



Region 4 Genetics Care Coordination Workgroup

January 27, 2009

11 am CST/ 12 pm EST

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

Agenda

- I) Welcome and Introductions
Arveson/Wood
Please give your name, state and role in the R4 Collaborative

- III) Medical Care Coordination
Wood/Hiner
 - A) Review REVISED draft plan (Handout 1)
 - B) Review and input from Stakeholder Groups (Handout 2)

- IV) Care Plans
Arveson/Hiner
 - A) Subcommittee product (Handout 3)
 - B) Next Steps
 - a. Provide samples / Turn the items into templates
 - b. Workgroup assistance

- V) Reminders Hiner
Please enter your contact information
<http://Region4genetics.org>

- VI) Other news and issues Group

Care Coordination Workgroup Telemeeting Notes

Meeting: Monthly workgroup telemeeting	Meeting Date: Tuesday, December 18, 2008
Co-Leads: Jennifer Arveson; Kathy Wood	Meeting time: 11 am CT/ 12 pm ET
Facilitator: Sally J. Hiner, Region 4 Genetics Collaborative Senior Project Coordinator	Meeting Place: Telemeeting
Participating: , Linda Drawhorn, IL; Rylin Rodgers, Kathy Wood, IN; Anne Weaver, KY; Jehad Adwan, Jennifer Arveson, MN; David Hoffman, Donna Gore Olsen, OH; Sally J. Hiner, Region 4.	

Agenda Item	Discussion	Recommendation/Action	Follow up
I. State Roll Call	Jennifer Arveson welcomed everyone. Introductions occurred by state roll call		
II. Emergency Care Plan (Handout 1) MEMSCIS Recommendation	Jennifer Arveson and Kathy Wood presented a recommendation to the Region 4 Advisory Group in November 2008 on behalf of this workgroup. The recommendation, to: Support, promote and encourage the use of MEMSCIS through Region 4 as a clinical tool for improving emergency care to individuals with heritable disorders, was adopted. The written recommendation (Handout 1) includes implementation strategies. A MEMSCIS Advisory group is being formed to provide guidance to this evolving tool.		
III. Medical Care	CCWG Telemeeting participants engaged in a	Sally Hiner will revise the draft	Distribute revised plan to

Agenda Item	Discussion	Recommendation/Action	Follow up
Coordination A) Draft plan	<p>detailed review and critique of the plan.</p> <p>CCWG members also discussed the need for best practices in supporting family members – and healthcare providers – in completing this tool. Important connections to make include:</p> <ul style="list-style-type: none"> • Where to fill out the form • When to fill out the form • How to fill out the form (detailed instructions for each section) <p>Considerations for available format should include jump drive.</p>	<p>plan based on consensus decisions of the group made during this telemeeting.</p> <p>Future CCWG agenda items are:</p> <ol style="list-style-type: none"> 1) detailed instructions for completing the form 2) best practices in supporting families to complete the form 3) formats for distribution 	<p>workgroup members for review of revisions (Hiner)</p> <p>Review revised plan prior to telemeeting to prepare for discussion (CCWG members)</p>
B) Input from stakeholder groups	Tabled due to lack of time	Put on January Agenda (Hiner)	Re-distribute relevant materials (Hiner)
IV. Care Plans	Tabled due to lack of time	Put on January Agenda (Hiner)	Re-distribute relevant materials (Hiner)
V. Reminders	CCWG members were reminded to please enter their contact information in the website member director www.region4genetics.org		
VI. Next Meeting	Tuesday, January 27, 2009 11 1m CT / 12 pm ET		
Notes by Hiner			

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

Asian/Southeast Asian or Pacific Islander

City: _____

Arab or Middle Eastern American

Multi-racial

State: _____ Zip Code: _____

Other: _____

Parent/Guardian Name: _____

Relationship: Custodial Parent(s) Guardian Health Care Representative

Minor Child Power of Attorney Informal Representative

Contact Information:

(if other than above): _____

Communication Preference: Phone Email Fax US Mail Other: _____

Primary Caregiver: _____ Relationship: _____

(if other than above)

Contact Information: _____

(if other than above): _____

Communication Preference: Phone Email Fax US Mail Other: _____

Additional Important Contacts

Emergency Contact: _____ Relationship: _____

Contact Information: _____

Communication Preference: Phone Email Fax US Mail Other: _____

Decision Maker: _____ Relationship: _____

& Contact Information: _____

(If other than primary)

caregiver)

Care Coordinator: _____ Phone: _____
Clinic/Office: _____ Email: _____
Medicaid caseworker: _____ Phone: _____
Other: _____

Health Insurance & Medical Assistance Benefits

Primary: _____ Phone: _____
ID #: _____ Anticipate change: _____
Secondary: _____ Phone: _____
ID #: _____ Anticipate change: _____
Next: _____ Phone: _____
ID# _____ Anticipate change: _____
Next: _____ Phone: _____
ID #: _____ Anticipate change: _____
Waiver Type: _____ Waiting list: _____

Home Care Equipment

Company A Name/Contact: _____ Phone: _____
Company B Name/Contact: _____ Phone: _____
Company C Name/Contact: _____ Phone: _____
 Oxygen; if checked also indicate: Stationary Portable
 Pulse Oximeter (SAT)
 BP Monitor Cuff: Yes No
 Wheelchair
 Car seat
 Trach Tube, Type/Size: _____
 Suction machine/supplies Vent, settings: _____
 Feeding pump/supplies Formula: _____
 GT/GJ, Type: _____ Size: _____
 Apnea monitor

N/G Tube

IV/TPN; RX:

Other, specify:

Functional Assessment					
Activities of Daily Living (ADL)	Independent	With Assistance	Dependent	Not Age applicable	Comments
Toileting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Feeding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Dressing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Bathing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Transfer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Telephone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Meal Prep	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Housework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Transportation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Managing Money	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Health Care Self-Management	Independent	With Assistance	Dependent	Not Age applicable	Comments
Taking medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Recognizing signs of illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Making doctor's appointments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Understanding medical conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Refilling medicines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Managing health insurance issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Making health care decisions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Patient Goals	What do you want for your child?	What are your child's goals?
---------------	----------------------------------	------------------------------

Life Domain	Parent Goal	Child Goal/Desires
Self-care		
Medical/ Treatment		
Education		
Recreational		
Spiritual/ Religious		
Employment		
Financial		
Transition to adult Services		
Future living		
Legal		

Diagnoses

1. _____ Age at DX: _____ ICD9 _____
2. _____ Age at DX: _____ ICD9 _____
3. _____ Age at DX: _____ ICD9 _____

4.	_____	Age at DX: _____	ICD9 _____
5.	_____	Age at DX: _____	ICD9 _____
6.	_____	Age at DX: _____	ICD9 _____
7.	_____	Age at DX: _____	ICD9 _____
8.	_____	Age at DX: _____	ICD9 _____

Medical, Healthcare and Service Providers

Primary Care: _____ Peds Adult

Contact Information: _____

Specialists *(please list all that apply – Name & Specialty)*

_____	<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
_____	<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
_____	<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

Psych/Behavioral: _____ Peds Adult Phone: _____ release

Dental: _____ Peds Adult Phone: _____ release

Vision: _____ Peds Adult Phone: _____ release

Hearing: _____ Peds Adult Phone: _____ release

Physical Therapy: _____ Phone: _____ 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
Other, specify:	_____	Phone: _____	<input type="checkbox"/> release

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

** Please continue on additional page, if necessary*

	Name	Dosage	Period Taken	Purpose
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				
11.				

12.				
13.				
14.				
15.				

Preferred Pharmacy: _____ Phone: _____ Fax: _____

Allergies/Allergic Reactions	
Allergies:	Reaction

Medical History

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

If yes, Responsible physician: _____

Patient has a medical home Care Plan No Yes

If yes, responsible person
& Clinic

Neurological:	
---------------	--

Cardiovascular:	
Respiratory:	
Gastrointestinal:	
Genourinary:	
Renal:	
Infectious Disease:	
Endocrine:	
Heme:	
Rheum/ Musculoskeletal:	
Ear, Nose & Throat	
Skin	
Dental	

Ophthalmologic:	
Behavioral	
Psychiatric	
Other, Specify	

Family History	
Maternal	Paternal
<input type="checkbox"/> Unknown _____	<input type="checkbox"/> Unknown _____
<input type="checkbox"/> Birth Defects _____	<input type="checkbox"/> Birth Defects _____
<input type="checkbox"/> Diabetes _____	<input type="checkbox"/> Diabetes _____
<input type="checkbox"/> Heart Disease _____	<input type="checkbox"/> Heart Disease _____
<input type="checkbox"/> Stroke _____	<input type="checkbox"/> Stroke _____
<input type="checkbox"/> Cancer _____	<input type="checkbox"/> Cancer _____
<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 _____	<input type="checkbox"/> Other _____
Sibling 1	Sibling 2
<input type="checkbox"/> Unknown _____	<input type="checkbox"/> Unknown _____
<input type="checkbox"/> Birth Defects _____	<input type="checkbox"/> Birth Defects _____
<input type="checkbox"/> Diabetes _____	<input type="checkbox"/> Diabetes _____
<input type="checkbox"/> Heart Disease _____	<input type="checkbox"/> Heart Disease _____
<input type="checkbox"/> Stroke _____	<input type="checkbox"/> Stroke _____
<input type="checkbox"/> Cancer _____	<input type="checkbox"/> Cancer _____
<input type="checkbox"/> Mental Retardation/ Learning Disabilities _____	<input type="checkbox"/> Mental Retardation/ Learning Disabilities _____

Learning Disabilities _____ <input type="checkbox"/> Abnormal Growth Patterns _____ <input type="checkbox"/> Other	Learning Disabilities _____ <input type="checkbox"/> Abnormal Growth Patterns _____ <input type="checkbox"/> Other
---	---

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:	_____
Prevnar	1	_____	2	_____	3	_____	4	_____			Reactions:	_____

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 & Reason

Vaccine	Reason for not administering

Additional Family Information

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

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

Comments/Notes: _____

Healthcare Provider Update

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 Update

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 Update

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 Update

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 Update

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 Update

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 Update

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 Update

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 Update

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 Update

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 Update

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 Update

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 Update

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 Update

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 Update

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 Update

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.	Patient Information	1	2	3	1	2	3
Comments:							
B.	Additional Important Contacts	1	2	3	1	2	3
Comments:							
C.	Health Insurance & Medical Assistance Benefits	1	2	3	1	2	3
Comments:							
D.	Home Care Equipment	1	2	3	1	2	3
Comments:							
E.	Functional Assessment	1	2	3	1	2	3
Comments:							
F.	Patient Goals	1	2	3	1	2	3
Comments:							
G.	Diagnoses	1	2	3	1	2	3
Comments:							
H.	Medical, Healthcare and Service Providers	1	2	3	1	2	3
Comments:							
I.	Medications, Foods, Formulas & over the counter medications	1	2	3	1	2	3
Comments:							
J.	Allergies/Allergic Reactions	1	2	3	1	2	3
Comments:							
K.	Medical History	1	2	3	1	2	3
Comments:							
L.	Family History	1	2	3	1	2	3
Comments:							
M.	Immunizations and Dates	1	2	3	1	2	3
Comments:							
N.	Additional Family Information	1	2	3	1	2	3
Comments:							
O.	Healthcare Provider Updates	1	2	3	1	2	3
Comments:							
3.	There is adequate space to collect family concerns and preferences	1	2	3	1	2	3
Comments:							
4.	Procedures/foods/activities to be avoided are documented and easy to identify	1	2	3	1	2	3
Comments:							
5.	Unique challenges and strengths of the child are documented	1	2	3	1	2	3
Comments:							

6.	The plan allows for clear specification of which medical/healthcare providers are responsible for which services	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	1	2	3
Comments:				
8.	The plan includes adequate prompts and opportunities to include disorder specific information	1	2	3
Comments:				
9.	I would be likely to use this plan with my patients with genetic conditions/heritable disorders or other special health care needs	1	2	3
Comments:				
10.	Additional comments/suggestions?			

Care Coordination Plan Assessment

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	
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	

Care Coordination Plan Assessment

	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

Care Coordination Plan Assessment

	<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:

Care Coordination Plan Assessment

	What could transfer easily?
	What would need to be adapted?

Care Coordination Plan Assessment

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?