



Region 4 Genetics Care Coordination Workgroup

December 16, 2008

11 am CST/ 12 pm EST

Call in number: 1/866/489-0573; *4545164*

Agenda

- | | |
|--|---------------|
| I) Welcome and Introductions
Please give your name, state and role in the R4 Collaborative | Arveson |
| II) Emergency Care Plan (Handout)
A) Region 4 Advisory Group Action | Arveson/Wood |
| III) Medical Care Coordination
A) Subcommittee product – Draft Plan (Handout)
B) Next steps
a. Review and input from Workgroup
b. Review and input from Stakeholder Groups (Handout) | Wood/Hiner |
| IV) Care Plans
A) Subcommittee product (Handout)
B) Next Steps
a. Provide samples / Turn the items into templates
b. Workgroup assistance | Arveson/Hiner |
| V) Reminders
Please enter your contact information
http://Region4genetics.org | Hiner |
| VI) Other news and issues | Group |



**Region 4 Genetics Collaborative Care Coordination Workgroup
Recommendation to the Advisory Group
November 17th, 2008**

RE: Midwest Emergency Medical Services for Children Information System (MEMSCIS)

Goal

Promote care coordination for children with heritable disorders

Strategies

- Promote care plans (emergency) for children with heritable disorders
- Implement use of emergency information forms specific to the needs of children with heritable disorders

Workgroup Activities Supporting This Recommendation

There are an estimated 250 babies born in Region 4 each year with inborn errors of metabolism ascertained through expanded newborn screening by MS/MS and many more children are born in Region 4 each year with other heritable conditions. Both populations of children face unique concerns in an emergency and would benefit from coordinated plans of care that are created in collaboration with their medical home and specialty health care providers.

The Region 4 Care Coordination Workgroup Emergency Subcommittee engaged in a process to become familiar with best- and promising practices based on findings in relevant literature, identify existing tools, assessing the identified tools, selecting a tool for adaptation to meet the needs of children with heritable disorders in an emergency situation, and assessing the selected tool for adaptability, feasibility, and resources needed.

A. Identifying and reviewing emergency information forms as clinical tools for improving emergency care for children with heritable disorders.

Several emergency care plans were reviewed and evaluated using a multi-step process. Emergency care plans reviewed included: Individual care plans currently being used by specialists' with Region 4 who treat children with heritable disorders; emergency plans/protocols developed for families and for professionals and promoted by disorder specific support groups; and emergency protocols from other genetic regional collaboratives.

Initially, the committee members reviewed plans according to a basic review tool developed by the Care Coordination Workgroup that directed the reviewer to comment on plan components (information captured), format, ease of use and strengths/weaknesses. Information was summarized so that the committee could compare components found in individual plans and the format in which the emergency information was provided.

B. MEMSCIS

After the review process was completed, the subcommittee reached consensus that the MEMSCIS program meets the essential elements of emergency care plans. MEMSCIS is a HIPAA compliant, web-based communication tool that utilizes the Emergency Information Form (EIF) developed and endorsed by the American Academy of Pediatrics and the American College of Emergency Physicians¹. With permission from the patient/family; the medical home providers, specialty providers, emergency providers, and other parties involved in the child's health care all have input into the content of the EIF and can access that information in an emergency. MEMSCIS is available anywhere in the world where there is internet access, and is not tied to any one particular health care system. The data on the EIF is owned by the patient.² Reporting functions enable use by, and identification of patients by, geographic area or resource needs in event of disaster.³

The MEMSCIS plan captured components of the plans reviewed and organized them in a logical, easy-to-read format. The subcommittee also compared the components of the MEMSCIS plan to information from the Newborn Screening ACT Sheets to ascertain that the MEMSCIS format was compatible to store information from the ACT sheets.

MEMSCIS, although web-based, includes a printer-friendly option that meets the needs of families who need, or desire, to keep the information available in hard-copy as well as accessible on the web.

C. Assessing the selected strategy for feasibility, adaptability and resources needed:

The subcommittee then assessed MEMSCIS according to adaptability, feasibility and resources needed to implement

Feasibility

Previous experience with Region 4 partners demonstrates the feasibility of implementing MEMSCIS. MEMSCIS is fully implemented at the University of Minnesota Children's Hospital, Fairview for use with children who have inborn errors of metabolism, congenital adrenal hyperplasia, and other chronic health conditions. As of September 2008, 233 children with special health care needs requiring emergency care plans were enrolled in MEMSCIS. Of the 233 enrolled, 83 have inborn errors of metabolism, 81 have cardiac conditions, 18 have endocrine conditions (congenital adrenal hyperplasia), and 51 have other chronic health conditions.

Adaptability

Programming of the MEMSCIS system is flexible and can accommodate different types of services and specialties by means of using specific diagnosis, medication list, and condition-specific common presenting problems and plans of care. Negotiations are in process to expand MEMSCIS availability to the University of Illinois at Chicago for use by patients with sickle cell disease.

¹ American Academy of Pediatrics Committee on Pediatric Emergency Medicine. Emergency Preparedness for Children with Special Health Care Needs. *Pediatrics*. 1999; 4:104. Available at: <http://www.pediatrics.org/cgi/contents/full/104/4/53e>

² Development of a web-based database to manage American College of Emergency Physicians / American Academy of Pediatrics Emergency Information Forms. *ACAD Emergency Med.* March 25, 2005. Vol 12 No 3 Available at: www.aemj.org

³ American Academy of Pediatrics Committee on Pediatric Emergency Medicine. Emergency Preparedness for Children with Special Health Care Needs. *Pediatrics*. 1999; 4:104. Available at:

Indiana is considering the use of MEMSCIS for their patients with inborn errors of metabolism. A teleconference was held in October 2008 to demonstrate MEMSCIS to researchers at Northwestern University in Illinois who are interested in improving access to vital, disorder specific information at the time of emergency transfer between medical care facilities.

MEMSCIS also is adaptable to meet family needs. Several participants do not have internet access in the home. These users can be given a copy of the EIF printed directly off the MEMSCIS system website. They can keep that copy for their record or when they visit the ED when needed. Other participants have a primary language other than English. A multi-language informational DVD has been made to teach families about MEMSCIS. Languages include: English, Spanish, and Hmong.

Resources

Resources are currently available to support the expansion of MEMSCIS through Region 4 Base Funding. In 2007, the Region 4 Genetics Collaborative agreed to support the expansion of the Minnesota Emergency Medical Services for Children Information System to include all metabolic centers in all seven Region 4 states, becoming the Midwest Emergency Medical Services for Children Information System (MEMSCIS). Later in the grant cycle, MEMSCIS expansion strategies include facilitating interoperability between the web-based server (DocSite) used in the IBEM-IS (Priority 2 activity) and the web-based server (ImageTrend) used in the MEMSCIS project. This will enable the data on emergency encounters for patients with inborn errors of metabolism to be integrated with long-term follow-up data.

Recommendation to the Region 4 Genetics Collaborative Advisory Group

Support, promote and encourage the use of MEMSCIS throughout Region 4 as a clinical tool for improving emergency care to individuals with heritable disorders.

To realize this recommendation, the following next steps will be initiated:

- Restructure the MEMSCIS Advisory Board to reflect a broader group of Region 4 stakeholders (disorder specific, role, etc.) to provide input, oversight, and access to expertise as MEMSCIS is expanded to include additional heritable disorders and a broader geographic region.
- Develop an implement a process to respond to inquires about MEMSCIS to engage interested parties in a timely fashion.
- Develop an implement a marketing plan, including recruiting clinics to enroll their patients.

Medical Care Coordination Plan

Patient Information

Name: _____ DOB: _____

Female Male Race/Ethnicity identified with:

Phone: _____ Hispanic or Latino

Fax: _____ Black or African American

Email: _____ White or Caucasian

Address: _____ American Indian or Alaskan Native

City: _____ Asian/Southeast Asian or Pacific Islander

State/Zip _____ Arab or Middle Eastern American

: _____ Multi-racial

_____ Other: _____

Legal Status: Custodial Parent Guardian Health Care Representative

Minor Child Power of Attorney Informal Representative

What you should know about me/my child and family is:

Important Contacts

Emergency Contact: _____

Communication Preference: Phone Email Fax US Mail Other: _____

Primary Caregiver: _____ Relationship: _____

Contact Information: _____

(If other than above) _____

Decision Maker: _____ Relationship: _____

(If other than primary caregiver) Contact info: _____

Care Coordinator: _____ Phone: _____

Clinic/Office: _____ Email: _____

Medicaid caseworker: _____ Phone: _____

Other: _____

Connection with local "disease specific" community-based organizations/support groups:

Functional Assessment				
Activities of Daily Living	Inde- pendent	With Assistance	Depen- dent	Comments
Telephone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Meal Prep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Managing Money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Bathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Toileting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Transfer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Feeding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Health Care Self- Management	Inde- pendent	With Assistance	Depen- dent	Comments
Taking medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Refilling medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Managing health insurance issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Recognizing signs of illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Making doctor's appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Understanding medical conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Making health care decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Patient Goals

Future living goals:

Patient Goals, continued

Self-care goals: _____

Education goals: _____

Employment goals: _____

Legal goals: _____

Financial goals: _____

Medical/Treatment goals: _____

Transition to Adult Services: _____

Family History

Maternal	Paternal
<input type="checkbox"/> Unknown	<input type="checkbox"/> Unknown
<input type="checkbox"/> Cancer	<input type="checkbox"/> Cancer
<input type="checkbox"/> Diabetes	<input type="checkbox"/> Diabetes
<input type="checkbox"/> Birth Defects	<input type="checkbox"/> Birth Defects
<input type="checkbox"/> Mental Retardation/Learning Disabilities	<input type="checkbox"/> Mental Retardation/Learning Disabilities
<input type="checkbox"/> Abnormal Growth Patterns	<input type="checkbox"/> Abnormal Growth Patterns
<input type="checkbox"/> Other, specify: _____	<input type="checkbox"/> Other, specify: _____
<input type="checkbox"/> Heart Disease	<input type="checkbox"/> Heart Disease
<input type="checkbox"/> Stroke	<input type="checkbox"/> Stroke

Home Care Equipment

Company Name A/Contact: _____ Phone: _____

Company Name B/Contact: _____ Phone: _____

Company Name C/Contact: _____ Phone: _____

Oxygen
(Stationary Portable)

Pulse Oximeter (SAT)

BP Monitor
Cuff: Yes No

Wheelchair

Car seat

Apnea monitor

Trach Tube, Type/Size: _____

Suction machine/supplies

Vent, settings: _____

Feeding pump/supplies

Formula: _____

GT/GJ, Type: _____ Size: _____

IV/TPN; RX: _____ N/G Tube

Other, specify: _____

Health Insurance

Primary: _____

ID No.: _____ Anticipate Change: _____

Secondary: _____

ID No.: _____ Anticipate Change: _____

Waiver _____ Waiting List: _____

Type: _____

Diagnoses

1.	_____	ICD9	_____
2.	_____	ICD9	_____
3.	_____	ICD9	_____
4.	_____	ICD9	_____
5.	_____	ICD9	_____
6.	_____	ICD9	_____
7.	_____	ICD9	_____
8.	_____	ICD9	_____

Medical, Healthcare and Service Providers

Primary Care: _____ Peds Adult

Contact Information: _____

Specialists *(please list all that apply)*

_____	<input type="checkbox"/> Peds	<input type="checkbox"/> Adult	Phone: _____	<input type="checkbox"/> release
_____	<input type="checkbox"/> Peds	<input type="checkbox"/> Adult	Phone: _____	<input type="checkbox"/> release
_____	<input type="checkbox"/> Peds	<input type="checkbox"/> Adult	Phone: _____	<input type="checkbox"/> release
_____	<input type="checkbox"/> Peds	<input type="checkbox"/> Adult	Phone: _____	<input type="checkbox"/> release
Dental: _____	<input type="checkbox"/> Peds	<input type="checkbox"/> Adult	Phone: _____	<input type="checkbox"/> release
Vision: _____	<input type="checkbox"/> Peds	<input type="checkbox"/> Adult	Phone: _____	<input type="checkbox"/> release
Hearing: _____	<input type="checkbox"/> Peds	<input type="checkbox"/> Adult	Phone: _____	<input type="checkbox"/> release
Psych/Behavioral: _____	<input type="checkbox"/> Peds	<input type="checkbox"/> Adult	Phone: _____	<input type="checkbox"/> release
Physical Therapy: _____			Phone: _____	<input type="checkbox"/> release
Occupational Therapy: _____			Phone: _____	<input type="checkbox"/> release

Speech Therapy:	_____	Phone: _____	<input type="checkbox"/> release
Early Intervention:	_____	Phone: _____	<input type="checkbox"/> release
School contact:	_____	Phone: _____	<input type="checkbox"/> release
Other, specify:	_____	Phone: _____	<input type="checkbox"/> release

Medications, Foods and Formulas, *also include over the counter medications*

	Name	Dosage	Period Taken	Purpose
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

Preferred Pharmacy: _____ Phone: _____ Fax: _____

Allergies: _____

Medical History

Patient has an Emergency Plan No Yes If yes, check if plan is attached

Responsible physician: _____

Patient has a medical home Care Plan No Yes

If yes, responsible clinic or person

Medical History, continued

Neurological: _____

Cardiovascular: _____

Respiratory: _____

Gastrointestinal: _____

Genourinary: _____

Renal: _____

Infectious
Disease: _____

Medical History, continued

Endocrine: _____

Heme: _____

Respiratory: _____

Respiratory: _____

Rheum/Musculoskeletal: _____

Ear/Nose/Throat: _____

Skin: _____

Medical History, continued

Dental: _____

Respiratory: _____

Ophthalmologic: _____

Behavioral: _____

Psychiatric: _____

Allergies: _____

Immunizations and Dates:

Responsible Provider: _____

DtaP	1	2	3	4	5	Reactions:	_____
	_____	_____	_____	_____	_____		
DT	1	2				Reactions:	_____
	_____	_____					
Polio	1	2	3	4		Reactions:	_____
	_____	_____	_____	_____			
HIB	1	2	3	4		Reactions:	_____
	_____	_____	_____	_____			

Prevna 1 _____ 2 _____ 3 _____ 4 _____ Reactions: _____
r

Immunizations, continued

MMR 1 _____ 2 _____ Reactions: _____

HBV 1 _____ 2 _____ 3 _____ Reactions: _____

Varicella 1 _____ Booster _____ Reactions: _____

TB _____ Reactions: _____

Flu _____ Reactions: _____

Other, specify: _____ Reactions: _____

_____ Reactions: _____

_____ Reactions: _____

_____ Reactions: _____

Vaccinations that were NOT Administered

Healthcare Provider Tracking

Provider: _____ Date of Contact: _____

Means of Contact: In Office Hospital Consult Phone Consult
 Other, specify: _____

Reason for contact: _____

Updates to diagnoses: No Yes; _____

Updates to medications: No Yes; _____

Tests ordered No Yes; _____

Test Results: _____

Recommendations: _____

Healthcare Provider Tracking

Provider: _____ Date of Contact: _____

Means of Contact: In Office Hospital Consult Phone Consult
 Other, specify: _____

Reason for contact: _____

Updates to diagnoses: No Yes; _____

Updates to medications: No Yes; _____

Tests ordered No Yes; _____

Test Results: _____

Recommendations: _____

Healthcare Provider Tracking

Provider: _____ Date of Contact: _____

Means of Contact: In Office Hospital Consult Phone Consult
 Other, specify: _____

Reason for contact: _____

Updates to diagnoses: No Yes; _____

Updates to medications: No Yes; _____

Tests ordered No Yes; _____

Test Results: _____

Recommendations: _____

Healthcare Provider Tracking

Provider: _____ Date of Contact: _____

Means of Contact: In Office Hospital Consult Phone Consult
 Other, specify: _____

Reason for contact: _____

Updates to diagnoses: No Yes: _____

Updates to medications: No Yes: _____

Tests ordered No Yes: _____
Test Results: _____
Recommendations: _____

Healthcare Provider Tracking

Provider: _____ Date of Contact: _____
Means of Contact: In Office Hospital Consult Phone Consult
 Other, specify: _____
Reason for contact: _____
Updates to diagnoses: No Yes; _____
Updates to medications: No Yes; _____
Tests ordered No Yes; _____
Test Results: _____
Recommendations: _____

Healthcare Provider Tracking

Provider: _____ Date of Contact: _____
Means of Contact: In Office Hospital Consult Phone Consult
 Other, specify: _____
Reason for contact: _____
Updates to diagnoses: No Yes; _____
Updates to medications: No Yes; _____
Tests ordered No Yes; _____
Test Results: _____
Recommendations: _____

Healthcare Provider Tracking

Provider: _____ Date of Contact: _____
Means of Contact: In Office Hospital Consult Phone Consult
 Other, specify: _____
Reason for contact: _____
Updates to diagnoses: No Yes; _____
Updates to medications: No Yes; _____

Tests ordered No Yes: _____
Test Results: _____
Recommendations: _____

Healthcare Provider Tracking

Provider: _____ Date of Contact: _____
Means of Contact: In Office Hospital Consult Phone Consult
 Other, specify: _____
Reason for contact: _____
Updates to diagnoses: No Yes: _____
Updates to medications: No Yes: _____
Tests ordered No Yes: _____
Test Results: _____
Recommendations: _____

Healthcare Provider Tracking

Provider: _____ Date of Contact: _____
Means of Contact: In Office Hospital Consult Phone Consult
 Other,
specify: _____
Reason for contact: _____
Updates to diagnoses: No Yes; _____
Updates to medications: No Yes; _____
Tests ordered No Yes; _____
Test Results: _____
Recommendations: _____

Healthcare Provider Tracking

Provider: _____ Date of Contact: _____
Means of Contact: In Office Hospital Consult Phone Consult
 Other, specify: _____
Reason for contact: _____
Updates to diagnoses: No Yes: _____
Updates to medications: No Yes: _____

Tests ordered

No Yes:

Test Results:

Recommendations:

Medical Care Coordination Plan Assessment

Score each statement with the following numerical scale: **1 = strongly disagree; 2 = neutral, 3 = strongly agree**

				Disagree	Neutral	Agree	
		Easy to use			Easy to understand		
1. The plan format is:		1	2	3	1	2	3
Comments:							
2. Please rate each section:		Information is complete			Information is helpful		
		Disagree	Neutral	Agree	Disagree	Neutral	Agree
A.	<u>Patient Information</u>	1	2	3	1	2	3
Comments:							
B.	<u>Important Contacts</u>	1	2	3	1	2	3
Comments:							
C.	<u>Functional Assessment</u>	1	2	3	1	2	3
Comments:							
D.	<u>Patient Goals</u>	1	2	3	1	2	3
Comments:							
E.	<u>Family History</u>	1	2	1	1	2	3
Comments:							
F.	<u>Home Care Equipment</u>	1	2	3	1	2	3
Comments:							
G.	<u>Health Insurance</u>	1	2	3	1	2	3
Comments:							
H.	<u>Diagnoses</u>	1	2	3	1	2	3
Comments:							
I.	<u>Medical, Healthcare and Service Providers</u>	1	2	3	1	2	3
Comments:							
J.	<u>Medications, Foods, Formulas & over the counter medications</u>	1	2	3	1	2	3
Comments:							
K.	<u>Medical History</u>	1	2	3	1	2	3
Comments:							
L.	<u>Immunizations and Dates</u>	1	2	3	1	2	3
Comments:							
M.	<u>Healthcare Provider Tracking</u>	1	2	3	1	2	3
Comments:							
3. <u>There is adequate space to collect family concerns and preferences</u>		1	2	3	1	2	3
Comments:							
4. <u>Procedures/foods/activities to be avoided are documented and easy to identify</u>		1	2	3	1	2	3
Comments:							
5. <u>Unique challenges and strengths of the child are documented</u>		1	2	3	1	2	3
Comments:							
6. <u>The plan allows for clear specification of which medical/healthcare providers are responsible for which services</u>		1	2	3	1	2	3
Comments:							

Score each statement with the following numerical scale: 1 = strongly disagree; 2 = neutral, 3 = strongly agree			
	Disagree	Neutral	Agree
7. This plan will improve communication and coordination of information between medical/health care providers Comments:	1	2	3
8. The plan includes adequate prompts and opportunities to include disorder specific information Comments:	1	2	3
9. I would be likely to use this plan with my patients with genetic conditions/heritable disorders or other special health care needs Comments:	1	2	3
10. Additional comments/suggestions?			

Reviewer:	Date completed:				
Name of Care Plan:					
Source (agency/organizations/entity/etc):					
URL:					
A. Care Plan Overview					
<i>Basic information is included that provides:</i>					
1. Are instructions/guidelines/suggestions for using the care plan provided? <input type="checkbox"/>					
Yes <input type="checkbox"/> No <input type="checkbox"/>					
If Yes, please rate the instructions provided using the following items and scale:					
	1	2	3	4	5
	Poor	Fair	Average	Good	Excellent
Clarity of information provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reading level	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Amount of information provided	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B. Initiating or getting the care plan started					
4. Is it clear who can initiate the care plan? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Other					
If Yes, please indicate who may initiate this care plan: <input type="checkbox"/> Provider <input type="checkbox"/> Family <input type="checkbox"/> Both					
5. Are their restrictions in place as to who can initiate the care plan or are there controls in place? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unsure					
If Yes, please describe					
6. Is a process for initiating the care plan provided/suggested? <input type="checkbox"/> Yes <input type="checkbox"/> No					
If yes, does the process include suggestions/strategies for encouraging and empowering parents to					
Talk with their medical team? <input type="checkbox"/> Yes <input type="checkbox"/> No					
Follow a care plan? <input type="checkbox"/> Yes <input type="checkbox"/> No					
Write things down? <input type="checkbox"/> Yes <input type="checkbox"/> No					
Please comment on the strengths/weaknesses of the prescribed process to <i>initiate</i> the care plan:					
C. Getting the information in – and out – of the care plan					
1. Is there a process in place for removing or correcting information in the care plan? <input type="checkbox"/> Yes <input type="checkbox"/> No					
If yes, please describe					
8. Are there controls built into the care plan that allow or prohibit access to information within the care plan? <input type="checkbox"/> Yes <input type="checkbox"/> No					
If yes, please describe					
9. Does the care plan provide information to help family members think about and address issues of confidentiality/privacy protecting information (i.e. who has access to information)? <input type="checkbox"/> Yes <input type="checkbox"/> No					
9a. If Yes, to whom such information directed? <input type="checkbox"/> providers <input type="checkbox"/> families <input type="checkbox"/> both families and providers					
9b. If Yes, Please describe					

	10. If it is electronic, which of the following are automatically recorded when any changes are made? (check all that apply) <input type="checkbox"/> Name of person who made changes <input type="checkbox"/> Date when changes were made
	Please comment on the strengths/weaknesses of the way this care plan provides information to address issues of confidentiality/privacy/protecting information
D.	Format
	10. In which of the formats is the care plan available?
	<input type="checkbox"/> Accordion File
	<input type="checkbox"/> Binder
	<input type="checkbox"/> Electronic with print option or save to flash drive
	<input type="checkbox"/> Electronic – download, fill-in and print
	<input type="checkbox"/> Electronic with web-based option
	<input type="checkbox"/> Other; Please describe
	12. Is the care plan arranged in modules or sections that allow for choosing what to include? <input type="checkbox"/> Yes <input type="checkbox"/> No
	11. Are there space limitations/restrictions on the amount of information that can be included? <input type="checkbox"/> Yes <input type="checkbox"/> No
	If yes, please describe
	12. Please comment on the strengths/weaknesses of the format(s) in which this care plan is available:
E.	Care Plan Components
	13. Please check to indicate this type of information is included in the care plan
	<input type="checkbox"/> Medical care
	<input type="checkbox"/> Insurance information
	<input type="checkbox"/> Medication list and schedule,
	<input type="checkbox"/> Health history
	<input type="checkbox"/> Drug/pharmaceutical now
	<input type="checkbox"/> Drug/pharmaceutical history
	<input type="checkbox"/> Nutritional Needs and Schedule
	<input type="checkbox"/> Allergies (medical, food and environmental)
	<input type="checkbox"/> Treatment(s) and treatment schedule (ie. Respiratory...Nutrition...)
	<input type="checkbox"/> “Typical day” info
	<input type="checkbox"/> How the child communicates
	<input type="checkbox"/> “About Me” information
	<input type="checkbox"/> Mobility Needs
	<input type="checkbox"/> Rest/Sleep Patterns/Needs
	<input type="checkbox"/> Social/Play Patterns/Needs
	<input type="checkbox"/> Information to inform school personnel
	<input type="checkbox"/> Information to inform child care provider
	<input type="checkbox"/> Transportation Needs
	<input type="checkbox"/> Contact information – family, emergency
	<input type="checkbox"/> Contact Information (Pharmacist, Specialist, Durable Medical Equipment and Supplies)
	<input type="checkbox"/> Other, Please list
F.	Audience – Who is the care plan intended to provide information for/to?

14. Does the care plan suggest/help you think about who might need access to information about your child to facilitate your child's quality of care (life) (outcomes)? <input type="checkbox"/> Yes <input type="checkbox"/> No	
If Yes, please check the audiences the care plan includes/identifies	
<input type="checkbox"/>	Those who regularly care for your child
<input type="checkbox"/>	teacher
<input type="checkbox"/>	bus aide
<input type="checkbox"/>	Other, please describe
<input type="checkbox"/>	Those who occasionally provide care for your child
<input type="checkbox"/>	information specific to substitute teacher
<input type="checkbox"/>	substitute bus aide
<input type="checkbox"/>	Other, please describe
G. Adaptability	
15	Does the care plan help you think about how your child's needs change as they grow? <input type="checkbox"/> Yes <input type="checkbox"/> No
If yes, please describe	
16	Does the care plan prompt you to regularly review and update information (e.g., every six months? Quarterly?)? <input type="checkbox"/> Yes <input type="checkbox"/> No
If Yes, please describe how the prompt is provided:	
H. Transitions	
17	Does the care plan help you think about transition to adult services and think about questions to help you plan, such as: <i>please check all that apply</i>
<input type="checkbox"/>	When will planning for transition to adult services start?
<input type="checkbox"/>	What program changes will be necessary?
<input type="checkbox"/>	What is needed for my child and how is this decided?
<input type="checkbox"/>	What services are available?
<input type="checkbox"/>	What are the options available?
<input type="checkbox"/>	What will my families new rights and responsibilities be?
<input type="checkbox"/>	How and when will the transition occur?
<input type="checkbox"/>	Who else, in my child's life, needs information because of the transition?
18	Does the care plan help you think about other changes, i.e. transitions (e.g. moving from a toddler program into a preschool; changing day care providers, etc.) and think about questions to help you plan, such as: <i>please check all that apply</i>
<input type="checkbox"/>	When will planning for this transition start?
<input type="checkbox"/>	What program changes will be necessary?
<input type="checkbox"/>	What is needed for my child and how is this decided?
<input type="checkbox"/>	What services are available?
<input type="checkbox"/>	What are the options available?
<input type="checkbox"/>	What will my families new rights and responsibilities be?
<input type="checkbox"/>	How and when will the transition occur?
<input type="checkbox"/>	Who else, in my child's life, needs information because of the transition?
I. Goals and measurements	

	19 Does the care plan allow you to set and complete goals for the future that can be evaluated regularly? <input type="checkbox"/> yes <input type="checkbox"/> No
J.	User Friendliness
	20 Is the care plan user-friendly, i.e. easy to use? Does the benefit of using balance the effort? <input type="checkbox"/> yes <input type="checkbox"/> No
	Please comment on the user-friendliness or balance between benefit and effort
K.	Use with Genetic/heritable disorders
	21 Can this care plan be adapted for children with heritable disorders? <input type="checkbox"/> Yes <input type="checkbox"/> No
	If yes, please describe:
	What could transfer easily?
	What would need to be adapted?

L.	Advocacy and Resources
20. Does the plan provide information to help families identify resources to help them advocate for their child's best interest as issues arise? <input type="checkbox"/> Yes <input type="checkbox"/> No	
If Yes, please describe <input type="checkbox"/>	

These issues are still under discussion:

1. Transition - how should care plans help families identify "transition situations"? Is it appropriate to include a broader transition mindset in the care plan (e.g. beyond focusing on transitioning from pediatric/adolescent health care to adult medical care providers to include other transitions that occur throughout the life span?
2. Goals:
3. Is it appropriate to include child and family goals in care coordination plans?
How are goals established and selected for inclusion in a care coordination plan?
Child may have multiple goals identified by individual systems. Would a goal sheet to record the goal with steps to achieve and steps to measure progress be helpful?

CSHCN has a transition plan group

What type of physician would be

Demographic target - where the kids are. Where the physicians are a little more progressive minded

Can we tie IEP in?

See the larger picture - everything the child does medically

Audiences - other add therapists, who else would you think it is important to know this about your child?