

**OHIO DEVELOPMENTAL DISABILITIES COUNCIL
CHILDREN AND HEALTH COMMITTEE**

**July 9, 2015
Cherry Valley Lodge
Newark, Ohio**

MINUTES

MEMBERS

Bill Adelsberger	X
Neil Castilow, Chair	X
Diane Cox	X
Karen Kerr	X
Lori Kershner	X
Laura Leach	X
Heather McFarlin	X
Paula Rabidoux	
Jill Radler	X
Roxanne Richardson	X
Ilka Riddle	
Rochelle Hall-Rollins	X
Michael Schroeder	X
Mark Smith	X
Joanna Spargo	X
Kimberly Stultz	X

ADDITIONAL COUNCIL MEMBERS

Mark Seifarth
Douglas Frank
Sue Willis
Greg Dormer

GUESTS

Kellie Brown
Tom Hess
Katrina Bush
Kim Weimer
Susan Jones
Chris Hurr

STAFF

Kay Treanor
Carolyn Knight

Call to Order and Approval of Minutes: Chair Neil Castilow called the meeting to order at 1:00pm. Neil called for approval of the May minutes. A motion to approve the minutes was made Mike/Karen. The minutes were approved as written.

Presentation: The committee heard from three presenters on the subject of Family Support. Each of the three provided perspectives on the subject from past and present involvement with various family support initiatives. Below are copies of handouts provided for the membership that not only cover the material presented but provide links to additional information.

Katrina Bush, Project Manager for DODD, spoke on family support in relation to young families and the early intervention system. She emphasized the recommendation of the Mission and Key Principles for family support to be present in natural environments. Here is her handout:

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A. IDEA Statute -- Part C of IDEA (Early Intervention)

"Congress finds that there is an urgent and substantial need to:

- 1) enhance the development of infants and toddlers with disabilities, to minimize their potential for developmental delay, and to recognize the significant brain development that occurs during a child's first 3 years of life;*
- 2) reduce the educational costs to our society, including our Nation's schools, by minimizing the need for special education and related services after infants and toddlers with disabilities reach school age;*
- 3) maximize the potential for individuals with disabilities to live independently in society;*
- 4) enhance the capacity of families to meet the special needs of their infants and toddlers with disabilities; and*
- 5) enhance the capacity of State and local agencies and service providers to identify, evaluate and meet the needs of all children, particularly minority, low income, inner city and rural children, and infants and toddlers in foster care."*

1. Federal and state regulations-- includes requirements for service type and delivery (multidisciplinary team approach, IFSP as driving document, functional outcomes, natural environments, and **based on available evidence/scientific research**)
 - *Agreed Upon Mission and Key Principles For Providing Early Intervention Services in Natural Environments* (see handout #1)
http://www.ectacenter.org/~pdfs/topics/families/Finalmissionandprinciples3_11_08.pdf

- B. 2010 “Future Directions for Ohio’s Part C/Early Intervention Program: Recommendations from the Part C/Early Intervention Workgroup of the Early Childhood Cabinet” (see handout #2, Executive Summary)
<http://www.helpmegrow.ohio.gov/~media/HelpMeGrow/ASSETS/Files/Professionals%20Gallery/HMG%20Early%20Intervention/Ohio%20PartC%20Review%202010.ashx>
- Recommendation E: “Given the importance of supporting families in raising their children with disabilities, Ohio’s Part C/EI system must assure family support services and the availability of family-to-family support statewide through the Family Information Network (FIN) of Ohio.”
 - Mission and Key Principles
 - ✓ *All families, with the necessary **supports and resources**, can enhance their children’s learning and development.*
 - ✓ *The primary role of a service provider in early intervention is to work with and **support** family members and caregivers in children’s lives.*
- C. National Trends:
- a. “Supporting Families of Individuals with Intellectual and Developmental Disabilities, the National Community of Practice, funded by the Administration of Intellectual and Developmental Disabilities <http://supportstofamilies.org/archive-of-focusing-on-the-triad-approach-innovations-series-webinar-now-available/>)
 - Principles of COMMUNITY, individual within the context of the family, caring “about” and “for”
 - Families will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support all individual members to achieve their goals
 - 3 types of supports:
 1. “Discovery and Navigation (Information and Training)”
 2. “Connecting and Networking (talking to someone who has been there)”
 - a. P2P, FIN, Sibling, Self-Advocates
 3. “Goods and Services (day to day, medical, financial)
 - b. Tennessee Council on Developmental Disabilities, magazine “Breaking Ground” Number 74 (<http://www.state.tn.us/cdd/breakingground/index.shtml>)
- D. Family Supports – Ohio
- a. HMG “SSIP” – one strategy for improving child outcomes is “family engagement;” stakeholders through HMG EI Advisory will be involved in developing a plan
 - Also 3 OSEP required Family Outcomes (know rights, effectively communicate child needs, help children develop and learn)
 - b. Other Family Support projects: Red Tree House Website, ECAC “Ohio Kids Matter” (which includes “family engagement”)—Partnership opportunities? See

also US Department of Education, <http://www.ed.gov/parent-and-family-engagement>

- c. DD Council Priorities?
 - What is the ultimate outcome?
 - What exists now (state and local and national)?
 - What is working and not working?
 - What is missing?
 - How align or set the stage for other Ohio Family Support work?
- ✓ EI Professionally directed “supports” (DODD and DDC Professional Dev focus for last 7 years)
 - **interventions** that are focused on supporting parent to support child development)
 - **Service coordinator** activities that include coordinating needed services (both EI and NON – EI)
 - **Team (interventionists and SC)** – making sure talking about all family needed supports and finding a way to provide or connect
- ✓ Parent to parent supports (in the past, had FIN, then Family Support Specialists, funded by ODH as part of HMG; currently no formal system)
 - Specific to EI?
 - Available to all families of young children with disabilities? (national report of 4.7 mil citizens with I/DD in US; more than 75% live in communities without the aid of formal disabilities)

Kim Weimer, Parent Advocate from ODH, spoke on a care notebook website for families called Ohio GPS, Guiding People through Systems. The purpose and goal of the GPS project is to provide an organizational tool for families and individuals. It will maintain and manage information in a notebook fashion about medical care of the individual as well as provide resources on services available at the local, state and federal level. This tool has been designed as a stand-alone website that will empower the parent/ professional/ individual partnership with a child and family focus. The website was developed through the collaborative effort of several organizations and has the potential for expansion. Kim said her hope is to provide families with various tools and resources tailored specifically for their needs and the needs of their family member. Kim supplied the committee with several “screen shots” to demonstrate what the site will look like. The website should be up and running soon at OhioGPS.org.

Susan Jones, Evidence Based Early Intervention Grant Consultant for the current DD Council grant, spoke on the work of the grant and what the grantee is finding to be gaps in the system of service. She provided information on sustainability, family centered practices, family driven applications of technology, and quality family driven outcomes. Here is her handout:

**OHIO STATEWIDE SYSTEM OF SERVICES FOR
EARLY INTERVENTION
Bridging the Gaps in Ohio Part C Service Delivery**

Original Charge:

- 3 areas of the state
- Access to a core team
- EBEl- natural environments, equal access, quality
- Technology to increase access
- IFSP quality outcomes demonstrating service access

Current Progress- 3 Regions/7 counties

- 6/7 Core teams at the table
- 7/7 Natural environments
- 6/7 Primary Service Provider approach
- 7/7 are using technology to expand participation in EBEl process
- 7/7 Have adopted EB Family Assessment, Eco Map

53 of 88 counties have had training in the Shelden and Rush approach to EBEl.
Grant trained counties from this and previous DD Council Grant (34) and DODD sponsored training (16) and 3 self-trained.

Focus for remaining time in grant- Sustainability

- Leadership training to hold trained teams to fidelity
- Family Centered Practices
- Using Technology to maximize participation and impact in short time
- Ongoing professional development for new staff entering an established team

Gaps going forward:

1. Family Centered Practices- Working definition that is adopted and encouraged by all departments with emphasis on self determination.
2. Family-to-Family Connections: System or process needed that is not agency based, but statewide, in the hands of parents. (P2P, an example)
3. Family driven applications of technology
 - Expand participation in EI and beyond- presence at all conversations, video examples for extended family participation, video examples to guide intervention that is parent generated and shared.
 - Enable Family to Family connections
 - To aid transition as well as everyday life (personal website application)
4. Part C to Part B transition maintaining focus on family centered practices (VERY Lacking in state at present)
5. Quality Family driven outcomes on IFSP – currently almost non-existent

Susan Jones, Consultant ,Ohio Statewide System Of Services For Early Intervention
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Throughout the presentation(s), committee members provided input, comments and asked questions on the subject of family support. Most agreed the work being done has merit but there is still much to do in this area.

Old Business/ New Business:

With little time left on the agenda, Kay provided a quick review of possible projects discussed by committee members for funding during the 2017 – 2021 State Plan. Kay also provided ideas for several health related projects she had received from Susan Havercamp PhD, Director of the Ohio Disability and Health Program. Kay suggested the committee make a decision on which initiatives to fund.

A member added one more idea for possible funding, children's adaptive sports. With just a few minutes of meeting time left, Kay suggested an extra meeting to make final choices of projects to fund. She said she would email everyone to find an agreed time.

Adjournment: Neil called for a motion for adjournment. Motion to end the meeting was made, Mike/Bill. The meeting adjourned at 2:35pm.