

State Systems Follow-Up Workgroup Notes – Tuesday, June 29th, 2010

Workgroup Lead: Janice Bach

Facilitator: Sally Hiner

Participating: Gerri Clark (IL-CSHCN); Claudia Nash (IL-NBS); and Jacqueline Thomas (IL-EI); Bob Bowman (IN-ISDH); Linda West (IN-CSHCN); Courtney Eddy (IN-NBS); Tom Rux (IN-CSHCS); Karen Mercer (KY-EDHI); Janice Bach (MI-NBS/Genetics/BD); Joan Ehrhardt (MI-BD); Tiffany Kostelec (MI-Early Intervention); Susan Stubblebine (MN-); Anna Starr (OH-Genetics/BD); Sheryl Jones (OH-Sickle Cell); Michele Kempf-Weibel (WI-Genetics); Elizabeth Oftedahl (WI-BD); Sally Hiner and Jodi Griffin (Region 4).

Meeting Goals:

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| a) Reach consensus on charge | c) Identify existing model practices | e) Define information to be collected |
| b) Reach consensus on terminology | d) Identify systems outcomes | f) Identify next steps |

Item	Discussion/Notes	Recommendation/ Action	Follow up who/when
I. Welcome, Telemeeting Protocol & Meeting Goals – Bach/Hiner			
A. Roll Call/Introductions			
B. Telemeeting common sense guidelines/reminders:			
<ul style="list-style-type: none"> - Please be aware of background noise and feel free to use the mute function on your phone - Please state your name so we know who you are - To be mindful of everyone’s time, we always plan to start and end each meeting on time 			
II. Project Background (Handouts 1&2) - Hiner			
<ul style="list-style-type: none"> - Hiner provided a brief background/overview of the Region 4 Genetics Collaborative (R4GC) - Bach mentioned the matrixes shared at the Regional Meeting (April 2010) based on information gathered on other states); those summaries are posted to the R4 website 			
III. Workgroup Roles - Hiner			
A. Facilitators – Sally Hiner and Jodi Griffin			
Take information, guidance and recommendations to develop products			
B. Workgroup Leadership – Janice Bach			
C. Workgroup Participants			
Serve in your representative role as we address state systems follow-up issues			
<ul style="list-style-type: none"> - 1 meeting/month, for about 1-1½ hours - Each month’s meeting materials are posted to the website on the workgroup’s page - Facilitators will send the materials out via email as well 			

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IV. Workgroup Charge & Year One Plan (Handout 3) – Bach/Hiner			
<p>A. <u>Discuss the Workgroup Charge:</u> “Identify model state systems that assure linking/referral to services, facilitate surveillance and support communication among programs for children with heritable conditions and their families.”</p>	<ul style="list-style-type: none"> - What does “facilitate surveillance” mean? - Look at what are the public health outcomes for those who are identified by NBS; and tracking over time. - Surveillance from the systems perspective; are the systems working for the families? - Outcome: Integrated follow up systems or models that increase access to genetic services for those identified with a genetic condition and their families - Idea: ensure that families are in all of the available service systems and provide information about relevant services - Focus should be more than just access to genetic services, such as respite, transition services, etc. - Secondary Outcome: improving access to services for those with other conditions 	<ul style="list-style-type: none"> - Use “genetic conditions” - Focus the charge: “Explore models and outcomes to identify and recommended promising practices for state implementation (of whole model or parts) to improve their own systems”. - “Increasing access” could be limiting - Make the outcome parallel with charge. Identify the promising practices for model state systems; recommend models that states could utilize. 	<ul style="list-style-type: none"> - Hiner to update language and resend for comment
<p>B. <u>Discuss the Year One Plan</u></p>	<ul style="list-style-type: none"> - Timelines are a guide to keep group focused on one task per month; it can be adjusted as needed - Obj. 1 will be revised and completed soon - Look at how states are following children now, and what are suggestions for improvement/ outcomes to identify. - Obj. 2: Develop a survey (one option) to see differences between service systems; may need more specific information from each state to develop models - State summary/matrixes are a start, but we need more detailed information of data elements systems are tracking; what timelines they are using, etc 	<p>Review the CDC outcomes for birth defects surveillance for a referral to services (Sent by Starr)</p> <ul style="list-style-type: none"> - Use the CDC document to start - Survey will need to look at the different systems; look for 	<p>Review during July meeting</p>
	<ul style="list-style-type: none"> - In terms of procedures and roles, likely different from system to system, as are purposes for follow up 	<ul style="list-style-type: none"> - models on how programs communicate and integrate with each other; look at the benefits and how did they work through barriers; and identify efficiencies. 	

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	<ul style="list-style-type: none"> - Obj. 3: Will want respondents to share procedures, forms and resources may be considered for adaptation - Process: find out what they are doing, do they work with other components of their system and how do they do it 	<ul style="list-style-type: none"> - Fine tune what we want, otherwise we will receive random protocols 	
	<ul style="list-style-type: none"> - Obj 4: How do we test the models once we have them? - Hypothetical for a condition but watch out for over-tailoring for one condition - Sub-objective 3 is redundant to #2, identify and put into a tool - Perhaps develop an exercise/tabletop scenario to identify elements of a model system to be adopted 		
	<ul style="list-style-type: none"> - Obj 5: actually develop the model systems and a testing protocol. Look for states to pilot recommendations and see if it works for them. - E-systems; they are one mechanism for follow-up and collecting data. These will likely come out during the survey when describing protocols and procedures. 	<ul style="list-style-type: none"> - Keep track of e-systems states are using and how they will work into the models, etc - Invite others to the table once models are ready for piloting 	
	<ul style="list-style-type: none"> - Concerns over barriers; acknowledging barriers and brainstorming what it would take to overcome - Why are barriers present in some states and not others - Ask the states how they problem solve; those who are successful, how did they get to that point? 	<ul style="list-style-type: none"> - 	
V. Telemeeting Schedule			
	4 th Tuesday, monthly at 9am CT/10am ET		
VI. Follow-up models, protocols & practices (Handout 4)			
A. Terminology	<ul style="list-style-type: none"> - May need to tailor more; emphasis on tracking. Collect information in an ongoing and systematic way to use it for program planning and evaluation to ensure families' needs are being met in terms of accessing services their children need. - Child Find – may not be the best; whatever it is, it needs to focus on identifying the children who could benefit 	<ul style="list-style-type: none"> - Tweak all terms to be compatible with charge - Follow-up definition, Jones to send what Ohio/SCD have developed - Develop a new term in place of “child find 	<ul style="list-style-type: none"> - Region 4 staff to tailor and tweak terminology

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	<ul style="list-style-type: none"> - from services and those falling through the cracks. - Perhaps take out young or use lost to follow-up, but this has its own definitions as well - Need to define how far and to what extent programs are responsible for making sure that the child is still enrolled, versus the family choice; how long is the system responsible for following? - With NBS, does the state have the responsibility to follow up to see if the child is receiving services? Could go both ways – would be nice to build it in to the system, but it could also cross some lines. - Families need education on coordinating child’s care and resources that are available to them - Need to be aware of the system liabilities and varied family experiences - Funding challenges for information referral throughout the life span; barely enough funds to maintain a surveillance system - Title V programs in each state could be a potential point of service; 211 is another option or other 800 number programs - Suggested development of a template for referral form 	<p><u>Other Survey Suggestions:</u></p> <ul style="list-style-type: none"> - When are you finished following up? At which age? - What types of referral systems are available in the state – i.e. call centers, Title V, 211, other 800 numbers, etc. - Share any Checklists or guides for family and/or service referral <p><u>SSFU Group membership</u></p> <ul style="list-style-type: none"> - perhaps we should invite physicians and parents to the group as well? - Attempt to come up with a master guide or checklist that component programs could use; depending on when/where a family hits the system 	<ul style="list-style-type: none"> - Each work - group member to investi-gate what types of resources referral systems are available to families in their state
VIII. Announcements/Comments			
Please go to the Region 4 website – membership directory to update or add your information: http://region4genetics.org/region4/members/search.aspx			
VIII. Next Steps			
	<ul style="list-style-type: none"> - Work through suggestions (terminology, survey, etc) - Will send materials back out ahead of next call 		Hiner & Griffin
IX. Adjourned @ 11:40am			

Notes by Griffin