



CHAMPAIGN COUNTY MENTAL HEALTH BOARD

CHAMPAIGN COUNTY BOARD FOR CARE AND TREATMENT OF PERSONS WITH A DEVELOPMENTAL DISABILITY

Champaign County Developmental Disabilities Board (CCDDDB) AGENDA

Wednesday, February 22, 2012

Brookens Administrative Building

Meeting Room 1

1776 E. Washington St., Urbana, IL 61802

8:00 AM

1. Call to Order – Mr. Michael Smith, President
2. Roll Call – Stephanie Howard-Gallo
3. Additions to Agenda
4. Citizen Input
5. CCMHB Input
6. Approval of CCDDDB Minutes
 - A. 1/18/12 Board Meeting*

Minutes are included in the packet. Board action is requested.
7. President's Comments – Mr. Michael Smith
8. Executive Director's Comments – Peter Tracy
9. Staff Report – Lynn Canfield

Included in the Board packet.
10. Agency Information
11. Financial Report
 - A. Approval of Claims*

Included in the Board packet. Action is requested.
12. New Business
 - A. April CCDDDB Meeting Schedule Change

Discussion of moving the April meeting from Wednesday the 18th to Tuesday the 17th.
 - B. PY13 Funding Applications

A list of applicants and amounts requested will be distributed at the meeting.
 - C. Board Liaison Assignments

For discussion, the packet includes guidelines employed by the CCMHB in Board to Board participation.
 - D. Communication with Provider Agency Boards

For information only, the packet includes a briefing memorandum regarding communication between CCDDDB/CCMHB staff and funded agency board members.

- E. Champaign County Anti-Stigma Alliance
 - An update on this year's post-Ebertfest event is included in the packet.*
- F. Cultural and Linguistic Competence
 - For discussion, the packet includes: a briefing memorandum on CLC; aggregated demographics data from FY2010 and FY2011 for all CCDDDB funded agencies; and an article by Deresha D. Gibson entitled "Racial Disparities in the Age of Diagnosis of Autism Spectrum Disorder"*
- G. Rural Transit Advisory Group (RTAG) Update
- 13. Old Business
 - A. Disability Resource Expo
 - Low activity this month; oral report only.*
- 14. Board Announcements
- 15. Adjournment

**Board action requested*

**CHAMPAIGN COUNTY BOARD FOR CARE AND TREATMENT
OF PERSONS WITH A DEVELOPMENTAL DISABILITY
(CCDDB)
BOARD MEETING**

Minutes –January 18, 2012

*Brookens Administrative Center
1776 E. Washington St.
Urbana, IL
Meeting Room 1 (Lyle Shields Room)*

8:00 a.m.

MEMBERS PRESENT: Joyce Dill, Elaine Palencia, Mike Smith

STAFF PRESENT: Peter Tracy, Lynn Canfield, Nancy Crawford, Mark Driscoll,
Stephanie Howard-Gallo

OTHERS PRESENT: Vicki Tolf, Patty Walters, Annette Becherer, Scott Turner, Laura Bennett, Developmental Services Center (DSC); Dennis Carpenter, Melissa McDaniel, Charleston Transitional Facility (CTF); Barb Bressner, Consultant; Sally Mustered, C-U Autism Network; Jennifer Knapp, Rebecca Thinnes, Linda and Pat Tortorelli, Jamie Stevens, Tiffany Dean, Community Choices; Lynn Watson, Head Start; Tracy Parsons, Shandra Summerville, ACCESS Initiative of Champaign County

CALL TO ORDER:

Mr. Michael Smith called the meeting to order at 8:00 a.m.

ROLL CALL:

Roll call was taken and a quorum was present.

ADDITIONS TO AGENDA:

None.

CITIZEN INPUT:

Two clients of Community Choices, Ms. Tiffany Dean and Mr. Pat Tortorelli, spoke regarding their positive experiences working with the agency.

CHAMPAIGN COUNTY MENTAL HEALTH BOARD (CCMHB) INPUT:

The CCMHB will meet later in the day.

APPROVAL OF MINUTES:

Minutes from the November 16, 2011 Board meeting were included in the packet.

MOTION: Ms. Dill moved to approve the minutes from the November 16, 2011 Board meeting. Ms. Palencia seconded and the motion passed unanimously.

PRESIDENT'S COMMENTS:

None.

EXECUTIVE DIRECTOR'S REPORT:

Mr. Tracy announced he will be meeting with Ms. Holly Jordan in the near future to discuss possible changes in the Memorandum of Understanding (MOU) between the CCMHB and the CCDDDB regarding administrative costs.

STAFF REPORT:

A report from Ms. Canfield was included in the packet.

AGENCY INFORMATION:

Ms. Dill asked agency representatives for verbal reports on the impact of the State of Illinois budget on their agencies. Mr. Dennis Carpenter and Ms. Patty Walters reported on slow payments from the state, which generally run three to five months late. Slow payments make program planning difficult and staff wage increases non-existent.

FINANCIAL INFORMATION:

Approval of Claims:

A copy of the claims report was included in the Board packet.

MOTION: Ms. Dill moved to accept the claims report as presented. Ms. Palencia seconded and the motion passed unanimously.

NEW BUSINESS:

Financial site Visit Protocol:

A Briefing Memorandum and a draft of staff protocol for monitoring financial procedures was included in the Board packet. The Protocol is a tool that is intended to be used by staff to improve and ensure an adequate level of financial accountability with our funded agencies.

FY2013 Contract Boilerplate:

A draft of the FY2013 Contract Boilerplate was included in the packet. Proposed changes in the document were highlighted in italics. Ms. Palencia suggested the document be more specific regarding what specifications in the contract are mandatory and what are suggested or encouraged. Mr. Tracy stated staff would consider her suggestion and will review the Contract Boilerplate further.

Ligas Consent Decree:

A Briefing Memorandum informing the Board of developments in Ligas v. Hamos was included in the Board packet.

Notice of Funding Availability:

A copy of the Notice of Funding Availability (NOFA) for CCMHB/CCDDB/Quarter Cent for Public Safety Funds that was published in the News Gazette on December 11, 2011 was included in the packet for information only.

Cultural and Linguistic Competence Plan:

The Cultural and Linguistic Competence Plan was included in the packet. The Plan is part of FY2013 application materials. A copy of a quarterly monitoring tool was included in the packet as well. Ms. Shandra Summerville, the Cultural and Linguistic Competency Coordinator from the ACCESS Initiative of Champaign County, provided additional explanation of the documents and offered technical assistance to anyone interested.

Anti-Stigma Alliance:

Ms. Lynn Canfield briefly discussed plans for Ebertfest 2012.

OLD BUSINESS:

Anti-Stigma Memorandum:

A draft memorandum focusing on stigma associated with developmental disabilities was included in the packet for information only.

BOARD ANNOUNCEMENTS:

None.

ADJOURNMENT:

The meeting adjourned at 8:47 a.m.

Respectfully Submitted by: Stephanie Howard-Gallo

**Minutes are in draft form and are subject to CCDDDB approval.*

Lynn Canfield, Associate Director for Developmental Disabilities Staff Report – February 22, 2012

FY2013 Applications, FY2012 Second Quarter Reports, and Web-based System: The deadline for submission of all required FY13 application forms and postmark on Authorization and Cover Form was Noon, Friday, February 17. During this month, we answered relatively few questions related to the web-based system, which might indicate that it functions as anticipated, especially with recent enhancements, and that agency users have some mastery. One agency user made suggestions for possible improvements for FY14 materials, to enhance readability and incorporate excel documents. FY12 second quarter reports of DD programs funded by the CCDDDB and CCMHB were submitted by the deadline of January 27. Revisions and/or clarification requested of CU Autism Network, PACE, and Charleston Transitional Facility were provided immediately, and performance data have been entered for all. Mark Driscoll and I worked with the website consultant on solutions to particular issues and on the use of sort and filter features which may reduce error and the time involved in creating data tables.

Agency Meetings and Correspondence: Jennifer Knapp of Community Choices met with Peter Tracy and me for discussion of progress of both the agency and the cooperative. She provided complete details on their recent DHS survey and on the technical support available to self-employed individuals (e.g., when filing taxes or considering benefits status); copies of protocol and consent form have been provided for the CCDDDB/CCMHB contract files. Pursuant to another agency's question about eligible diagnoses, I reviewed IDHS definitions of Developmental Disability and found that they have not been modified in recent years; Pre-Admission Screening remains the key to qualifying an individual for state-funded Medicaid-waiver services. With increased identification of Autism Spectrum Disorders and sensory processing disorders, I will continue to seek guidance from the local PAS agency.

At the January meeting of the **Birth to Six Council**, Michael Trout gave a brief presentation on the Infant-Parent Institute and its new "Prenatal Bonding" service. Old Business included annual plans and budget, committee updates, including Child Find with low December referrals (20). New business included formation of an ad hoc bylaws committee and upcoming training collaboration with Family Matters, and using the large clinics as distribution points for information.

The Mental Health Agencies Council met on January 24 for updates and discussion. One point of interest was that the agreements in the three large class action suits, along with the closure of State Operated Developmental Centers, would result in approximately 20,000 individuals statewide moving into communities and out of institution. Crisis Nursery announced a bit of good news, that they can now accommodate children up to their seventh birthday.

Quarter Cent Administrative Meeting: We discussed referral coordination; JUMP; recidivism data, for which a report will be available in October and how PLL data connects to Quarter Cent (recidivism

for those who completed deep-end PLL would be a judgment against them within a year); mobile crisis unit update, particularly how such a project would be funded and who would partner.

Ebertfest and Anti-Stigma Alliance planning: The Anti-Stigma Alliance Steering Committee met twice during this period to plan for our post-festival screening and related events. Roger Ebert's anti-stigma selection for the festival, still embargoed, may be too intense for our community event, which welcomes families with children. The Steering Committee was satisfied with a suggestion that had come from multiple sources, so our Sunday, April 29 event will feature "Antwone Fisher." The 14th Annual Roger Ebert's Film Festival will be held April 25th through the 29th and, as was the case last year, will share a city with the Illinois Marathon on Saturday. Barb Bressner and I have had several additional discussions about promotions of our Sunday film and events; we will collaborate with ACCESS staff who are designing activities for Children's Mental Health Awareness Week, May 6-12, 2012.

Other Activity: For both the CCDDDB and the CCMHB FY2013 contract boilerplates, I incorporated the suggestions offered. We are scheduling a workgroup meeting on behavioral health and nutrition with Dr. Ordal; please let me know if you have an interest in joining us. I attended a meeting of the Community Response Group, with focus on collaborating with the Effingham group to address downstate economic development. The Transition Planning Committee held a Transition Roundtable in January; this well-attended event featured representatives of agencies and organizations serving transition-aged youth and adults with disabilities in this community, and many CCDDDB- and CCMHB-funded programs were described. Peter Tracy and I participated in an ACHMAI teleconference with focus on developing the agenda for April's legislative conference. I attended a breakfast meeting with Chancellor Wise, hosted by UI School of Social Work, and the Transformative Leadership Summit cohosted by the Chancellor, the Cities of Urbana and Champaign, and the Community Foundation of East Central Illinois.

Unmet DD Service Needs in Champaign County:

At the time of this writing, the updated PUNS reports page of DHS's website does not appear to contain data different from that reported in early December, so this report is merely a summary.

From PUNS reports of the last year, for residents of Champaign County, we have noted:

- 2/1/11: **194** with emergency need; of **269** in crisis, **116** recent or coming HS graduates.
- 4/5/11: **198** with emergency need; of **274** in crisis, **120** recent or coming grads.
- 5/12/11: **195** with emergency need; of **272** in crisis, **121** are recent or coming grads.
- 6/9/11: **194** with emergency need; of **268** in crisis, **120** are recent or coming grads
- 10/4/11: **201** with emergency need; of **278** in crisis, **123** are recent or coming grads.
- 12/5/11: **196** with emergency need: of **274** in crisis, **122** are recent or coming grads.
- 1/9/12: **no change** from 12/5/11 report.

The majority of existing supports are in Education, with Speech and Occupational Therapy following. Desired supports include Transportation, Personal Support, Occupational Therapy, Support to work in community, Support for in-center activities, Speech Therapy, Behavioral Supports, 24 hour Residential, Respite, Physical Therapy, Other Transportation, Intermittent Residential, and Assistive Technology.

CHAMPAIGN COUNTY

EXPENDITURE APPROVAL LIST

1/12/12

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VENDOR NO	VENDOR NAME	TRN B TR	TRN NO	PO NO	CHECK NUMBER	CHECK DATE	ACCOUNT NUMBER	ACCOUNT DESCRIPTION	ITEM DESCRIPTION	EXPENDITURE AMOUNT
***	FUND NO. 108	DEVLPMNTL DISABILITY FUND								
***	DEPT NO. 050	DEVLMTNL DISABILITY BOARD								
90	CHAMPAIGN COUNTY TREASURER									
	1/04/12 02 VR 108-	16	463137	1/06/12	108-050-533.07-00	PROFESSIONAL SERVICES	JAN ADMIN FEE		24,367.00	
							VENDOR TOTAL		24,367.00 *	
104	CHAMPAIGN COUNTY TREASURER									
	1/04/12 02 VR 108-	11	463139	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN EARLY HEADSTART		3,473.00	
							VENDOR TOTAL		3,473.00 *	
5352	AUTISM SOCIETY OF ILLINOIS									
	1/04/12 02 VR 108-	9	463154	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN AUTISM SOCIETY		1,000.00	
							VENDOR TOTAL		1,000.00 *	
16011	CHARLESTON TRANSITIONAL FACILITY									
	1/04/12 02 VR 108-	12	463174	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN NURSING SERVICE		1,684.00	
							VENDOR TOTAL		1,684.00 *	
18203	COMMUNITY CHOICE									
	1/04/12 02 VR 108-	13	463178	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN CUSTOM EMPLOYMN		2,500.00	
							VENDOR TOTAL		2,500.00 *	
22300	DEVELOPMENTAL SERVICES CENTER OF									
	1/04/12 02 VR 108-	14	463187	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN APARTMNT SVRS		34,277.00	
	1/04/12 02 VR 108-	14	463187	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN CLIENT/FAM SUPR		33,018.00	
	1/04/12 02 VR 108-	14	463187	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN CLINICAL SUPPOR		14,831.00	
	1/04/12 02 VR 108-	14	463187	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN DT/EMPLOYMENT		98,559.00	
	1/04/12 02 VR 108-	14	463187	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN FAM DEVELOP CTR		31,786.00	
	1/04/12 02 VR 108-	14	463187	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN INDIV/FAM SUPPR		28,194.00	
	1/04/12 02 VR 108-	14	463187	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN CILA-RESIDENTIA		12,833.00	
							VENDOR TOTAL		253,498.00 *	

CHAMPAIGN COUNTY

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1/12/12

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VENDOR NO	VENDOR NAME	TRN B TR DTE N CD	TRANS NO	PO NO	CHECK NUMBER	CHECK DATE	ACCOUNT NUMBER	ACCOUNT DESCRIPTION	ITEM DESCRIPTION	EXPENDITURE AMOUNT
*** FUND NO. 108 DEVLPMNTL DISABILITY FUND										
22816	DOWN SYNDROME NETWORK	1/04/12 02 VR 108-	10		463189	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN DOWN SYNDROME	1,250.00
									VENDOR TOTAL	1,250.00 *
54930	PERSONS ASSUMING CONTROL OF THEIR	1/04/12 02 VR 108-	15		463228	1/06/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JAN OPPRT INDEPENDN	4,962.00
									VENDOR TOTAL	4,962.00 *
									DEPARTMENT TOTAL	292,734.00 *
									FUND TOTAL	292,734.00 *

CHAMPAIGN COUNTY

EXPENDITURE APPROVAL LIST

2/09/12

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VENDOR NO	VENDOR NAME	TRN B	TR	TRANS NO	PO NO	CHECK NUMBER	CHECK DATE	ACCOUNT NUMBER	ACCOUNT DESCRIPTION	ITEM DESCRIPTION	EXPENDITURE AMOUNT
***	FUND NO. 108	DEVLPMNTL	DISABILITY	FUND							
***	DEPT NO. 050	DEVLMTNL	DISABILITY	BOARD							
90	CHAMPAIGN COUNTY	TREASURER									
	2/08/12 01 VR 108-	25				464371	2/09/12	108-050-533.07-00	PROFESSIONAL SERVICES	FEB ADMIN FEE	24,367.00
										VENDOR TOTAL	24,367.00 *
104	CHAMPAIGN COUNTY	TREASURER									
	2/08/12 01 VR 108-	20				464373	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB EARLY HEADSTART	3,473.00
										VENDOR TOTAL	3,473.00 *
5352	AUTISM SOCIETY OF ILLINOIS										
	2/08/12 01 VR 108-	18				464398	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB AUTISM SOCIETY	1,000.00
										VENDOR TOTAL	1,000.00 *
16011	CHARLESTON TRANSITIONAL FACILITY										
	1/26/12 03 VR 108-	17				463985	1/31/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	DEC RESIDENTIAL	3,167.00
	2/08/12 01 VR 108-	21				464422	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB NURSING SERVICE	1,684.00
										VENDOR TOTAL	4,851.00 *
18203	COMMUNITY CHOICE, INC										
	2/08/12 01 VR 108-	22				464427	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB CUSTOM EMPLOYMN	2,500.00
										VENDOR TOTAL	2,500.00 *
22300	DEVELOPMENTAL SERVICES CENTER OF										
	2/08/12 01 VR 108-	23				464436	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB APARTMENT SVCS	34,277.00
	2/08/12 01 VR 108-	23				464436	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB FAMILY SUPPORT	33,018.00
	2/08/12 01 VR 108-	23				464436	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB CLINICAL SUPPORT	14,831.00
	2/08/12 01 VR 108-	23				464436	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB DT/EMPLOYMENT	98,559.00
	2/08/12 01 VR 108-	23				464436	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB FAM DEVELOP CTR	31,786.00
	2/08/12 01 VR 108-	23				464436	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB INDIV/FAM SUPPR	28,194.00
	2/08/12 01 VR 108-	23				464436	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB CILA RESIDENTIA	12,833.00
										VENDOR TOTAL	253,498.00 *

CHAMPAIGN COUNTY

EXPENDITURE APPROVAL LIST

2/09/12

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VENDOR NO	VENDOR NAME	TRN B TR DTE N CD	TRANS NO	PO NO	CHECK NUMBER	CHECK DATE	ACCOUNT NUMBER	ACCOUNT DESCRIPTION	ITEM DESCRIPTION	EXPENDITURE AMOUNT
*** FUND NO. 108 DEVLPMNTL DISABILITY FUND										
22816	DOWN SYNDROME NETWORK	2/08/12 01 VR 108-	19		464439	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB DOWN SYNDROME VENDOR TOTAL	1,250.00 1,250.00 *
54930	PERSONS ASSUMING CONTROL OF THEIR	2/08/12 01 VR 108-	24		464513	2/09/12	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB OPPORT INDEPNDN VENDOR TOTAL	4,962.00 4,962.00 *
								DEVLPMNTL DISABILITY BOARD	DEPARTMENT TOTAL	295,901.00 *
								DEVLPMNTL DISABILITY FUND	FUND TOTAL	295,901.00 *

CCDDB 2012-2013 Meeting Schedule

Board Meetings

8:00 AM

Brookens Administrative Building

Meeting Room 1

1776 East Washington Street, Urbana, IL

March 21, 2012 – 8:00 AM

April 18, 2012 – 8:00 AM

May 23, 2012 – 8:00 AM

June 20, 2012 – 8:00 AM

July 18, 2012 – 8:00 AM

November 14, 2012 – 8:00 AM (off cycle)

December 19, 2012 – 8:00 AM

This schedule is subject to change due to unforeseen circumstances.

Please call the CCMHB/CCDDB office to confirm all meetings.

CHAMPAIGN COUNTY MENTAL HEALTH BOARD GUIDELINES FOR BOARD TO BOARD PARTICIPATION

CCMHB members provide liaison to agencies we contract with to help further educate the Board of agency goals, accomplishments and problems. Continuing contact through liaisons is one way of fostering positive relationships with these agencies. The following guidelines are intended to clarify the CCMHB member's responsibility and expectations while acting as a liaison to contracting agencies:

1. Each agency liaison should attend an orientation session at the agency. The session should include the agency's mission, goals, programs as well as the ways in which CCMHB funds are used by the agency. Attendance at board meetings is encouraged as your schedule permits. Participation by the County Board representative is optional.
2. CCMHB members are not members of the provider board. We neither vote nor perform functions typically associated with members of the provider's board (with the exception of the Children's Advocacy Board).
3. You may expect to be notified of all meetings, to receive board packets and any appropriate written information given to the provider's board members in preparation for board meetings.
4. Questions may be answered about CCMHB processes as appropriate, but no commitments about CCMHB policy or action should be made. Opinions on issues may be given, but be clear that it is only your individual opinion and is not the official position of the CCMHB.
5. It is not appropriate to attempt to influence another CCMHB member to take action pertaining to the agency to which you are assigned.
6. Information received during the course of the provider board meeting that is of special interest or concern may be reported back to the CCMHB.
7. It is appropriate to ask questions and seek additional information while attending an agency's board meeting.
8. Honor any confidentiality requirements associated with board assignments.
9. Avoid any possible conflict of interest situations related to your board to board assignment. Questions about potential conflict of interest situations should be directed to the CCMHB executive director. Legal opinions will be sought through Champaign County State's Attorney's office.



CHAMPAIGN COUNTY MENTAL HEALTH BOARD

CHAMPAIGN COUNTY BOARD FOR CARE AND TREATMENT OF PERSONS WITH A DEVELOPMENTAL DISABILITY

BRIEFING MEMORANDUM

Date: February 22, 2012
Memo To: Members, Champaign County Developmental Disabilities Board
From: Peter Tracy, Executive Director
Subject: Communication with Provider (Funded) Agencies

Background

In our ongoing focus on development of CCMHB/CCDDB staff financial monitoring activities, we must also define the proper role of staff in the resolution of identified issues. The purpose of this memorandum is to update members of the Champaign County Developmental Disabilities Board on questions raised at the January 18, 2012 CCMHB meeting concerning appropriate communication channels with funded agencies and their boards of directors. Specifically, is it appropriate and advisable for board staff to have direct communication with members of the Boards of funded agencies?

This briefing memo was developed with the generous input of my ACMHAI colleagues, other funding organizations in Champaign County (e.g., Ms. Lyn Jones, CEO of United Way of Champaign County), not-for-profit organization staff, and perusal of various relevant documents concerning this subject. Legal counsel was not included as part of this process.

Analysis

Simply stated, not for profit organizations are governed by the Board and managed by the staff. The duties and responsibilities of a Board usually include selecting and working with the executive director, promulgating and amending bylaws, developing long term strategic plans, and approving the organization's budget. The Board can also provide advice and counsel to the executive director but should not become involved in the day-to-day operations of the organization. It is the purview of staff to tend to business and the day to day administration of the organization. Within this context the following is a summary of my "research" as it relates to whether and under what circumstances CCDDB staff should have direct communications with members of the Boards of funded organizations.

1. It is reasonable and appropriate for the CCDDB to require all contracts and amendments be signed by the President of the Board or his/her authorized designee.
2. It is also reasonable to require evidence (e.g., board meeting minutes) the full board was notified and approved of contracts with the CCDDB.

3. "Board to Board" liaison assignments might offer opportunity for direct communication between CCDDDB members and the funded agency Board.
4. There was a general consensus that direct CCDDDB staff contact with a funded agency Board could be viewed as "going around," "going over the head of," or subverting the authority of the funded agency executive director, and this could be damaging to the working relationship between the CCDDDB and the funded agency.
5. If contacted by a funded agency Board member, it is not inappropriate for CCDDDB staff to listen and engage in conversation. Depending on the reason for the call, it might well be of benefit to schedule a subsequent meeting which would include the agency's executive director.
6. If the CCDDDB executive director determines there to be a breach of contract or a violation of the terms and conditions of the contract which results in any sanction, it is appropriate for all signatories of the contract to be formally notified. This would include the agency's Board President or designee.

ANTI-STIGMA ALLIANCE

Board Report

February, 2012

The Champaign County Anti-Stigma Alliance will again be sponsoring a free community film on Sunday, April 29, following the close of the Roger Ebert Film Festival. The Alliance has chosen "Antwone Fisher" as this years' film. This film depicts the life of a young man who suffers from Post Traumatic Stress Disorder resulting from severe childhood abuse and neglect.

Alliance members met on January 30 to begin planning for this years' event. Their next meeting will be February 14.

Although not yet finalized, activities this year will include an art show/sale on Saturday, introduction of the film by Champaign's mayor, and panel discussion at the close of the film on Sunday. The art show will feature local artists/entrepreneurs who made up the Pride Room at the Disability Resource Expo in 2011. These artists are very excited about having this venue to display and sell their works. Panel members are yet to be identified by the Alliance. We are also considering a musical performance outside the theater just prior to the film.

The Alliance is considering producing a small booklet to be distributed to movie-goers. It would define the mission of the Anti-Stigma Alliance, include some information on advocates and providers (Alliance members), list the local artists, and provide a listing of other films with anti-stigma themes.

A budget and plan for promotion of the event have been developed.

Respectfully submitted,

Barb Bressner
Consultant



CHAMPAIGN COUNTY MENTAL HEALTH BOARD

CHAMPAIGN COUNTY BOARD FOR CARE AND TREATMENT OF PERSONS WITH A DEVELOPMENTAL DISABILITY

BRIEFING MEMORANDUM

Date: February 22, 2012
To: Members, Champaign County Developmental Disabilities Board (CCDDB)
From: Shandra Summerville, Cultural & Linguistic Competence Coordinator;
Lynn Canfield, Associate Director for Developmental Disabilities
Re: Cultural and Linguistic Competence Plans

Purpose: At the January 2012 meeting of the CCDDB, a request was made for background on the Cultural and Linguistic Competence Plans submitted by agencies applying for FY2013 funding. The purpose of this memorandum is to clarify the CLC Plan's role.

Background: In 2006, the CCDDB approved the requirement that funded agencies submit written plans addressing issues raised in "The Surgeon General's Report on Mental Health: Culture, Race, and Ethnicity." Since 2006, these Cultural and Linguistic Competency plans have become more accessible and attainable with the support of ongoing monitoring, training, and technical assistance. Providers have expressed appreciation of clear guidance on the form of plans. For FY2013 funding requests, a template for CLC plans along with instructions and an example of quarterly monitoring report were included in application materials.

Analysis: Champaign County is rich with resources for individuals with developmental disabilities; many formal and informal supports exist to address the concerns of the Disability community. A challenge which remains is the utilization of and access to these resources by communities of color as well as by residents of medically underserved areas of the county. Cultural and Linguistic Competence Plans address racial and ethnic disparities. The attached aggregated demographics data submitted by funded agencies for fiscal years 2010 and 2011 appear to show a decrease in percentage of African American individuals receiving services; variations in agencies' data collection methods, along with changes in funded programs, may account for part of this decrease, but key informants have raised concerns about disparities in service delivery. Attached is an example of the growing body of published research which examines disparities in diagnosis and treatment, which result in adverse outcomes for African-Americans, Latinos, and persons of lower socio-economic status. Cultural barriers, including negative beliefs (about disabilities and providers as well as racial and ethnic groups), contribute to misdiagnosis and late identification of Autism Spectrum Disorders, e.g., at a great cost to individuals and their families. The CCDDB seeks to increase awareness and reduce the stigma associated with disability so that, among other positive results, individuals may access quality care and be valued members of a fully inclusive community. It is important to remember that CLC is an ongoing process. Efforts made by CCDDB-funded agencies and organizations are notable, and progress has been accomplished in the face of great challenges. All persons with developmental disabilities deserve access to quality care, formal and informal supports, inclusion in their community, and freedom from stigma. Increased awareness of the stigma associated with developmental disabilities will in turn help eliminate disparities and allow Champaign County to move forward.

Definitions: Adapted from Cross, Bazron, Dennis & Isaac's (1989) *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed: Volume I* and Goode & Jones (modified 2004), National Center for Cultural Competence, Georgetown University Center for Child & Human Development.

“*Cultural Competence*” is

1. a defined set of values and principles which are reflected within the behaviors, attitudes, policies and structures of agencies, family/youth/consumer organizations, providers, and community stakeholders to result in appropriate and effective services for all;
2. the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference (4) to view cultural knowledge as a part of the organization (5) adapt to diversity and be aware of the cultural contexts of the communities and individuals served.
3. Integration of the above in all aspects of policy making, administration, practice, service delivery, consumers and their support systems in the infrastructure of the organization.

“*Linguistic Competence*” is the capacity of an organization and its personnel to communicate effectively and convey information in a manner that is easily understood by diverse audiences. Linguistic competence involves the development of interagency and internal capacity to respond effectively to the behavioral health/disability literacy and communication needs the populations that are served and to implement the policy, structures, practices, procedures, and dedicated resources to support this capacity.

“*Competence*” implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by individuals and families and their communities.

“*Culture*” - vast structures of behavior, ideas, attitudes, values, habits, beliefs, customs, language, rituals, ceremonies, and practices peculiar (identified) to a group of people... that provides them with a general design for living and patterns for interpreting reality.”

(Wade Noble MD, adapted from the TA Partnership)

Reading List:

Gibson, Deresha D. (2007). Racial Disparities in the Age of Diagnosis of Autism Spectrum Disorder: Examining Factors that May Contribute to Delayed Diagnosis in African-American Children. *PRAXIS, Fall 2007, Volume 7: 34-38.* (ATTACHED)

Johnson, J, Guinan, M, Brown, SE., and Shearer, V. (2005). Disability, Culture, and Health Disparities. *Impact: Feature Issue on Enhancing Quality and Coordination of Health Care for Persons with Chronic Illness and/or Disabilities. Winter 2005, Volume 18, Number 1: 6-7.*

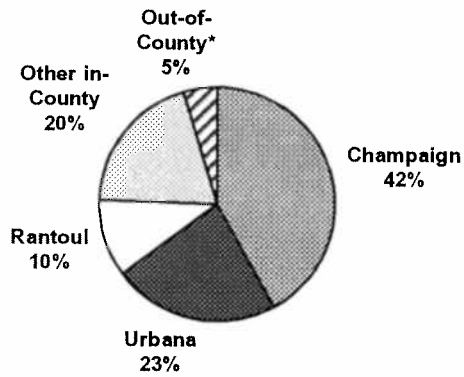
Johnson, K and Theberge, S. (2007). Reducing Disparities Beginning in Early Childhood. *National Center for Children in Poverty, Columbia University: Project Thrive. Short Take No. 4.*

Mandell, DS, Wiggins, LD, Carpenter, LA, Daniels, J, DiGuseppi, C, Durkin, MS, Giarelli, E, Morrier, MJ, Nicholas, JS, Pinto-Martin, JA, Shattuck, PT, Thomas, KC, Yeargin-Allsopp, M, Kirby, RS. (2008). Racial/Ethnic Disparities in the Identification of Children with Autism Spectrum Disorders. *American Journal of Public Health, March 2009, v.99(3): 493-498.*

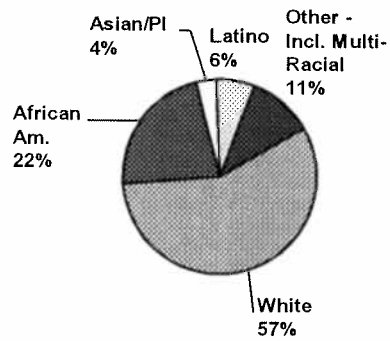
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Demographics of Persons Served By CCDDB Programs - 2010

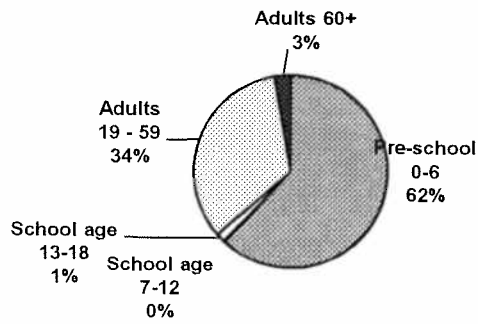
Residency of Persons Served
Included but not funded*



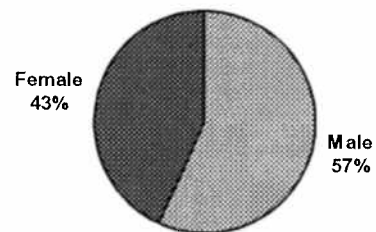
Race or Ethnicity of Persons Served



Age Distribution of Persons Served

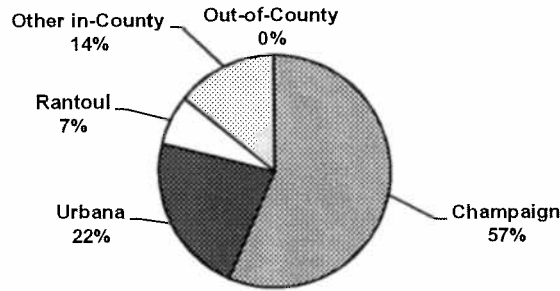


Gender Distribution of Persons Served

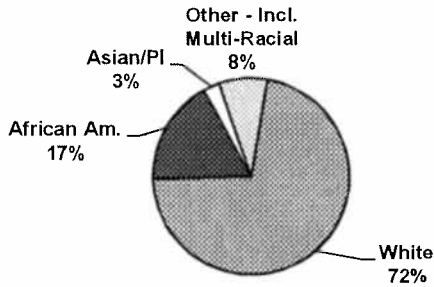


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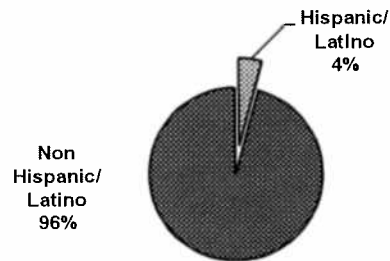
Residency of Persons Served



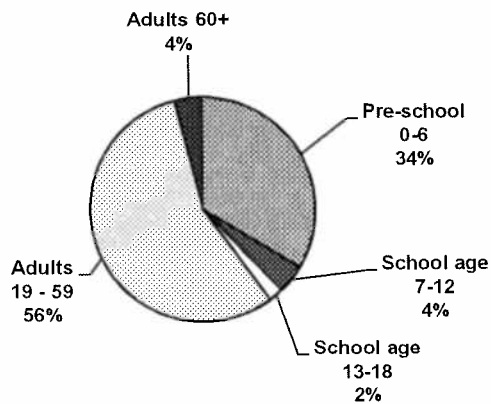
Race of Persons Served



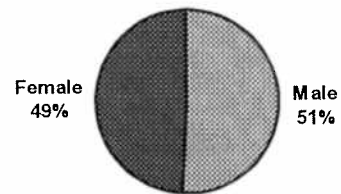
Ethnic Origin of Persons Served



Age Distribution of Persons Served



Gender Distribution of Persons Served



Racial Disparities in the Age of Diagnosis of Autism Spectrum Disorder: Examining Factors That May Contribute to Delayed Diagnosis in African-American Children

By Deresha D. Gibson

Abstract

Autism is a neurobiological disorder that affects approximately 1 child in 150 and occurs equally across demographic groups. While there is a similar rate of occurrence among African-American children and Caucasian children, there is a disparity in the age of diagnosis between the two groups. African-American children are likely to be diagnosed 1.5 years later than Caucasian children. Because it is critical to the long-term outcomes of children with autism to be diagnosed as early as possible and to participate in interventions, it is imperative that the reasons for this later diagnosis of African-American children be understood and action be taken to eliminate this disparity. This paper will identify possible factors that may contribute to the disparity in age of diagnosis between African-American and Caucasian children, make recommendations for intervention and policy, and discuss implications for social workers.

Introduction

A recent study released by the Centers for Disease Control and Prevention calls Autism Spectrum Disorder (ASD) a continuing public health concern (Centers for Disease Control and Prevention, 2007a). Autism, a neurobiological disorder of development, has been described as a “national crisis” and is the fastest growing disability in the United States, with approximately one child diagnosed with autism every twenty minutes (Autism Speaks, 2007). Rates of autism have increased from 1 child in every 166 to 1 child in every 150 as reported in January 2004 (Centers for Disease Control and Prevention, 2007b).

Although autism has a similar prevalence rate for African-American and Caucasian children, a disparity in the age of diagnosis has been identified for these two populations (Mandell, Listerud, Levy, & Pinto-Martin, 2002). It is important that the reasons for this disparity are identified so children can begin necessary interventions as soon as possible. This paper will examine factors that may contribute to late diagnosis in African-American children, make recommendations for intervention and policy, and discuss implications for social workers.

Prevalence and Diagnosis of Autism

Autism falls under the umbrella of Pervasive

Developmental Disorders (PDD) which includes conditions such as Rett’s Disorder, Childhood Disintegrative Disorder, and Asperger’s Disorder. Pervasive Developmental Disorders share the characteristics of a delay in the development of social skills, language and communication, and behavioral repertoire. According to the American Psychiatric Association (2000), autism is the most well known of the PDD’s and is characterized by sustained impairment in comprehending and responding to social cues, aberrant language development and usage, and restricted, stereotypical behavioral patterns. The American Academy of Pediatrics (2001) writes:

Children with autism demonstrate behaviors and skills that span a broad continuum extending from very mild peculiarities to severe developmental challenges. It is now known to be a very heterogeneous disorder, with milder forms being more common than the classic form. Although clinical patterns vary depending on severity, all children with autism demonstrate some degree of qualitative impairment in reciprocal social interaction, qualitative impairment of communication, and restricted, repetitive, and stereotypic patterns of behaviors, interests, and activities. Because of qualitative and quantitative variations in symptoms, autism is often referred to as autistic spectrum disorder (ASD) (p. 1221).

Autism knows no racial, ethnic, or social boundaries. “Family income, lifestyle, and educational levels do not affect the chance of autism’s occurrence” (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004, p. 212); however, a difference in the occurrence of autism between genders has been found, with autism affecting one girl for every four boys. A study on the prevalence of autism found that prevalence rates were remarkably similar when examined by race, but a predominance of males was found in each racial category (Yeargin-Allsop et al., 2003). Because of the racial homogeneity of the children included in published studies, little has been done to specifically examine the prevalence of autism by race. In one study of 987 Caucasian and African-American children, it was found that the prevalence of autism did not vary by race, even within race and sex subgroups (Yeargin-Allsop, Rice, Karapurkar, Doernberg, Boyle &

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Murphy, 2003).

Autism is believed to have a genetic component as the underlying cause of the disorder with possible environmental triggers, but its exact etiology is not known. Collins, Ma, Whitehead, Martin, Wright, Abramson, et al. (2006) found that the malfunctioning of two receptor genes, *GABRB1* and *GABRA4*, contribute to autism susceptibility among African-Americans and Caucasians. Although the susceptibility is the same, evidence suggests that some autistic characteristics, such as "indicators of language development, may be more severe in African-Americans, compared to non-Hispanic Caucasians" (Collins et al., 2006, p. 168). Researchers have also looked at possible neurological, environmental, and immunization links, but nothing conclusive has been found to cause autism (American Academy of Pediatrics, 2001).

Although much is still unknown about the cause(s) of autism, a body of knowledge has been accumulating on the diagnosis and treatment of autism. Autism can be diagnosed as early as 18 months of age. A child may exhibit autistic behaviors in infancy or develop normally for a year or more and then begin to exhibit autistic behaviors. Autism typically comes to the attention of a pediatrician from parents sharing their concerns and/or observing delays in the child meeting developmental milestones. A screening tool may be used and further testing can be done if autism is suspected. The process of diagnosing ASD entails a comprehensive evaluation by a medical team, including a psychologist, neurologist, psychiatrist, and speech, developmental, and occupational therapists. The process of identifying and diagnosing children early is critical as "early diagnosis resulting in early, appropriate, and consistent intervention has . . . been shown to be associated with improved long-term outcomes" (American Academy of Pediatrics, 2001, p. 1223).

Once children have been appropriately diagnosed with ASD, they and their families can have access to and receive appropriate services and interventions to improve outcomes for children and to help families cope with the disabling effects of autism, which can be a constant source of stress on a family system (Mandell et al., 2002; Higgins, Bailey, & Pearce, 2005). Beginning at the age of three, children diagnosed with ASD are covered under the Individuals with Disabilities Education Act (IDEA) and are eligible to receive services through the public education system for special education and related services (Mandell et al., 2002). Children under the age of three are eligible for the Early Intervention Program, which identifies children with developmental delays and works with them to improve their skills in the areas where they are deficient. Other interventions may be in the areas

of speech, communication, or sensory processing. Services received in Early Intervention can be continued in the public school system.

Despite the increasing ability to identify the early signs of ASD, knowledge of the benefits of identifying and treating children with ASD early, and the general growing awareness of this set of disorders, children with ASD often do not receive a diagnosis until they enter elementary school (Mandell, Novak, & Zubritsky, 2005). Although no significant difference in prevalence of autism among African-Americans and Caucasian children has been found, a study of 406 Medicaid-eligible children found that African-American children with ASD received a diagnosis an average of 1.5 years later than Caucasian children did (Mandell et al., 2002). In this study, Caucasian children received a diagnosis at an average of 6.3 years of age and African-American children at an average of 7.9 years of age (Mandell et al., 2002). Although there may be several reasons for the delay in diagnosis of ASD in children in the general population, the disparity in the age of diagnosis between African-American and Caucasian children is disturbing and necessitates further examination.

Factors Contributing to the Disparity in Age of Diagnosis

There are a number of factors that may contribute to African-American children being diagnosed with ASD 1.5 years later than Caucasian children. Misdiagnosis, pediatrician-parent relationships, access to health care, and biases of healthcare providers have been studied and discussed in the literature as factors contributing to the delay in diagnosis of African-American children.

The misdiagnosis of autism seems to be a factor contributing to a delay in the diagnosis of ASD in general, but particularly to the later diagnosis of ASD in African-American children. Symptoms common to autism, such as delayed speech, poor response to others, and behavioral difficulties, can lead to a misdiagnosis of language impairment or Attention Deficit/Hyperactivity Disorder (ADHD). In older children, repetitive behavior may steer clinicians toward a diagnosis of Obsessive-Compulsive Disorder and non-compliance related to resistance to change may lead clinicians to diagnose Oppositional Defiant Disorder (Mandell, Ittenbach, Levy, & Pinto-Martin, 2006). Mandell et al. (2006) examined the disparities in the diagnosis of children with autism using insurance claims of 406 Medicaid-eligible children, including 242 African-American, 118 Caucasian, 33 Latino, and 13 children falling into other categories. They found that African-American children were three times more likely than Caucasian children to receive another

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diagnosis first and were 2.6 times less likely than Caucasian children to receive an autism diagnosis on their first specialty care visit (Mandell et al., 2006). Once African-American children entered treatment, they required three times the number of visits over a period three times as long as Caucasian children before receiving an autistic disorder diagnosis (Mandell et al., 2006).

African-American children were also 5.1 times more likely than Caucasian children to receive a diagnosis of Adjustment Disorder than of ADHD, and 2.4 times more likely to receive a diagnosis of Conduct Disorder than of ADHD (Mandell et al., 2006). Diagnosing children with Adjustment Disorder may allow clinicians more time to evaluate a child, enable reimbursement for services and the opportunity to see the child again. Clinicians may diagnose Conduct Disorder when they interpret the child's behavior as disruptive or aggressive or see other characteristics associated with Conduct Disorder manifested in the child's behavior (Mandell et al., 2006). Mandell et al. (2006) state,

...the more frequent diagnosis of Conduct Disorder among African-Americans may be associated with clinicians' erroneous beliefs regarding the higher prevalence of Conduct Disorder among African-American children, while the more frequent diagnosing of Adjustment Disorder among all groups other than Caucasian children may be the result of clinicians' misinterpretations of parental concerns (p. 1483).

The quality and continuity of pediatrician-parent relationships is another factor contributing to the disparity in age of diagnosis between African-American and Caucasian children. "Early diagnosis of ASD is challenging in the context of primary care visits, because there is no . . . laboratory test to detect it" (American Academy of Pediatrics, 2001, p. 1221). If a pediatrician consistently sees the same child and has a relationship with the parents, identifying atypical behavior may be easier. Mandell et al. (2005) found that children who had four or more primary care physicians before diagnosis received a diagnosis an average of 0.5 years later than children who had one primary care physician. "Children who were referred to a specialist in response to parental concerns received a diagnosis an average of 0.3 years earlier than other children" (Mandell et al., 2005, p. 1483). Having many primary care physicians may be related to poor access to healthcare that results in discontinuity of care and misdiagnosis. As reported by Weinick and Krauss (2000),

studies have shown that Black and Hispanic children are more likely to lack a usual

source of care and less likely to have an office-based source of care than are White children . . . Black and Hispanic children are more likely than White children to be uninsured . . . Children without health insurance are more likely to lack a usual source of care, a regular clinician, and access to after-hours medical care than those with coverage (p. 1771).

Because children with autism manifest a complex array of deficits in communication and social interaction skills as well as behavior patterns, obtaining an accurate diagnosis is often the culmination of a long and protracted evaluation period, including the efforts of multiple professionals from a variety of disciplines (Seltzer, Krauss, Orsmond, & Vestal, 2000). If African-American children are more likely to not have access to healthcare, experience greater discontinuity in healthcare, and/or are more likely to see multiple primary care physicians, the opportunity for a provider to make an accurate and timely diagnosis is greatly jeopardized.

Physician bias is another possible factor contributing to the disparity of diagnosing ASD in African-American children. Since cultural factors are intertwined with thoughts and behaviors and can contribute to bias, culture may assume a major role in the way physicians see and respond to deviations in their patients' development and may influence the extent to which they subscribe to assessment, diagnosis and intervention strategies (Mandell & Novak, 2005). A family's culture and a physician's lack of knowledge about that culture could contribute to a child being misdiagnosed.

Clinicians may be influenced in their decision to screen for ASD in African-American children due to having different expectations about treatment and service needs by ethnicity and may therefore not screen for ASD as quickly as they would among Caucasian children (Mandell & Novak, 2005). "Physicians may also more quickly discount the concerns of African-American parents than they do the concerns of white parents related to their children's developmental delays, or not elicit those concerns in the first place" (Mandell & Novak, 2005, p. 112). Cooper-Patrick et al. (1999) found, in 32 primary care practices, that African-Americans rated their visits as significantly less participatory than Caucasians did. This could be due to racial and ethnic differences between physicians and their patients (Cooper-Partrick et al, 1999).

There may also be a bias on the part of the professional related to the notion of socioeconomic status (SES) as a relevant etiologic consideration for autism. Although it is clear that SES is not a determinant as to whether a child has autism, it may play a factor in

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whether a physician screens for ASD. Cuccaro et al. (1996) writes,

An alternative hypothesis involves the ambiguity of low SES and how clinicians factor in the contributions of disadvantage. In a low SES context, there may be a preponderance of biopsychosocial factors which could explain observed behaviors. In a high SES context, the number of possibilities is diminished as children born in “advantaged” settings are more likely to have had adequate environmental supports (p. 468).

This bias may determine how a physician reacts to parents’ concerns about their child’s development. Sociodemographic factors might also influence who gets evaluated for developmental concerns, how these concerns are documented, how soon a child is referred for specialty services, and who participates in studies (Mandell et al., 2002).

Implications for Social Workers

Due to the rise in the number of cases of autism and the importance of early diagnosis and treatment, it is crucial that social workers become more knowledgeable about ASD and be aware of the disparity in age of diagnosis of African-American children and the factors that contribute to this disparity. Social workers are often in positions to identify and screen children for ASD, educate other professionals, advocate on behalf of children and families, and influence and develop policies to ensure appropriate and timely diagnosis and treatment of ASD and equitable care for African-American children. Because of social workers’ training and sensitivity to racial and socioeconomic factors, they are well positioned to respond to the disparity in age of diagnosis of African-American children and take steps to close the gap. Social workers are also well positioned, once children have received a diagnosis, to be culturally sensitive when intervening with children who have been diagnosed with ASD. It is also essential that social workers help families understand the life-long impact of autism and ensure that children and families are receiving culturally appropriate care, and that all available services and social supports are being used to help families cope (Newsome, 2000). “Intervention in the form of information at the family level may be an appropriate policy response, par-

ticularly among harder-to-reach subpopulations, such as those with lower incomes or lower literacy” (Porterfield & McBride, 2007, p. 328).

Social workers can also contribute to the understanding of both the disparity in the age of diagnosis of African-American children as well as the experiences of African-American families and children who have been diagnosed with ASD by conducting research targeted specifically to African-Americans and other communities of color. Despite autism being recognized as a disorder that knows no racial, ethnic, or social boundaries, the majority of research has ignored or minimized race, and autism studies that specifically target African-Americans are rare (Dyches et al., 2004; Collins et al., 2006). Few studies look at the impact autism has on African-American families and, although it is clear there is a disparity in the age of diagnosis, there is only speculation as to why. It seems researchers have attempted to generalize their findings to a population that deserves to be studied independently. Social workers can contribute to the body of knowledge on ASD by conducting research that is specific to the experiences of African-American children and families, further helping us understand the disparities in the age of diagnosis and developing specific interventions and policy recommendations from the research findings.

Conclusion

Although we know disparities in the age of diagnosis of African-American children exist, it is unclear if the misdiagnosis of children, physician-parent relationships, access to health care, physician bias, or another factor yet to be identified is most responsible. It is likely a combination of all these that factor into African-American children being diagnosed an average of 1.5 years later than Caucasian children. Although we do have some information on the reasons for the disparity, there clearly needs to be further research to examine the various factors that contribute to the later age of diagnosis in African-American children. Because early diagnosis and treatment of ASD is so important to the long-term outcomes of children with ASD, it is crucial that we understand the factors that contribute to later diagnosis in African-American children and take steps to close the gap. Social workers are uniquely positioned to make an impact on this problem and help children and families who have been affected by ASD through clinical work with children and families, advocacy, teaching, policy development, and research.

Deressa Gibson has completed her first-year in the MSW program. Her first-year internship was at Heart to Heart, a program that works with older adults in the Edgewater community. She was recently selected as a 2007-08 Schweitzer Fellow to do a project on autism awareness that will target the African-American community. After graduation she would like to work in the medical social work field.

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