



Care coordination Workgroup  
Telemeeting Agenda

Tuesday, August 26<sup>th</sup>, 2008 11 am CT/12 pm ET  
1/866/489-0573; at the prompt, enter \*4545164\*

- |   |                  |
|---|------------------|
| I. Welcome & Role Call by State   | Jennifer Arveson |
| II. Regional Meeting Update   | Members          |
| III. HRSA Performance Review – focus on Care Coordination<br>( <i>Handout</i> ) | Sally Hiner      |
| IV. Subcommittee Updates  | Kathy Wood       |
| Care Coordination – ( <i>Handout</i> )  | Members          |
| Progress to date  |                  |
| Need from CC WG   |                  |
| CC WG reaction/recommendations  |                  |
| Next Steps  |                  |
| Emergency Plan  | Members          |
| Progress to date  |                  |
| Need from CC WG   |                  |
| CC WG reaction/recommendations  |                  |
| Next Steps  |                  |
| Care Plan – ( <i>Handout</i> )  | Members          |
| Progress to date  |                  |
| Need from CC WG   |                  |
| CC WG reaction/recommendations  |                  |
| Next Steps  |                  |
| V. Announcements  | Members          |
| VI. Adjourn   | Jennifer Arveson |

Reviewer:		Date completed:				
Name of Care Plan:						
Source (agency/organizations/entity/etc):						
URL:						
<b>A. Care Plan Overview</b>						
<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>B. Initiating or getting the care plan started</b>						
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:						
<b>C. Getting the information in – and out – of the care plan</b>						
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.	<b>Format</b>
	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.	<b>Care Plan Components</b>
	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"/> “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.	<b>Audience – <i>Who is the care plan intended to provide information for/to?</i></b>
	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
<b>G. Adaptability</b>		
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:	
<b>H. Transitions</b>		
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?
<b>I. Goals and measurements</b>		
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	
<b>I. User Friendliness</b>		
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	
<b>J. Use with Genetic/heritable disorders</b>		
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?	

<b>K</b>	<b>Advocacy and Resources</b>
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?

Care Coordination Performance Improvement Options  
*(prioritized order)*

1. Make care plan web-based and menu driven
2. Collaborate with disease-specific resources to develop tailored care plans. Linked to:
  - a. No standardization across the states and some are more basic and some more detailed
  - b. AAP has model care plans but not as comprehensive as families would like
  - c. Existing care plans don't address specific genetic disorders
3. Pilot with ACMG to promote the use of care plans with their geneticists and then with lessons learned – spread to other disease specific groups (ie, cystic fibrosis) after researching whether they already have care plans available. Relates to:
  - d. Utilize electronic as well as print media
  - e. Define population – families, providers (PCP and Specialty)
4. To target PCPs to pilot in one state (Michigan) of record for children diagnosed through NBS. Linked with:
  - f. Linking with Electronic Health Record (this may fall off the list)
  - g. Utilize electronic as well as print media

# DRAFT – Medical Care Coordination Document

Revised 9-11-08

## Patient Information

Name: \_\_\_\_\_ DOB: \_\_\_\_\_

Male  Female

Address: \_\_\_\_\_ Race/Ethnicity

City/State/Zip: \_\_\_\_\_   African American  Caucasian

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_  American Indian  Hispanic

Email: \_\_\_\_\_  Asian  Other

Emergency Contact: \_\_\_\_\_

Communication Preference:  Phone \_\_\_\_\_  Fax \_\_\_\_\_

Email \_\_\_\_\_  Mail  Other \_\_\_\_\_

Decision Maker: \_\_\_\_\_ Relationship: \_\_\_\_\_

Legal Status:  Guardian  Health Care Representative  Power of Attorney

Informal Rep  Minor Child

Primary Caregiver: \_\_\_\_\_ Relationship: \_\_\_\_\_

Contact information: \_\_\_\_\_  
(if other than above) \_\_\_\_\_

Health Insurance Plan: Primary \_\_\_\_\_

ID No: \_\_\_\_\_ Anticipate change: \_\_\_\_\_

Secondary \_\_\_\_\_

ID No: \_\_\_\_\_ Anticipate change: \_\_\_\_\_

Waiver Type: \_\_\_\_\_ Waiting List: \_\_\_\_\_

**Patient Says "What you should know about my child and family is (i.e., How does your child communicate?):** \_\_\_\_\_

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## Diagnoses

1. \_\_\_\_\_ ICD9 \_\_\_\_\_
2. \_\_\_\_\_ ICD9 \_\_\_\_\_
3. \_\_\_\_\_ ICD9 \_\_\_\_\_
4. \_\_\_\_\_ ICD9 \_\_\_\_\_
5. \_\_\_\_\_ ICD9 \_\_\_\_\_
6. \_\_\_\_\_ ICD9 \_\_\_\_\_
7. \_\_\_\_\_ ICD9 \_\_\_\_\_
8. \_\_\_\_\_ ICD9 \_\_\_\_\_

## Medical and Service Providers

### Health Care Providers

Primary Care: \_\_\_\_\_  Peds  Adult; Plan for change:

Contact Information: \_\_\_\_\_

Specialists:

- \_\_\_\_\_  Peds  Adult Phone: \_\_\_\_\_  release
- \_\_\_\_\_  Peds  Adult Phone: \_\_\_\_\_  release
- \_\_\_\_\_  Peds  Adult Phone: \_\_\_\_\_  release
- \_\_\_\_\_  Peds  Adult Phone: \_\_\_\_\_  release
- \_\_\_\_\_  Peds  Adult Phone: \_\_\_\_\_  release
- Dental: \_\_\_\_\_  Peds  Adult Phone: \_\_\_\_\_  release
- Vision: \_\_\_\_\_  Peds  Adult Phone: \_\_\_\_\_  release
- Hearing: \_\_\_\_\_  Peds  Adult Phone: \_\_\_\_\_  release
- Psych/Behavior: \_\_\_\_\_  Peds  Adult Phone: \_\_\_\_\_  release

### Service Providers

- Physical Therapy Contact: \_\_\_\_\_ Phone: \_\_\_\_\_  release
- Occupational Therapy Contact: \_\_\_\_\_ Phone: \_\_\_\_\_  release
- Speech Therapy Contact: \_\_\_\_\_ Phone: \_\_\_\_\_  release
- Early Intervention Contact: \_\_\_\_\_ Phone: \_\_\_\_\_  release
- School Contact: \_\_\_\_\_ Phone: \_\_\_\_\_  release

### Service Providers

Other: \_\_\_\_\_ Phone: \_\_\_\_\_  release

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## Medical History

### Past History Summary

Neurologic-	Cardiovascular-
Respiratory-	Gastrointestinal-
Genourinary-	Renal-
Endocrine-	Infectious Disease-
Rheum/Musculoskeletal-	Heme-
Skin-	Ear Nose Throat-
Ophthal-	Dental-
Psych-	Behavior-

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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**Medications** *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: \_\_\_\_\_

**Immunizations and Dates:**

DtaP	1. __ 2. __ 3. __ 4. __ 5. __	Reactions: _____
DT	1. __ 2. __	Reactions: _____
Polio	1. __ 2. __ 3. __ 4. __	Reactions: _____
HIB	1. __ 2. __ 3. __ 4. __	Reactions: _____
Pevnar	1. __ 2. __ 3. __ 4. __	Reactions: _____
MMR	1. __ 2. __	Reactions: _____
Varicella	1. __ Booster _____	Reactions: _____
HBV	1. __ 2. __ 3. __	Reactions: _____
TB _____	Reactions: _____	
Flu _____	Reactions: _____	

Other:


Vaccinations that Were Not Administered:


**Allergies:** \_\_\_\_\_

\_\_\_\_\_

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## Home Care Equipment:

Company Name A/contact: \_\_\_\_\_ Phone: \_\_\_\_\_

Company Name B/contact: \_\_\_\_\_ Phone: \_\_\_\_\_

Company Name C/contact: \_\_\_\_\_ Phone: \_\_\_\_\_

- O2 ( stationary  portable)       Pulse oximeter (SAT)
- Apnea monitor                               Trach tube, Type/Size: \_\_\_\_\_ Cuff:  Yes  No
- Suction machine/supplies                       Vent (Settings: \_\_\_\_\_ )
- \_\_\_\_\_ )
- Feeding pump/supplies                       Formula: \_\_\_\_\_
- N/G tube     GT/GJ (Type: \_\_\_\_\_ size: \_\_\_\_\_)
- Wheelchair                                         Car seat
- BP monitor                                         IV/TPN (Rx: \_\_\_\_\_ )

Other \_\_\_\_\_

## Family History:

### Maternal:

- unknown
- Cancer       Heart Disease
- Diabetes     Stroke
- Birth defects
- Mental retardation/learning disabilities
- Abnormal growth patterns
- Other: \_\_\_\_\_

### Paternal:

- unknown
- Cancer       Heart disease
- Diabetes     Stroke
- Birth defects
- Mental retardation/learning disabilities
- Abnormal growth patterns
- Other: \_\_\_\_\_

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## Social History, Financial & Legal Information

### Social History

Family Unit: \_\_\_\_\_

Individuals residing in home: \_\_\_\_\_

Caregiver concerns: \_\_\_\_\_

\_\_\_\_\_

Source/frequency of respite from each other: \_\_\_\_\_

Home access: \_\_\_\_\_  Own  Rent

### Education/Employment

Education: Level: \_\_\_\_\_ School/District: \_\_\_\_\_ Contact: \_\_\_\_\_

Adaptive educational services: \_\_\_\_\_  IEP  Other

Employer: \_\_\_\_\_ Contact: \_\_\_\_\_

Support services: \_\_\_\_\_ Contact: \_\_\_\_\_

Previous experience/volunteer: \_\_\_\_\_

### Recreation/Social Activities:

Hobbies/interests: \_\_\_\_\_

Circle of friends: \_\_\_\_\_

Religion/Organization/Clubs: \_\_\_\_\_ Congregation: \_\_\_\_\_

Self-perceived strengths: \_\_\_\_\_

### Legal/Financial

Independent  Dependent, Contact: \_\_\_\_\_

Financial Source: \_\_\_\_\_

### Transition

Future living goals: \_\_\_\_\_

\_\_\_\_\_

Future self-care goals: \_\_\_\_\_

Future education goal: \_\_\_\_\_

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Future employment goals: \_\_\_\_\_

Future recreation/social goals: \_\_\_\_\_

Future legal goals: \_\_\_\_\_

Future financial goals: \_\_\_\_\_

**Functional Assessment:**

	Independe nt	Assistanc e	Dependent	Comments
<b>Activities of Daily Living</b>				
Telephone				
Transportation				
Shopping				
Meal prep				
Housework				
Managing money				
Bathing				
Dressing				
Toileting				
Transfer				
Feeding				
<b>Health Care Self-Management</b>				
Taking medicines				
Refilling medicines				
Managing health insurance issues				
Recognizing signs of illness				
Making doctor's appt.				
Understanding medical conditions				
Making health care decisions				

Future self-care goal: \_\_\_\_\_

\_\_\_\_\_

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## Community Resources:

Care Coordinator: \_\_\_\_\_ Phone: \_\_\_\_\_

- Medicaid Waiver Program      Child Care Assistance     Travel/Transportation Assistance  
 Food Stamps      Housing Assistance      SSI      WIC

Medicaid Caseworker: \_\_\_\_\_ Phone: \_\_\_\_\_

Other: \_\_\_\_\_

Connection with the local "disease specific" community based organization; support groups \_\_\_\_\_

\_\_\_\_\_

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## Physician Updates

Physician: \_\_\_\_\_ Date of contact: \_\_\_\_\_

Means of contact:  In office  Hospital consult  Phone consult  Other: \_\_\_\_\_

Reason for contact: \_\_\_\_\_

Updates to diagnoses:  No  Yes: \_\_\_\_\_

Updates to medications:  No  Yes: \_\_\_\_\_

Tests Ordered:  No  Yes: \_\_\_\_\_

Test Results: \_\_\_\_\_

Recommendations: \_\_\_\_\_

Physician: \_\_\_\_\_ Date of contact: \_\_\_\_\_

Means of contact:  In office  Hospital consult  Phone consult  Other: \_\_\_\_\_

Reason for contact: \_\_\_\_\_

Updates to diagnoses:  No  Yes: \_\_\_\_\_

Updates to medications:  No  Yes: \_\_\_\_\_

Tests Ordered:  No  Yes: \_\_\_\_\_

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Test Results: \_\_\_\_\_  
\_\_\_\_\_  
Recommendations: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Physician: \_\_\_\_\_ Date of contact: \_\_\_\_\_  
Means of contact:  In office  Hospital consult  Phone consult  Other: \_\_\_\_\_  
Reason for contact: \_\_\_\_\_  
Updates to diagnoses:  No  Yes: \_\_\_\_\_  
\_\_\_\_\_  
Updates to medications:  No  Yes: \_\_\_\_\_  
\_\_\_\_\_  
Tests Ordered:  No  Yes: \_\_\_\_\_  
\_\_\_\_\_  
Test Results: \_\_\_\_\_  
\_\_\_\_\_  
Recommendations: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Physician: \_\_\_\_\_ Date of contact: \_\_\_\_\_  
Means of contact:  In office  Hospital consult  Phone consult  Other: \_\_\_\_\_  
Reason for contact: \_\_\_\_\_  
Updates to diagnoses:  No  Yes: \_\_\_\_\_  
\_\_\_\_\_  
Updates to medications:  No  Yes: \_\_\_\_\_  
\_\_\_\_\_

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Tests Ordered:	<input type="checkbox"/> No	<input type="checkbox"/> Yes:	_____
Test Results:	_____		
Recommendations:	_____		
Physician:	_____	Date of contact:	_____
Means of contact:	<input type="checkbox"/> In office	<input type="checkbox"/> Hospital consult	<input type="checkbox"/> Phone consult <input type="checkbox"/> Other: _____
Reason for contact:	_____		
Updates to diagnoses:	<input type="checkbox"/> No	<input type="checkbox"/> Yes:	_____
Updates to medications:	<input type="checkbox"/> No	<input type="checkbox"/> Yes:	_____
Tests Ordered:	<input type="checkbox"/> No	<input type="checkbox"/> Yes:	_____
Test Results:	_____		
Recommendations:	_____		

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Physician: _____	Date of contact: _____
Means of contact: <input type="checkbox"/> In office <input type="checkbox"/> Hospital consult <input type="checkbox"/> Phone consult <input type="checkbox"/> Other: _____	
Reason for contact: _____	
Updates to diagnoses: <input type="checkbox"/> No <input type="checkbox"/> Yes: _____	
_____	
Updates to medications: <input type="checkbox"/> No <input type="checkbox"/> Yes: _____	
_____	
Tests Ordered: <input type="checkbox"/> No <input type="checkbox"/> Yes: _____	
_____	
Test Results: _____	
_____	
Recommendations: _____	
_____	
_____	

## Notes from Parent Telemeeting in August:

- Make available on flash drives, on the web, or electronically
- These are recommendations, take what's there and fit your needs
- Like having a universal form that can be changed to fit our needs
- The form could go on the Region 4 website then have a "print a copy link" as well
- Health Insurance Plan section "waiver type" – What does that mean? Each state has so many different waivers, it needs to go separately (for example, Kentucky got a new waiver)