-ASQSE—format
- Improvement project
- Total system in place with blood dot funding source in place
- Family support F to F Hearing
- Immunization ahead
- Genetic Testing

Weaknesses and Threats
- 0-4 year hearing/vision/developmental (loss for follow-up, family do not receive results)
- Blood (hearing—need to LINK)
- Two way links all screening
- Vision screening—inconsistent across the state
- Consistency in doing and reporting screening—follow –up
- Monitoring to make sure all kids are screened
- No stat monitoring (dental)
- Funding vision (hearing is threatened)
- Education of families on need for screening/dental
- No mental health screening
- ASW-ASQSE—development screen recommendation
- Dental screening
- Lack of providers
- Need for PR in blood screening
- MCIR—Data likened data
- Genetic testing—is ethical to screen

Brainstorming Ideas
- Develop a "linked" data system that is accessible by all
- Use newborn screening and follow up program as model for best practice for all screening and follow up programs
- Monitor health care system for new screening opportunities that includes effective screening methods and effective interventions
- Support need for Medical Home with the inclusion screening for 0-4 years and beyond which should include hearing and vision and use of ASQ
- Work with insurance to ensure annual well-child exams that include valid screenings through age 21

Parking Lot
- Screening for all children (EPSOT vs. MA only)

Outcome 5: Community-based service systems will be organized so families can use them easily.

Problem Statement
Michigan has a statewide network of diversified multiple services with dedicated, caring people who display a willingness to collaborate and coordinate services within and across community settings. The problem lies with disconnected and insufficient funding streams/programs/resources. We believe opportunities exist to improve communication,

collaboration, and coordination, creating an organized system of care which families may use easily.

Recommendations
Priority Recommendations presented to large group
Increase system efficiency by 1). Resolve the transportation problem (singular definition/provider); 2). Streamline documentation among and between agencies; 3). Provide webpage directions for who to go to in the agency ("Guide for Dummies", for services); 4). Develop a Who's/who list of important contacts within the county; 5). Develop a Statewide Plan with incentives/reward for collaboration, 6). Change the hours of operation of community agencies to allow for "non-work hour" availability to parents.
Funding: Develop/Implement alternative resources for funding community services, identify cost-efficiency within the system, and enhance revenue generation by community agencies to support services being rendered.
Educate the Masses re: CSHCS/ Develop Public Relations Materials: Directed to Family, Provider, and Community agencies as to available services in the community; attempting to eliminate the turf campaigns. Increase family-to-family mentoring and support; develop web page instructions as to how one enters, to utilize services.
Health Communications Technology: (1) Implement Telemedicine statewide; (Example: incentives to communities to make it worthwhile to host a site for multiple users) (2) Increase the use of Infomatics (example: Portable Health Record, which is family-controlled, HIPPA Compliant, allow for distribution of thumb drives)

Strengths and Opportunities
- Communication technologies, telemedicine (the ability to utilize)(grants from fed to improve, expertise to develop)
- Partner with Advocacy groups
- Public/Private Partnerships
- Incentives Innovation/Investigations
- Involvement of stakeholders
- Coordination of transportation opportunities
- Coordination of Top level administration
- Broadcasts on PBS of resources
- Common forms for similar services
- Improve approval/review process
- Coordinate with private foundations for funding

Weakness and Threats
- Standards
- Coalitions
- Cultural Competence

Brainstorming Ideas
- Portable Electronic Records
- Prioritize opportunities develop/employ/deploy
- Telemedicine Synchronize ways to bring together pts/hcp
- Working with other agencies DAS/DCH/CMH

- Coordinate at state/Co. levels
- Contact list of Important people
- Providers: HCP contacts @ institutions
- Resource Guide (web based)
- Directions to web pages "guide to dummies" for organization of services
- Innovate/Incentives foster collaboration, breaking down barriers
- Who's part of the team
- No wrong door for enter (How to get to/within the organization)
- Definition of (1) Clarification of CC/CM; (2) Language of Discipline
- Hours of operation
- Analyze where the problem lies
- Solve the transportation problem statewide
- Reduce fear: system, technology, bureaucracy, change
- Education of masses: HCP, ISD, family
- Funding increase
- Organized services (state and local efforts)
- Co wide brown bags to discuss what is going on
- Δ paperwork to access
- Private industry involvement
- Restructure authorization process, extension of success
- External/internal participants
- Electronic processing
- Apply for services online
- Combine agencies (smaller groups getting together)
- Explore opportunities to reorganize agencies
- Family Mentoring Program

Outcome 6: All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work and independence.

Problem Statement
Michigan has embraced the importance of transition for youth from children services to adult services. Michigan is committed to creating a successful transition pathway. Barriers to the pathway include lack of a safety net to support adults with special health care needs as well as poor coordination and availability and support services for youth and adults.

Recommendations
Priority Recommendations presented to large group
Create addition services to cover adults: health care, insurance coverage, CSHCS buy-in, pharmacy coverage, mental health
Create standard requirements and training for all youth with special health care needs at age 14. Review at least annually and expand who wouldn't be eligible to bill for care coordination for transition planning.
Create a collaboration between organizations and/or agencies that serve youth and those that serve adults
Identify all available services and establish a state-wide point of entry for transition services.

Recommendations	
Priority Recommendations **presented to large group**	
Offer training/education awareness to providers and medical schools. Continue work to establish Medical Home concept. Provide incentives and or increased reimbursement rates for providers. (Emphasize transition)	

Strengths and Opportunities
- Transition staff person
- Info distribution (Letters)
- Interest and support within the program and MDCH
- LHD-Care coordination/Case Management (early and often)
- Transition process for private duty nursing
- Focus on transition
- Local Health- Mechanism for payment for care coordination
- Blog
- Address Guardianship Alternatives
- Enrollment/Utilization Data
- EATT- Connectiveness/sharing/network
- Transition Manual
- Family involvement
- Family practice—medical home
- Center for independent living (15 within the state)
- Inter-Agency Resources
- Dept of education for all over age 14

Weaknesses and Threats
- Lack of prescription coverage
- Unmanageable co-pays
- Local Health Dept's not fully funded
- Disconnect between children and adult programs
- Lack of adult programs
- Different "language" between child and adult resources
- Insurers don't think about unique needs of this population
- Prevention (lack of)
- Parents fostering dependency on parent
- Lack of transition to MRS services
- Tight timeframe for evaluation to qualify for programs such as MCTI—when transitioning from special ed
- No coordination follow-up how successful transition process has been
- Overwhelming when transitioning
- Diabetic other supplies—money
- Affordable Health Care—money
- Transportation, lacking especially in rural areas
- Struggles with Dept of Human Services
- No single point of entry
- Lack of space in waivers/waiting list
- Lack of incentive

Brainstorming Ideas

- All young adults with special care needs will initiate a transition plan by 14 (Local level through medical home and or care coordinator)
- COBRA-like coverage
- Freedom to work (transition)
- Administrative support-focus/family support
- Guardianship alternatives

Parking Lot
- Data: Coordination with Special ed (up to age 26) is there data to let us know if youth could qualify for other special ed programs POHI? Could be included in transition process
- How many are in foster care system?
- Certificate of credible coverage—do they work? CSHCS and Medicaid—what diagnosis do they work for? What kind of health plans accept it? How can we encourage this within companies
- Improve website at state level- provide increased ability to search topics (spider bots)