Illinois Chapter, American Academy of Pediatrics
Committee on Children with Disabilities (COCWD) Meeting

Wednesday, April 6, 2016
Conference Call: 3-4 pm CT

MINUTES

Present:
Co-Chairs: Larry Gray, Mary Keen
Members: Ann Cutler, Miriam Kalichman, Gerri Clark, Faye Manaster, Edith Chernoff, Sara Parvinian, Sue Mukerjee, Larry Desch, Jamie Weedon, Michael Msall
Staff: Kathy Sanabria, Dru O’Rourke, Elsie Divinagracia
Guest: Access Living Chicago, Amber Smock

Welcome
Drs Larry Gray and Mary Keen welcomed the conference call participants. The committee was provided minutes from its January 8, 2016 meeting as well as its updated strategic plan January 2016-December 2017. Dr Kalichman motioned and Dr Gray seconded approval of the minutes and strategic plan. The action items from the last meeting were reviewed. Status on the strategic plan was discussed and action items will be updated in the document. Ms Sanabria contacted Ms Dorelia Rivera and invited her to join the COCWD as a parent partner/family representative. Ms Rivera accepted the invitation but was not able to participate on today’s call.

ACTION: Ms Sanabria will contact Ms Rivera and welcome her to the COCWD as a parent partner and encourage her to attend future meetings.

ACTION: Ms Sanabria will update the status of action items in the strategic plan and send to the COCWD with the meeting minutes.

Access Living Chicago Presentation
Ms Amber Smock, Director of Advocacy and Internal Affairs at Access Living (AL) Chicago, joined the call to provide committee members with a brief overview of the agency. Access Living is an independent living center in Chicago that serves people with all types of disabilities. This is a federal designation that requires that the organization be run and staffed by a majority of people with disabilities. The two main branches of Access Living are 1) independent living and 2) advocacy. The independent living branch allows adults with disabilities to live on their own. The majority of residents are low-income African Americans from Chicago. The advocacy branch monitors state policy and the Chicago Public Schools budget related to people with disabilities and assists families with the Individualized Education Plan (IEP) process. There are also programs that teach elementary age children about different disabilities to promote awareness as well as a young adult mentoring program to assist young adults in the transition from high school to college or employment. AL operates within a network of 22 centers for
Independent Living. Ms Smock provided the COCWD with several resources to assist them with their efforts to care for children and youth with disabilities.

COCWD members can call or email Amber at asmock@accessliving.org with any questions or problems. https://www.accessliving.org/

Resources Discussed

1) Access Living website: www.accessliving.org
2) Rod Estvan, Access Living Education Policy Analyst: restvan@accessliving.org or 312/640-2149. Please keep in mind he tends to help with more complex IEP situation and will make appropriate referrals if at capacity.
3) Family Resource Center on Disability: www.frcd.org - Parents working directly with parents to help them through the IEP process and other advocacy issues. They offer trainings on becoming an IEP advocate.
5) Colorado-based PEAK Parent Center: https://www.peakparent.org/
6) Video--We All Belong: https://www.youtube.com/watch?v=AFoLsYDQzzY

Review List of Past COCWD Members
The group will discuss how to reengage with inactive members and conduct outreach to expand membership at future meetings.

ACTION: The COCWD will discuss how to re-engage with inactive members and reach out to potential new members at upcoming meetings.

Transition Training at Midwest Clinical Conference, May 20, 2016, Chicago
ICAAP was invited to provide a 3.25 hour transition training session for adult providers at the May 20, 2016 Chicago Medical Society Midwest Clinical Conference. Drs Caskey, Kalichman, Keen and Ms Sanabria will be presenters. The training has a focus on caring for young adults with childhood onset conditions and/or disabilities.

ICAAP Annual Conference, March 18, 2016 a Success
The ICAAP annual conference was held Friday, March 18, 2016 at the Hyatt in Lisle. There were over 100 attendees. The evaluation was positive. Dr Rachel Caskey presented a transition training in the afternoon. COCWD members are invited to suggest future program topics for the next meeting to occur Friday, March 3, 2017 in the Chicago area.

ACTION: The COCWD members are invited to submit to Ms Sanabria and Ms O’Rourke ideas for session topics for the March 3, 2017 ICAAP annual conference.

Status on Autism, Behavior, and Complex Medical Needs (ABC) - Downstate Conference May 20, 2016, O’Fallon, IL
The ABC Conference was held November 20, 2015 at Moraine Valley Community College. It was well attended with about 230 registrants. The conference title was “A Trauma-Informed, Interprofessional Approach to Caring for Children and Adolescents with Special Needs”. The program will be repeated at a conference downstate to occur Friday, May 20, 2016, 2nd Annual ABCD (Downstate) Conference at the
Regency Conference Center, 400 Regency Park Drive, O'Fallon, IL 62269. It was noted some members of the COCWD are interested in being included in planning for future ABC conferences as this is part of the charge to the committee. See below.

**Planning for Future ABC Conferences**

It was noted the IL LEND program has been supportive of the ABC conference from the beginning (the first ABC conference was organized as part of the LEND leadership project of Dr Jamey Weedon, who was then a LEND fellow). LEND director Dr Kruti Acharya had arranged the CME for the earlier conferences. More recently the Committee on Child Development and their staff have taken the lead in developing the 2015 and 2016 conferences. In 2016 ICAAP became CME accredited and as such ICAAP is providing CME credit for the ABCD conference May 20th and can also provide CME credit for future conferences. Dr Cutler advises the LEND program wishes to continue to support the conference. Drs Acharya and Cutler will be happy to be involved with planning. This will also be a topic of conversation at the joint meeting with the COCWD and COCD to occur July 15, 2016.

COCWD members interested in participating on future ABC Conference planning groups include: Larry Gray, Kruti Acharya, Anne Cutler, Peter J Smith, and Edith Chernoff.

**Advocacy for Children with Autism**

Dr Msall spoke about the work of Dr Alice Carter and others in Massachusetts to support children with autism and their families. MA has been successful in providing services for children with autism. Their Early Intervention (EI) system is also supportive and has some models that may be of interest in other states. They are well funded. The COCWD members are concerned that children that need services are being left behind. It was noted there are not good programs available for kids in IL who do not meet the threshold for program participation, but still need services.

Trained as a clinical psychologist, Professor Alice Carter's work focuses on young children's development in the context of family relationships, and socio-contextual factors. She is dedicated to the early identification of children at risk for difficulties in social and emotional development as well as those with clinically significant psychopathology and neuro-developmental disorders. Her primary area of research is infant, toddler, and preschool psychopathology. Dr Carter has received funding from the National Institute of Mental Health (NIMH) to conduct an epidemiological, longitudinal study of early emerging psychopathology from infancy through the transition to formal schooling. She is currently funded by the Health Resources and Services Administration and the NIMH to address health disparities in age of autism spectrum disorder and service receipt. Professor Carter also researches the identification of infants and toddlers at risk for problems in social, behavioral, and emotional functioning and understanding the role of family functioning in the developmental course of children at genetic risk for or exhibiting clinical disorders such as autism, Tourette's Disorder, and Obsessive Compulsive Disorder. She is also studying young children with autism spectrum disorders and their families as part of the Boston University Studies To Advance Autism Research (STAART). Her teaching interests include developmental psychopathology, child assessment, and child and family functioning. It was suggested that there may be some webinars already available that describe her work or perhaps she could be invited to present a webinar about her efforts or be an invited speaker at a future ABC or ICAAP annual conference.

**Alice Carter, PhD**

Professor, College of Liberal Arts, University of Massachusetts, Boston
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Work Email: Alice.Carter@umb.edu
100 Morrissey Blvd. Office Location: McCormack Hall, 04, 00266

ACTION: Ms O’Rourke will advise the ICAAP Annual Conference Planning group that Dr Alice Carter is a good speaker on the topic of young children’s development in the context of family relationships and socio-contextual factors, especially as these relate to neuro-developmental disorders.

Suggested Agenda Items for Future COCWD Meetings
Below are topics that were suggested for future meetings or TA calls by Ms Manaster:

1) DRS Home Services for children—who is being served, how to enroll, family and provider feedback
2) Family/provider feedback re children already enrolled in Medicaid Managed Care at the time of CSHCN diagnoses
3) Medicaid Managed Care, network adequacy and children with delays not eligible for EI in Illinois
4) Family/provider feedback re children on SSI who get inadvertently enrolled in Medicaid Managed Care (FYI- we are able to disenroll them)
5) Family/provider feedback on experiences of children enrolled in WIC at the time of their 5th birthdays
6) Family/provider feedback on IEP modifications and the School Nutrition Program (breakfasts, lunches and summer programs)

Note: Ms Deb Fornoff is job-sharing for F2F. She can be reached at 708-212-4758. Deb is located in central Illinois. See IL fact sheet from Family Voices.

Chicagoland Autism Connection Support Group
Ms Manaster provided information about the support group and written information was shared with the COCWD by Email.

The Arc of Illinois Annual Convention April 20-21, 2016 in Lisle
Information on the program for the 66th annual ARC of IL convention can be found here:


Healthy Minds, Healthy Lives: Promoting Mental Health in Children and Adults with Intellectual/Developmental Disabilities or Other Special Needs The Arc of Illinois May 10, 2016,
Doubletree Hotel, 5000 West 127th St., Alsip, IL 60803 708-371-7300 - Faye

Joint Session with Committee on Child Development, Friday, July 15, 2016 3 to 4:30 pm CT at ICAAP
The COCWD is interested in meeting jointly with the Committee on Child Development (COCD). The co-chairs of both groups have been in communication and agreed to hold the in-person joint session at ICAAP on Friday, July 15, 2016 from 3:00 pm to 4:30 pm. A call-in option will be available. This will be an opportunity for the committees to share information and discuss issues of mutual interest and collaboration. Ms Sanabria will coordinate with the co-chairs to develop the meeting agenda.

ACTION: Ms Sanabria will send meeting outlook invites to the members of the COCWD and COCD for the joint meeting July 15, 2016.
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**ACTION:** Ms Sanabria will coordinate with the co-chairs of the COCWD and COCD to develop the joint committee meeting agenda.

**COCWD Quarterly Conference Call Dates 2016 - 2017**
The COCWD will convene quarterly conference calls. The co-chairs will review and approve agendas/minutes and energize members to accomplish action items. The COCWD conference call dates and times through 2017 are below. Calls alternate on Wednesday and Friday afternoons from 3-4 pm CT to make it easier for members who have clinics to participate.

- Friday, July 15, 2016 (changed to joint meeting with COCD)
- Wednesday, October 5, 2016
- Friday, January 6, 2017
- Wednesday, April 5, 2017
- Friday, July 14, 2017
- Wednesday, October 4, 2017

**SAVE THE DATE FOR JOINT MEETING WITH COCWD and COCD FRIDAY, JULY 15, 2016 FROM 3 PM TO 4:30 PM AT ICAAP – call in available**

Minutes prepared by: Kathy Sanabria. Also see COCWD strategic plan with updated status on action items.