



CHAMPAIGN COUNTY MENTAL HEALTH BOARD

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

Champaign County Developmental Disabilities Board (CCDDB) AGENDA

Wednesday, October 23, 2013

Brookens Administrative Building

Lyle Shields Room

1776 E. Washington St., Urbana, IL 61802

8:00AM

1. Call to Order – Ms. Elaine Palencia, President
2. Introduction of New Board Members – Peter Tracy, Executive Director
3. Roll Call – Stephanie Howard-Gallo
4. Additions to Agenda
5. Citizen Input
6. CCMHB Input
7. Approval of CCDDB Minutes
 - A. 7/17/13 Board Meeting*

Minutes are included in the packet. Board action is requested.
8. President's Comments – Ms. Elaine Palencia
9. Executive Director's Comments – Peter Tracy
10. Staff Report – Lynn Canfield

Deferred.
11. Agency Information
12. Financial Report
 - A. Approval of Claims*

Included in the Board packet. Action is requested.
13. New Business
 - A. Election of Secretary*
 - B. Draft FY13 Program Performance Outcomes

A summary of all funded agency utilization data and performance measure outcome reports for FY13 is included in the packet for information only.
 - C. Draft Three Year Plan 2013-2015 with FY 2014 Objectives

A Briefing Memorandum and Draft Three Year Plan with Objectives for FY2014 are included in the packet.
 - D. FY15 Allocation Criteria

A Briefing Memo is included in the packet.
 - E. Draft Meeting Schedule and FY15 Allocation Schedule

Included in the Board packet are a draft CCDDDB meeting schedule and the FY15 allocation timeline.

14. Old Business

A. Disability Resource Expo

An oral report will be provided.

B. Public Hearing on Intellectual and Developmental Disabilities

From the September 18 event, Stakeholder's Consolidated Statement, Melissa Picciola's Power Point Presentation, Court Reporter's Transcript, and Additional Submitted Written Testimony are included in the packet.

15. Board Announcements

16. Adjournment

**Board action requested*

7.A

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

Minutes – July 17, 2013

*Brookens Administrative Center
Lyle Shields Room
1776 E. Washington St.
Urbana, IL*

8:00 a.m.

MEMBERS PRESENT: Mike Smith, Sue Sutter

MEMBERS ABSENT: Elaine Palencia

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

OTHERS PRESENT: Laura Bennett, Dale Morrissey, Patty Walters, Jennifer Carlson,
Danielle Matthews, Developmental Services Center (DSC); Linda
Tortorelli, Community Choices (CC); Kathy Kessler, Community
Elements (CE); Pam Klassert, PACE; Tracy Parsons, ACCESS
Initiative (AI Barb Bressner, Consultant; Dennis Carpenter,
Charleston Transition Facility (CTF); Sheila Krein, The Autism
Program (TAP); Joyce Dill, parent

CALL TO ORDER:

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

INTRODUCTION OF NEW BOARD MEMBER:

Ms. Sue Suter was introduced.

ROLL CALL:

Roll call was taken and a quorum was present.

DRAFT

ADDITIONS TO AGENDA:

None.

CITIZEN INPUT:

None.

CHAMPAIGN COUNTY MENTAL HEALTH BOARD (CCMHB) INPUT:

The CCMHB will meet later today .

APPROVAL OF MINUTES:

Minutes from the May 22, 2013 Board meeting were included in the packet.

MOTION: Ms. Sutter moved to approve the minutes from the May 22, 2013 Board meeting. Mr. Smith seconded and the motion passed unanimously.

PRESIDENT'S COMMENTS:

None.

EXECUTIVE DIRECTOR'S REPORT:

The Person Centered Planning training will be held on September 9-11, 2013. On September, 18, 2013 a public hearing will be held regarding developmental disability and intellectual disability needs in the community. Legislators will be invited. The hearing will be held at the Champaign Library on Green St. in Champaign at 5 p.m.

STAFF REPORT:

A Report from Ms. Canfield was included in the Board packet.

AGENCY INFORMATION:

None.

FINANCIAL INFORMATION:

Approval of Claims:

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

MOTION: Ms. Sutter moved to accept the claims report as presented. Mr. Smith seconded the motion. The motion passed unanimously.

NEW BUSINESS:

Election of Officers:

MOTION: Mr. Smith moved for Ms. Palencia to serve as President for the CCDDDB. Ms. Sutter seconded the motion. A voice vote was taken and the motion passed unanimously.

Anti-Stigma Alliance:

A Decision Memorandum on a 2014 Anti-Stigma Alliance event was included in the Board packet.

MOTION: Ms. Sutter moved to approve up to \$15,000 as the CCDDDB share, contingent on approval of \$15,000 by the CCMHB to fund an equal share. In addition, FY13 excess revenue options should be utilized first if available. Mr. Smith seconded the motion. A roll call vote was taken and the motion passed.

DSC—Family Development Center Contract Amendment:

A Decision Memorandum regarding increasing the FY14 Developmental Services Center—Family Development Center contract maximum by \$29,852 was included in the Board packet.

MOTION: Ms. Sutter moved to amend contract # DD-14-086 for Developmental Services Center—Family Development Center, increasing the contract maximum to \$99,855. Mr. Smith seconded the motion. A roll call vote was taken and the motion passed.

2013-2014 CCDDDB Meeting Schedule:

Drafts of a meeting schedule (September 2013 through June 2014) and a schedule with subjects and allocation timeline was included in the Board packet for review.

CCDDDB FY14 Budget:

A Decision Memorandum on the CCDDDB Fiscal Year 2014 Budget was included in the Board packet.

MOTION: Mr. Smith moved to approve the budget document for County Fiscal Year 2014 for the Champaign county Developmental Disabilities Board. Ms. Sutter seconded the motion. The motion passed.

Proposed FY14 CCMHB Budgets:

Copies of the budgets for the CCMHB, Drug Court, ACCESS Initiative and Quarter Cent for Public Safety were included in the packet for information only.

OLD BUSINESS:

Disability Resource Expo:

A written report from Ms. Bressner was included in the packet.

BOARD ANNOUNCEMENTS:

The CCDDDB will not have a September meeting. A public hearing will be held instead on September 18th at 5 p.m. at the Champaign Library on Green Street in Champaign.

ADJOURNMENT:

The meeting adjourned at 8:27 a.m.

Respectfully Submitted by: Stephanie Howard-Gallo

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

DRAFT

CHAMPAIGN COUNTY
EXPENDITURE APPROVAL LIST

8/08/13

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VENDOR NO	VENDOR NAME	TRN DTE	B N CD	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							MENT HLTH BD FND 090			
		7/12/13	04 VR 108-	62		490586	7/17/13	108-050-533.07-00	PROFESSIONAL SERVICES	JUL ADMIN FEE	26,460.00
										VENDOR TOTAL	26,460.00 *
5352	AUTISM SOCIETY OF ILLINOIS							GRANTS			
		7/12/13	04 VR 108-	56		490608	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL AUTISM	1,000.00
										VENDOR TOTAL	1,000.00 *
16011	CHARLESTON TRANSITIONAL FACILITY										
		7/09/13	01 VR 108-	55		490285	7/11/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAY NURSING	1,102.00
		7/09/13	01 VR 108-	55		490285	7/11/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAY RESIDENTIAL	4,204.00
		7/12/13	04 VR 108-	64		490629	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL NURSING	1,430.00
		7/12/13	04 VR 108-	64		490629	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL RESIDENTIAL	3,042.00
		7/18/13	04 VR 108-	65		491048	7/25/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUN RESIDENTIAL	4,201.00
		7/18/13	04 VR 108-	65		491048	7/25/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUN NURSING	1,100.00
										VENDOR TOTAL	15,079.00 *
18203	COMMUNITY CHOICE, INC										
		7/12/13	04 VR 108-	58		490636	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL CUSTOM EMPLOY	4,167.00
		7/12/13	04 VR 108-	58		490636	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL COMMUNITY LIVIN	4,583.00
										VENDOR TOTAL	8,750.00 *
18209	COMMUNITY ELEMENTS										
		7/12/13	04 VR 108-	59		490637	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL COORD OF SVCS	2,922.00
										VENDOR TOTAL	2,922.00 *
22300	DEVELOPMENTAL SERVICES CENTER OF							CHAMPAIGN COUNTY INC			
		7/12/13	04 VR 108-	60		490648	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL APARTMENT SVCS	34,963.00
		7/12/13	04 VR 108-	60		490648	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL AUGMTD DT	14,850.00
		7/12/13	04 VR 108-	60		490648	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL AUGMTD EMPLOY	12,150.00

12.A.

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*** FUND NO. 108 DEVLPMNTL DISABILITY FUND												
		7/12/13	04	VR	108-	60	490648	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL CARE MGMT	33,678.00
		7/12/13	04	VR	108-	60	490648	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL CLINICAL SVCS	15,127.00
		7/12/13	04	VR	108-	60	490648	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL CONNECTIONS	7,083.00
		7/12/13	04	VR	108-	60	490648	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL FDC	5,834.00
		7/12/13	04	VR	108-	60	490648	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL INDIV & FAM SUP	30,008.00
		7/12/13	04	VR	108-	60	490648	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL NON MEDCD DT	40,098.00
		7/12/13	04	VR	108-	60	490648	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL NON MEDCD EMPLO	32,807.00
											VENDOR TOTAL	226,598.00 *
22816	DOWN SYNDROME NETWORK									C/O WENDY BARKER		
		7/12/13	04	VR	108-	57	490651	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL DOWN SYNDROME	1,250.00
											VENDOR TOTAL	1,250.00 *
54930	PERSONS ASSUMING CONTROL OF THEIR									ENVIROMENT, INC		
		7/12/13	04	VR	108-	61	490710	7/17/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	JUL OPPPORT 4 INDEP	4,885.00
											VENDOR TOTAL	4,885.00 *
										DEVLNMNTL DISABILITY BOARD	DEPARTMENT TOTAL	286,944.00 *
										DEVLPMNTL DISABILITY FUND	FUND TOTAL	286,944.00 *

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VENDOR NO	VENDOR NAME	TRN DTE	B N CD	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							MENT HLTH BD FND 090			
		8/08/13	02 VR	108- 73		491914	8/15/13	108-050-533.07-00	PROFESSIONAL SERVICES	AUG ADMIN FEE	26,460.00
		9/03/13	02 VR	108- 80		493054	9/06/13	108-050-533.07-00	PROFESSIONAL SERVICES	SEP ADMIN FEE	26,460.00
										VENDOR TOTAL	52,920.00 *
5352	AUTISM SOCIETY OF ILLINOIS							GRANTS			
		8/08/13	02 VR	108- 66		491944	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG AUTISM	1,000.00
		9/03/13	02 VR	108- 74		493074	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP AUTISM	1,000.00
										VENDOR TOTAL	2,000.00 *
16011	CHARLESTON TRANSITIONAL FACILITY										
		8/08/13	02 VR	108- 68		491969	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG NURSING SVCS	1,430.00
		8/08/13	02 VR	108- 68		491969	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG RESIDENTIAL	3,042.00
		9/03/13	02 VR	108- 81		493095	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP NURSING SRVCS	1,430.00
		9/03/13	02 VR	108- 81		493095	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP RESIDENTIAL	3,042.00
										VENDOR TOTAL	8,944.00 *
18203	COMMUNITY CHOICE, INC										
		8/08/13	02 VR	108- 69		491979	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG CUSTOM EMPLOY	4,167.00
		8/08/13	02 VR	108- 69		491979	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG COMM LIVING	4,583.00
		9/03/13	02 VR	108- 76		493101	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP CUSTOM EMPLOY	4,167.00
		9/03/13	02 VR	108- 76		493101	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP COMMUN LIVING	4,583.00
										VENDOR TOTAL	17,500.00 *
18209	COMMUNITY ELEMENTS										
		8/08/13	02 VR	108- 70		491980	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG CCORD OF SVCS	2,922.00
		9/03/13	02 VR	108- 77		493102	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP COORD OF SRVCS	2,922.00
										VENDOR TOTAL	5,844.00 *
22300	DEVELOPMENTAL SERVICES CENTER OF							CHAMPAIGN COUNTY INC			
		8/08/13	02 VR	108- 71		491995	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG APARTMENT SVCS	34,371.00

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VENDOR NO	VENDOR NAME	TRN DTE	B N CD	TR TRANS NO	PO NO	CHECK NUMBER	CHECK DATE	ACCOUNT NUMBER	ACCOUNT DESCRIPTION	ITEM DESCRIPTION	EXPENDITURE AMOUNT
*** FUND NO. 108 DEVLPMNTL DISABILITY FUND											
		8/08/13	02 VR 108-	71		491995	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG AUGMENTED DT	14,850.00
		8/08/13	02 VR 108-	71		491995	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG AUGMENTED EMPLO	12,150.00
		8/08/13	02 VR 108-	71		491995	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG CARE MGMT	33,109.00
		8/08/13	02 VR 108-	71		491995	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG CLINICAL SVCS	14,871.00
		8/08/13	02 VR 108-	71		491995	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG CONNECTIONS TRA	7,083.00
		8/08/13	02 VR 108-	71		491995	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG FDC	8,547.00
		8/08/13	02 VR 108-	71		491995	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG INDIV/FAM SUPPO	29,500.00
		8/08/13	02 VR 108-	71		491995	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG NONMEDICAID DT	40,098.00
		8/08/13	02 VR 108-	71		491995	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG NONMEDICAID EMP	32,807.00
		9/03/13	02 VR 108-	78		493109	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP APARTMENT SVCS	34,371.00
		9/03/13	02 VR 108-	78		493109	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP AUGMNTD DT	14,850.00
		9/03/13	02 VR 108-	78		493109	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP AUGMNTD EMPLOY	12,150.00
		9/03/13	02 VR 108-	78		493109	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP CARE MANAGEMENT	33,109.00
		9/03/13	02 VR 108-	78		493109	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP CLINICAL SRVCS	14,871.00
		9/03/13	02 VR 108-	78		493109	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP CONNECTN TRNSNL	7,083.00
		9/03/13	02 VR 108-	78		493109	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP FAM DEVELOPMENT	8,547.00
		9/03/13	02 VR 108-	78		493109	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP INDV/FAM SUPPOR	29,500.00
		9/03/13	02 VR 108-	78		493109	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP NON MEDICAID DT	40,098.00
		9/03/13	02 VR 108-	78		493109	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP NON MEDICAID EM	32,807.00
										VENDOR TOTAL	454,772.00 *
22816	DOWN SYNDROME NETWORK								C/O WENDY BARKER		
		8/08/13	02 VR 108-	67		491998	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG DOWN SYNDROME	1,250.00
		9/03/13	02 VR 108-	75		493112	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP DOWN SYNDROME	1,250.00
										VENDOR TOTAL	2,500.00 *
54930	PERSONS ASSUMING CONTROL OF THEIR								ENVIROMENT, INC		
		8/08/13	02 VR 108-	72		492079	8/15/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	AUG OPPORT 4 INDPDN	4,885.00
		9/03/13	02 VR 108-	79		493150	9/06/13	108-050-533.92-00	CONTRIBUTIONS & GRANTS	SEP OPPORT INDPENDN	4,885.00
										VENDOR TOTAL	9,770.00 *
									DEVLPMNTL DISABILITY BOARD	DEPARTMENT TOTAL	554,250.00 *
									DEVLPMNTL DISABILITY FUND	FUND TOTAL	554,250.00 *

DRAFT FY13 Program Performance Outcomes (Actual Utilization)

The Autism Society of Illinois -----

CU Autism Network

Community Service Event target 1200, actual 1881.

Demographics (large events present challenges to complete data collection; duplication may result related to small event attendance): 36 aged 0-6, 54 aged 7-12, 36 aged 13-18, 626 aged 19-59, 65 over 60, 60 data not available; 294 white, 15 black/African American, 6 Asian/Pacific Islander, 10 other, 561 data not available; 4 Hispanic/Latino, 712 data not available; 337 male, 540 female.

Zip code (similar data collection issues): 43 Urbana, 35 Champaign, 1 Fisher, 1 Dewey, 2 Longview, 3 Mahomet, 4 Philo, 6 Rantoul, 4 St. Joseph, 1 Savoy, 5 Sidney, 4 Tolono.

Performance Outcomes: 8 regular meetings were held; two childcare options were offered at each of the 8 meetings - these were childcare for those aged 0 to 6 and yoga for persons with ASD and aged 6 and up, as the Sibling Group was suspended due to low attendance over the last two years; two workshops were sponsored, on Autism Spectrum Disorder-related topics; outreach included 1200 individuals, family members, and professionals; New Parent packets were distributed to families; three family events were staged; Autism Walk & Safety Fair was held in April, Autism Awareness Month; internet presence and local phone maintained; and Spanish language materials on Autism events were being developed.

Charleston Transitional Facility -----

Residential & Day Services

Continuing Treatment Plan Client target 1, as the Devonshire CILA continued to serve one individual, with no bedhold days, billing out the Fee for Service contract.

Nursing

This Fee for Service contract was also billed out.

Continuing Treatment Plan Client target 7, actual 7.

Demographics: 6 aged 19-59, 1 over 60; 6 white, 1 black/African American; 7 non Hispanic/Latino; 2 male, 5 female.

Zip Code: all reside in Champaign.

Performance Outcomes: **Residential** placement was coordinated with PAS agent initially; consents, continued need for service, and staffing consistent with DHS CILA rules; Person-Centered service plan includes goals also consistent with DHS rule and consumer/guardian input, including **Day Services** contracted through DSC and two part-time jobs in the community; guardians expressed satisfaction in all 12 categories surveyed, with comments indicating high satisfaction, over 95%; progress indicated on self-directed service goals; high interest and participation in community activities; on BQM survey, agency received 97% rating for CILA and high marks for Nursing (Rule 116) compliance; person centered planning is central to Cultural Competency Plan, including Self-Advocate Group, rooms decorated to residents' specifications, and individuals deciding where/what time/who attends their planning meetings; **Nursing** services were available 24/7 (on-call) and full time Nurse Trainer/RN, at the house one day per week; more efficient oversight was especially valuable for a resident with progressive dementia and another with psychiatric/behavioral issues; in addition to coordination of those higher

levels of care, RN is involved with reviews, monitoring, interdisciplinary planning process, staff training, etc. on behalf of all residents; annual individual/guardian surveys show 95% level of satisfaction; monthly staff notes and assessments demonstrate progress among all residents in medication goals; BQM survey positive wrt Nursing services, including 100% for staff medication authorization files and "that CTF was one of the top two agencies in compliance with Rule 116."

Community Choices -----

Customized Employment

Continuing Treatment Plan Client target 12, actual 18.

New Treatment Plan Client target 10, actual 11.

Community Service Event target 4, actual 4.

Service/Screening Contact target 440, actual 808.

Demographics: 28 aged 19-59, 1 over 60; 27 white, 2 black/African American; 29 not of Hispanic/Latino origin; 19 male, 10 female.

Zip code: 6 in Urbana; 14 in Champaign; 1 Dewey; 1 Fisher; 1 Ivesdale; 2 Mahomet; 2 Rantoul; 1 St. Joe; 1 Savoy.

Performance Outcomes: 10 started and 7 completed Discovery process; a job skills training class (6 sessions) was developed, completed by 10 individuals; 2 started a Career Expansion Course; 4 negotiated paid job placement; 5 used short-term job coaching and skills training; 15 received ongoing employment support (increasing hours/wk, expanding responsibilities, requesting and getting a promotion, obtaining company health insurance, changing job tasks and supervisor, working with SSDI, requesting accommodations, maintaining work relationships, managing anxiety, navigating social situations at work, educating the workplace on autism); 3 had ongoing support for self-employment. *Beyond the CCDDDB contract:* Department of Rehabilitation Services contract for securing jobs for 7; job search support for 3 with other types of disability; bus training for 1; continuing education for 5.

Community Living

New Treatment Plan Client target 15, actual 16.

Community Service Event target 2, actual 3.

Service/Screening Contact target 564, actual 566.

Demographics: 16 aged 19-59; 14 white, 2 black/African American; 16 not of Hispanic/Latino origin; 12 male, 4 female.

Zip Code: 3 Urbana, 10 Champaign, 1 Mahomet, 2 Savoy.

Performance Outcomes: Person-centered planning meetings for 16 individuals, with goals identified and reached (budgeting, schedules/routines, job skills development, bus access, nutrition and wellness, household management, continuing education, linkage/referral); 3 individuals moved into a shared living environment with 4th roommate as a support (Community Builder) and outcomes achieved (lease agreements, finding roommates, recruiting Community Builder, house meetings/family meetings, independent living support, job skills development, budgeting, household management, recreation and leisure access). *Beyond the CCDDDB contract:* 3 life skill courses (8 sessions) completed, 6 individuals in budgeting and grocery shopping, 5 in social skills/relationships, 5 connections/sexuality; 18 individuals received service Facilitation for HBSS, Personal Support Workers were trained; rent assistance for Community Builder, weekly independent living support for 8 living on their own and 5 living with family.

Self-Determination Support (CCMHB funded)

Continuing Non-Treatment Plan Client target 60, actual 104.

New Non-Treatment Plan Client target 15, actual 27.

Community Service Event target 5, actual 6.

Service/Screening Contact target 708, actual 795.

Demographics: 7 aged 13-18, 108 aged 19-59, 16 over 60; 115 white, 6 Asian/Pacific Islander, 9 black/African American, 1 Other; 2 of Hispanic/Latino origin, 129 not; 63 male, 68 female.

Zip Code: 31 Urbana; 71 Champaign; 3 Fisher; 1 Ivesdale; 15 Mahomet; 2 Philo; 3 Savoy; 2 Seymour; 3 Tolono.

Performance Outcomes: 42 social events held (lunch club, dinner, Six Flags, movies, shopping, Sweet Corn Festival, museum, ballet, Illini Wrestling and Baseball, Pottery Place, Girls Night Out, Guys Night Out, Horseback Riding, Springfield Zoo); 8 self-advocacy meetings and 1 community event; 8 parent meetings; 3 family parties. *Beyond the CCMHB contract: with support, 4 individuals created Gaming Group with support, 2 were connected with college-student mentor, 6 hosted social events/invited friends.* Total program enjoyed positive feedback: increased number of social connections, stronger existing connections; improved self-awareness and self-esteem; increased knowledge of community options and sense of inclusion; increased awareness by community members of persons with disabilities and how to include them.

Community Elements -----**Coordination of Services DD/MI**

New Treatment Plan Client target 20, actual 12.

New Non-Treatment Plan Client actual 2, no target.

Community Service Event target 4, actual 12.

Service/Screening Contact target 20, actual 22.

Demographics: 2 aged 13-18, 11 aged 19-59, 1 over 60; 11 white, 2 black/African American, 1 Asian/Pacific Islander; 1 Hispanic/Latino, 13 non-Hispanic/Latino; 10 male, 4 female.

Zip Code: 2 Urbana, 9 Champaign, 1 Mahomet, 1 Rantoul, 1 St. Joseph.

Performance Outcomes: new program, focus on meetings/relationships with service providers (DSC, Community Choices, high schools, RPC PAS agents, DRS) and training on ID/DD to local law enforcement; contact with 22 potential clients includes screening and assessment, direct support for 14 individualized to unique mental health and other needs, coordination with family as well.

Developmental Services Center -----**Apartment Services**

Continuing Treatment Plan Client target 65, actual 63.

New Treatment Plan Client target 3, actual 3.

Service hours: 11,640.25.

Demographics: 56 aged 19-59, 10 over 60; 55 white, 8 black/African American, 2 Asian/Pacific Islander, 1 Other; 65 non Hispanic/Latino, 1 data not available; 39 male, 27 female.

Zip Code: 40 Urbana, 22 Champaign, 1 Mahomet, 1 Rantoul, 1 St. Joseph, 1 Savoy.

Performance Outcomes: target of 90% cases presented to admissions committee within 30 days, actual outcome 100%; 3 individuals entered the program; target of 80% making progress in independent living skills objectives, actual outcome 82.8%; target of 20 new opportunities for consumers to participate in new activities with priority on individualized leisure, actual 41 (gym membership, horseback riding, ziplining, use of ipad for communication, a week in Cape Cod).

CILA

Continuing Treatment Plan Client target 47, actual 46.

New Treatment Plan Client target 1, actual 3.

Demographics: 43 aged 19-59, 6 over 60; 45 white, 4 Black/African American; 1 Hispanic/Latino, 48 non Hispanic/Latino; 25 male, 24 female.

Zip code: 16 Urbana, 25 Champaign, 8 Rantoul.

Performance Outcomes: target of 90% cases presented to admissions within 30 days, actual outcome 100%; 3 individuals entered the program in FY13; target of 70% maintain or make progress on independent living skills objectives, actual outcome 89.5%.

Client/Family Support Services

Continuing Treatment Plan Client target 440, actual 397.

New Treatment Plan Client target 10, actual 28.

Actual 20 *Continuing* and 21 *New Non-Treatment Plan Clients*, no targets.

Community Service Event target 3, actual 3.

Service/Screening Contact target 125, actual 174.

Service hours: 11,446.25

Demographics: 7 aged 0-6, 42 aged 7-12, 30 aged 13-18, 344 aged 19-59, 43 over 60; 373 white, 67 black/African American, 18 Asian/Pacific Islander, 8 other; 5 Hispanic/Latino, 461 non Hispanic/Latino; 276 male, 190 female.

Zip code: 3 Ludlow, 133 Urbana, 1 Bondville, 200 Champaign, 5 Fisher, 3 Homer, 1 Ivesdale, 34 Mahomet, 1 Ogden, 1 Penfield, 2 Pesotum, 1 Philo, 30 Rantoul, 2 Sadorus, 19 St. Joseph, 3 Savoy, 3 Seymour, 2 Sidney, 21 Tolono

Performance Outcomes: target of 90% cases presented to admissions within 30 days, actual outcome 100%; target of 90% satisfaction (by surveys), actual outcome 95%; target of 85% of Individual Service Plans completed within 14 days of annual planning meeting, actual outcome 91.5%; target of 90% consumers opened to agency within 30 days of admissions approval, actual outcome 100%; target 90% of Home Based Support Services facilitation Request for Payment forms submitted by 7th business day of the month, actual outcome 100%.

Clinical Services

Continuing Treatment Plan Client target 90, actual 95.

New Treatment Plan Client target 30, actual 47.

Continuing Non-Treatment Plan Client target 3, actual 2.

New Non-Treatment Plan Client target 3, actual 7.

Community Service Event target 3, actual 2.

Service/Screening Contact target 25, actual 56.

- 7 (Quarter 1), 4 (Q2), 7 (Q3), and 9 (Q4) continuing clients received a new service and were not counted as new clients; in addition, at least 32 clients received two types of service, and at least 2 received three or more.

Demographics: 3 aged 7-12, 136 aged 19-59, 12 over 60; 126 white, 23 black/African American; 2 Asian/PI; 1 of Hispanic/Latino origin, 150 non-H/L; 85 male, 66 female.

Zip code: 2 Ludlow, 39 Urbana, 74 Champaign, 3 Fisher, 2 Homer, 1 Ivesdale, 4 Mahomet, 1 Penfield, 20 Rantoul, 3 St. Joseph, 2 Tolono.

Performance Outcomes: target 120 individuals served, actual 151 served; target 100% quarterly progress reviews, actual 100%; target 100% psychiatric patient medication review to focus on possible med reduction, actual 100% reviews completed; target 100% psychiatric patients participate in annual evaluations, actual outcome 96%; target 90% consumer satisfaction , actual outcome 90%.

Developmental Training/Employment Services

Continuing Treatment Plan Client target 300, actual 262.

New Treatment Plan Client target 6, actual 30.

New Non-Treatment Plan Client target 5, actual 13.

Community Service Event target 8, actual 42.

Service/Screening Contact target 8, actual 53.

Service hours: 255,623

Demographics: 255 aged 19-59, 25 over 60, 4 data not available; 230 white, 40 black/African American, 8 Asian/Pacific Islander, 2 other, 4 data not available; 4 Hispanic/Latino, 275 non Hispanic/Latino, 5 data not available; 160 male, 120 female, 4 data not available.

Zip code: 3 Ludlow, 90 Urbana, 126 Champaign, 2 Fisher, 1 Homer, 1 Ivesdale, 12 Mahomet, 1 Ogden, 1 Penfield, 2 Pesotum, 28 Rantoul, 1 Sadorus, 1 Savoy, 16 St. Joseph, 1 Seymour, 16 Tolono, 1 Other.

Performance Outcomes: target 90% cases presented to admissions committee within 30 days, actual 100%; target 90% consumer satisfaction, actual 93%; target 90% consumers in monthly community-based activity, actual 97%; target 45% consumers in community-based vocational or volunteer setting, actual outcome 58%; target of 5 individuals promoted to Supported Employment, actual outcome 4; target of 8 new employer-paid job sites, actual outcome 8 (including Gordman's, U of I Plant Research, Flightstar, CarX).

Family Development Center

Continuing Treatment Plan Client target 550, actual 426.

New Treatment Plan Client target 200, actual 209.

New Non-Treatment Plan Client (no target), actual 802.

Community Service Event target 300, actual 1004.

Service/Screening Contacts target 200, actual 203.

Demographics: 635 aged 0-6; 367 white, 132 black/African American, 24 Asian/Pacific Islander, 108 Other, 4 DNA; 75 Hispanic/Latino, 560 non-Hispanic/Latino; 359 male, 276 female.

Zip code: 2 Ludlow, 133 Urbana, 2 Bondville, 280 Champaign, 6 Fisher, 3 Gifford, 4 Homer, 1 Ivesdale, 30 Mahomet, 2 Ogden, 3 Penfield, 1 Pesotum, 3 Philo, 88 Rantoul, 1 Royal, 3 Sadorus, 17 St. Joseph, 28 Savoy, 2 Seymour, 4 Sidney, 7 Thomasboro, 14 Tolono.

Performance Outcomes: target 90% assessments completed within 14 days of evaluation, actual 98%; target 90% consumer satisfaction, actual 100%; target 90% children making progress toward developmental outcomes, actual 100%.

Individual and Family Support

Continuing Treatment Plan Client target 24, actual 21.

New Treatment Plan Client target 3, actual 7.

Continuing Non-Treatment Plan Client target 14, actual 18.

New Non-Treatment Plan Client target 13, actual 5.

Community Service Event target 3, actual 4.

Service/Screening Contact target 10, actual 22.

Demographics: 6 aged 0-6, 12 aged 7-12, 5 aged 13-18, 26 aged 19-59, 2 over 60; 34 white, 8 black/African American, 4 Asian/Pacific Islander, 5 Other; 0 Hispanic/Latino, 51 non Hispanic/Latino; 36 male, 15 female.

Zip code: 22 Urbana, 21 Champaign, 1 Fisher, 2 Mahomet, 1 Ogden, 1 Sadorus, 1 St. Joseph, 1 Seymour, 1 Tolono.

Performance Outcomes: target 90% of cases to admission within 30 days, actual 100%; target 90% consumer satisfaction, actual 100%; target 90% of consumers who request community outings will participate in at least two per month, actual 96%; target of 100% of individuals/guardians have their choice of IFS provider, actual outcome 100%.

Down Syndrome Network -----

Community Service Event target 1060, actual 1430 (headcount at events)

Demographics (not easily collected at large events, slight duplication of count at small meetings): 26 aged 0-6, 24 aged 7-12, 14 aged 19-59; 17 white, 10 data not available; 5 of Hispanic/Latino origin, 0 non H/L, 72 data not available; 51 male, 43 female.

Zip code (similar difficulty collecting data): 18 in Urbana, 2 Bondville, 58 Champaign, 7 Dewey, 1 Fisher, 1 Homer, 10 Mahomet, 1 Philo, 2 Rantoul, 1 Royal, 3 St. Joe, 1 Savoy, 1 Sidney, 1 Thomasboro.

Performance Outcomes: 10 monthly meetings, open to public, childcare provided, with average of 15 families attending regularly; holiday party in December and picnic in July; social interaction (bowling, book clubs, pool parties, museum, tween group); October 2012 Buddy Walk had over 1300 registered walkers; parent support group info distributed at hospitals, schools, workplaces, agencies, etc; website maintained; membership in national organizations maintained, allowing links from two national websites; monthly newsletter to professionals and approx. 125 families; book club activity for young adults/teens; lending library at DSC; new parent packets to hospitals and clinics, which in turn refer families to DSN; home visits and support at IEP, rec, and vocational meetings by parent volunteers; collaborations with other groups, such as Gigi's Playhouse and with UI (approx. 30 students completed special projects for DSN, provided childcare, or assistance with events); participation/collaboration in 4 advocacy events, including "Spread the Word to End the Word" and "Chalk the Word to End the Word" contest, utilizing many volunteers, promoted by 2 billboards; annual conference with FY13 topic Classroom instruction; monthly board meetings. *Currently developing a board code of conduct.*

Head Start/Early Head Start -----

Social Emotional Disabilities

Continuing Treatment Plan Client target 25, actual 73.

New Treatment Plan Client target 75, actual 119.

New Non-Treatment Plan Client target 60, actual 309.

Community Service Event target 15, actual 3.

Service/Screening Contact target 775, actual 699.

Other target 18, actual 22.

Demographics: 171 aged 0-6, 1 aged 7-12, 10 aged 19-59; 43 white, 99 black/African American, 1 Asian/Pacific Islander, 22 other, 17 data not available; 28 of Hispanic/Latino origin, 154 non-H/L; 103 male, 79 female.

Zip code: 45 Urbana, 91 Champaign, 1 Gifford, 1 Mahomet, 32 Rantoul, 9 St. Joseph, 1 Tolono.

Performance Outcomes: Continuing Treatment Plan Clients (75) consisted of those (27) with individual social emotional goals on lesson plans plus those (37) with Individual Success Plans (behavior plans) carried over to the new school year plus those (12) in counseling; New Treatment Plan Clients were those with new individual social emotional goals and those with new referrals to play therapy and those for whom a new ISP was developed; 54 had ISP plans developed, 20 counseling cases were opened, 45 received new social emotional goals; Non-Treatment Plan Clients include parent/teacher meetings (296), parent trainings (13) and parent support groups (difficult to count, so not included); Community Service Events difficult to attend, as referrals and high demand for services took precedence; Service/Screening Contacts were the number of children included in the observations of classrooms (215), conducted twice a year, plus ASQ-SE screenings of children (430) at enrollment and when they move from Early Head Start to Head Start, plus children referred for observation of difficulties in class (96); the "Other" category tallies mass screening events staged during summer, staff trainings on mental health and social/emotional, policy council meetings, and mental health/social emotional information in parent newsletters.

PACE -----

Opportunities for Independence

Non-Treatment Plan Client target 10, actual 29.

Treatment Plan Client target 30, actual 10 (2 new plus 8 continuing).

Community Service Event target 25, actual 71.

Service/Screening Contact target 750, actual 788.75 (report of hours).

Demographics (includes 7 new Non-TPCs from Q1): 15 aged 19-59, 2 over 60; 16 white, 1 Asian/Pacific Islander; 1 not of Hispanic/Latino origin, 16 data not available; 9 male, 8 female.

Zip Code: 6 Urbana, 9 Champaign, 2 Mahomet.

Performance Outcomes: outcomes are collected monthly but can be determined at any time, and they consist of those attained by an individual as a result of their association with PACE are counted; these are achievements the individual agrees they've made. FY13 total of 71 consumer outcomes consists of 19 in Communication (e.g., communicates confidently), 2 in Education and Training (e.g., started vocational training), 8 in Employment (e.g., entered employment), 7 in Equipment/Assistive Technology (e.g., uses adaptive equipment for maximum independence), 4 in Finance and Benefits (e.g., manages personal funds), 2 in Health Care/Medical (e.g., prevents health emergency), 3 in Daily Living/Self-Care (e.g., moves effectively in new location or area), 19 Self Help/Personal (e.g., applies problem solving and

decision making skills), 5 Social Recreation (e.g., found friend to share activities with), 2 Transportation (e.g., acquired desired transportation).



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

BRIEFING MEMORANDUM

DATE: October 23, 2013
TO: CCDDDB Members
FROM: Lynn Canfield, Associate Director
SUBJECT: Draft Three-Year Plan 2013-2015 with FY 2014 Objectives

The current Three-Year Plan 2013-2015 enters its second year of implementation. The DRAFT Plan with objectives for Fiscal Year 2014 is an extension of the prior fiscal year. While many objectives reflect on-going commitments, others have been revised or added to advance the goals of the Plan or respond to changes in the operating environment. As the intellectual disability and developmental disability services and supports system responds to implementation of the Ligas Consent Decree, closures of State facilities, implementation of the Employment First Act, expansion of Medicaid, managed care, and more, the input of self-advocates and other stakeholders should be central to planning. An objective to monitor implementation of Employment First has been added, and existing related objectives are continued. Objectives have been added regarding collaboration with the Champaign County Mental Health Board on early intervention, with United Way on 211 system, and as an administrative function, to investigate options for moving to a web-based fee for service billing system.

Three-Year Plan for FY 2013 – 2015 with One-Year Objectives for 2014

The goals listed are for the period of 2013 through 2015. Objectives are for the 2014 fiscal year. A draft of the Plan is attached with proposed new or modified objectives italicized and underlined while completed objectives are lined out.

Staff has had an opportunity to review the draft document and will hold further discussions. This will include consideration of comments received from interested parties. At the time the draft Plan was released to the Board, the document was disseminated for comment.

The updated Three Year Plan will be presented for approval at the November 20, 2013 Board meeting.

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

THREE-YEAR PLAN

FOR

**FISCAL YEARS 2013 - 2015
(12/1/12 – 11/30/15)**

WITH

ONE YEAR OBJECTIVES

FOR

**FISCAL YEAR 2014
(12/1/13 – 12/31/14)**

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

WHEREAS, the Champaign County Developmental Disabilities Board has been established under the Illinois County Care for Persons with Developmental Disabilities Act (IL Compiled Statutes, Chapter 55, Sections 105/0.01 to 105/13 inclusive) in order to “provide facilities or services for the benefit of its residents who are mentally retarded or under a developmental disability and who are not eligible to participate in any such program conducted under Article 14 of the School Code, or may contract therefore with any privately or publicly operated entity which provides facilities or services either in or out of such county.”

MISSION STATEMENT

The mission of the Champaign County Board for Care and Treatment of Persons with a Developmental Disability (CCDDB) is the promotion of a local system of programs and services for the treatment of *intellectual disabilities and* developmental disabilities in accordance with the assessed priorities of the citizens of Champaign County.

STATEMENT OF PURPOSES

1. Planning for the *intellectual disability and developmental disability* services system to assure accomplishment of the CCDDB goals.
2. Allocation of local funds to assure the provision of a comprehensive system of community based *intellectual disability and developmental disability services and supports*.
3. Coordination of affiliated providers of *intellectual disability and developmental disability services and supports* to assure an interrelated accessible system of care.
4. Evaluation of the system of care to assure that services *and supports* are provided as planned and that services are effective in meeting the needs and values of the community.

In order to accomplish these purposes, the Champaign County Developmental Disabilities Board must collaborate with the public and private sectors in providing the resources necessary for the effective functioning of the *intellectual disability and developmental disability* service and support system. The CCDDB shall perform those duties and responsibilities as specified in Sections 105/01 to 105/13 inclusive of The County Care for Persons with Developmental Disabilities Act.

CHILDREN AND FAMILY FOCUSED PROGRAMS AND SERVICES

Goal #1: Identify children at-risk of developmental delay and intellectual disability or developmental disability and support early intervention services and family supports.

Objective #1: Support use of evidence based/informed models for provider programs serving families with children age birth to five, and require collaboration and coordination by providers to limit duplication of effort.

Objective #2: Participate in collaborative bodies such as the Champaign County Birth to Six Council whose mission focuses on serving families with young children.

Objective #3: Collaborate with the Champaign County Mental Health Board on issues of mutual interest associated with early intervention services and programs.

Objective #4: Prioritize children and families involved with the ACCESS Initiative to facilitate access to supportive or early intervention services, if appropriate.

Objective #5: In consultation with the Champaign County Mental Health Board, continue realignment of funding to support early intervention services for children with an intellectual disability or developmental disability or delay.

Goal #2: Support adults' and families' access to services and programs, including evidence based practices to increase positive outcomes.

Objective #1: Support a continuum of services for persons with an intellectual disability or developmental disability in response to reduced state supported services.

Objective #2: Promote wellness for people with intellectual disabilities and developmental disabilities, to prevent and reduce early mortality, as embodied in the "10x10 Wellness Campaign."

Objective #3: Encourage training of staff across the service spectrum on use of evidence based/informed practice and associated outcome measurement.

COMMUNITY ENGAGEMENT & ADVOCACY

Goal #3: Address the stigma associated with intellectual disabilities and developmental disabilities through broad based community education efforts/events designed to challenge discrimination and to promote acceptance, dignity, and social inclusion.

Objective #1: Continue support for and involvement in the signature anti-stigma and community education events, disAbility Resource Expo: Reaching Out for Answers and Roger Ebert's Film Festival.

Objective #2: Encourage consumer and advocacy groups' community education efforts to reduce stigma and promote inclusion.

Objective #3: Participate in other community based activities such as walks, forums, and presentations to raise awareness.

Goal #4: Stay abreast of emerging issues affecting the local systems of care and consumer access to services and be proactive through concerted advocacy efforts.

Objective #1: Monitor implementation of the Affordable Care Act and the expansion of Medicaid by the State of Illinois and advocate for increased service capacity sufficient to meet consumer demand through active participation in the Association of Community Mental Health Authorities of Illinois (ACMHAI) and other state and national associations. ~~Participate with organizations such as the National Association of County Behavioral Health and Developmental Disabilities Directors (NACBHDDD), the Illinois Council on Developmental Disabilities, the ARC of Illinois, the Illinois Association of Rehabilitation Facilities (IARF), and others to strengthen local systems of care.~~

Objective #2: Track state implementation of class action suit settlements involving persons with intellectual disabilities and developmental disabilities, including Ligas vs. Hamos Consent Decree, and ~~proposed~~ closure of state facilities, and advocate for the allocation of state resources sufficient to meet the needs of clients returning to home communities.

Objective #3: Monitor implementation of the Illinois Employment First Act including any associated rulemaking.

Objective #4: Through our association with NACBHDDD, follow developments at the state and federal levels of other Olmstead and Olmstead-related cases.

Objective #5: Continue broad based advocacy efforts at the state and local levels to respond to continued reductions in state funding and increasing delays in payment for local community-based intellectual disability and developmental disability services and supports and to the broader human services network under contract with the State of Illinois.

Objective #6: Continue to promote effective methods of engaging consumer and family groups in advocacy, including parent groups currently funded, and coordinate with ACCESS Initiative as feasible.

Objective #7: Statewide and locally, explore and promote service system redesign efforts consistent with recommendations of the Blueprint for System Redesign in Illinois, including appropriate state funding for development of community-based services and infrastructure.

Objective #8: Assess impact, on local systems of care for persons with intellectual disabilities and developmental disabilities, of the State of Illinois' and provider networks' movement to a regional service/managed care delivery model.

Objective #9: In collaboration with the United Way of Champaign County, monitor implementation of the regional 211 information and referral system and its impact on local utilization of funded information and referral services.

Goal #5: Maintain an active needs assessment process, relying heavily on key informants and public testimony from stakeholders, to identify current issues affecting consumer access and treatment.

Objective #1: Continue to assess the impact of state funding reductions on consumer access to care and provider capacity.

Objective #2: Participate in other county-wide assessment activities to ensure CCDDDB target populations are represented.

Objective #3: Track Illinois Department of Human Services Division of Developmental Disabilities' Prioritization of Urgency of Need for Services (PUNS) database for state and local trends and to ensure full representation of the service preferences of Champaign County residents.

Objective #4: Using Child and Family Connections data for Champaign County, track the identification of intellectual disabilities and developmental disabilities or delays among children, Birth to 6, and engagement in Early Intervention and Prevention services.

RESOURCE DEVELOPMENT & COLLABORATION

Goal #6: Increase investment in programs and services through promotion of collaborative and innovative approaches.

Objective #1: Through participation in the Association of Community Mental Health Authorities of Illinois (ACMHA), seek input and feedback on innovative approaches for resource development or cost containment.

Objective #2: Partner with other local entities for a coordinated response to needs of at-risk populations.

Objective #3: Consider non-financial support to agencies to offset state funding reductions and control costs.

Objective #4: Support and assist with affiliations and mergers of providers as a means to streamline the delivery of services and enable administrative cost savings through economies of scale.

Objective #5: Encourage development of collaborative agreements between providers to increase or maintain access and coordination of services for consumers residing in Rantoul and rural Champaign County.

Objective #6: Continue participation and support for Champaign County Specialty Courts serving persons with substance use disorders and/or mental health disorders, sharing information on services for those who also have intellectual disabilities or developmental disabilities in order to maintain adequate support for those with dual diagnoses.

Goal #7: Sustain the collaborative working relationship with the Champaign County Mental Health Board (CCMHB).

Objective #1: Implement the Intergovernmental Agreement between CCDDDB and CCMHB.

Objective #2: Coordinate integration, alignment, and allocation of resources with the CCMHB to ensure the efficacious use of resources within the intellectual disability and developmental disability service and support continuum.

Objective #3: Assess alternative service strategies that empower consumers and increase access to needed but underutilized services.

Objective #4: Continue to include person-centered planning as a component of the funding application.

ORGANIZATIONAL DEVELOPMENT, ADMINISTRATION, AND ACCOUNTABILITY

Goal #8: Implement policies and procedures to assure financial accountability for CCDDDB dollars tied to co-funded programs. The primary focus is related to programs which are also funded by revenue from the State of Illinois. Utilize the online application and reporting system to track all objectives pertaining to this goal.

Objective #1: Identify each CCDDDB funded contract that budgets state revenue as part of program revenue and develop mechanisms to track the level of state payments during the term of the contract.

Objective #2: Clarify how CCDDDB dollars are used in each co-funded contract. Enforce policies to assure that reductions in state contract maximums are not supplanted by CCDDDB dollars without prior notice or negotiation.

Objective #3: All CCDDDB grant contracts that receive State of Illinois funding as part of the total program revenue shall be required to report all staffing changes to the CCDDDB. At the discretion of the CCDDDB, agencies shall provide a full listing of all full, part-time, and contractual employees on a quarterly basis.

Objective #4: Require all CCDDDB funded agencies to notify the CCDDDB of the termination or lay off of employees funded in full or in part with CCDDDB funds accompanied by an explanation of the projected impact on consumers' access to or utilization of services.

Objective #5: Evaluate risk for loss of co-supported services resulting from state funding reductions.

Goal #9: Set priorities for funding through an annual review and allocation process to ensure access to core intellectual disability and developmental disability services and supports by consumers.

Objective #1: Draft priorities based on current service needs and operating conditions including consideration of changes in state funding and payment practices and obligations established through Memoranda of Understanding and Intergovernmental Agreements.

Objective #2: Solicit input from the service network and community at large on proposed funding priorities prior to adoption.

Objective #3: Utilize a competitive application process to evaluate proposals in relation to annual priorities.

Goal #10: Maintain program and financial accountability of service providers and programs under contract with the Board.

Objective #1: Evaluate program performance on a quarterly and annual basis.

Objective #2: Implement the Audit and Financial Accountability policy.

Objective #3: ~~Maintain the on-line application and reporting system and provide enhancements as necessary.~~ Investigate the possible options for developing a web based billing system to support fee-for-service contracts and improvement of accountability.

Objective #4: Evaluate provider administrative expenses and cost allocation plans to ensure maximum investment in consumer services.

Goal #11: Respond to State funding reductions for intellectual disability and developmental disability services and supports through administrative efficiencies at the Board level enabling maximum investment in community service grants and contracts.

Objective #1: Continue the administrative services agreement as defined in the Intergovernmental Agreement the Board and the Champaign County Mental Health Board.



13. D.

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

DRAFT BRIEFING MEMORANDUM

DATE: October 23, 2013
TO: Members, Champaign County Developmental Disabilities Board
FROM: Peter Tracy, Executive Director
SUBJECT: FY15 Allocation Priorities and Decision Support Criteria

In Illinois, we are currently in the midst of major changes in the delivery of supports and services for people with intellectual disabilities and developmental disabilities. The changes are being brought about by the State's rebalancing efforts (i.e., state operated facility closures), lawsuits and consent decrees, national trends and paradigm shifts, new statutes (e.g., Employment First), implementation of the Affordable Care Act, Medicaid expansion, and various managed care pilot projects being implemented by the Illinois Department of Healthcare and Family Services. Community based providers are faced with the problems of positioning to adapt to change in the continued climate of fiscal austerity, payment delays, and antiquated state policy.

Of concern to community mental health authorities (708 Boards) and county developmental disabilities boards (377 Boards) is how the myriad of changes will affect established and traditional funding patterns and exactly where we fit in this brave new world. The State's shift away from General Revenue Funding (GRF) to Federal Financial Participation (FFP) will continue to redefine our funding parameters and will create additional stress on an already stressed system because of the inadequacy of Medicaid rates.

On the positive side (for 708 and 377 Boards), the changes cited above will actually open up tremendous opportunities for rethinking how we prioritize local dollars. Specifically, we can anticipate the State will control costs by making adjustments in

clinical and service eligibility requirements. It is reasonable to predict that a significant cohort of people will be in need of services and supports but will not meet the intellectual disability or developmental disability threshold necessary to receive an award. We have seen this pattern play out with the Early Intervention program.

Lastly, even though we know radical changes are coming, we still don't know the details of how the State systems (e.g., Department of Human Services, Department of Healthcare and Family Services, and the Department of Children and Family Services) will be organized and how services and supports will be operationalized. As they say, "the devil's in the details." So to the extent possible we will try to influence change, but I anticipate we will mostly be watching and positioning ourselves to respond to change in a way which best meets the needs of the people of Champaign County.

Statutory Authority

Funding policies of the Champaign County Developmental Disabilities Board (CCDDB) are predicated on the requirements of the County Care for Persons with Developmental Disabilities Act (55 ILCS 105/ Section 0.01 et. seq.). All funds shall be allocated within the intent of the controlling act as codified in the laws of the State of Illinois. The purpose of this memorandum is to recommend and confirm service and program priorities for the FY15 (July 1, 2014 through June 30, 2015) funding cycle. CCDDB Funding Guidelines require annual review and update of decision support criteria and priorities in advance of the funding cycle application process.

Upon approval by the Board, this memorandum shall become an addendum to the CCDDB funding guidelines incorporated in standard operating procedures.

Expectations for Minimal Responsiveness

Applications that do not meet these thresholds are "non-responsive" and will be returned to the applicant. All agencies must be registered using the on-line system. The application(s) must be completed using the on-line system.

1. Eligible applicant – based on the Organization Eligibility Questionnaire.
2. Compliance with the application deadline. Late applications will not be accepted.
3. Application must relate directly to intellectual disabilities and developmental disabilities programs, services, and supports.
4. Application must be appropriate to this funding source and shall provide evidence that other funding sources are not available to support this program/service.

FY15 Priorities and Decision Support Criteria

Upon approval by the CCDDDB, the items included in this section will be heavily weighted in the decision of which applications should receive funding during the FY15 contract year (July 1, 2014 through June 30, 2015). These items are closely aligned with CCDDDB planning and needs assessment processes, State and federal statute changes, intergovernmental agreements, memoranda of understanding, and the recommendations of consultants hired by the board. Individuals with disabilities should have the opportunity to live like those without, should have control over their own day, and should have control over where and how they live. The FY15 allocation process is intended to respond to a wide range of stakeholder/resident input, including that learned through the September 18, 2013 Public Hearing on Intellectual Disabilities and Developmental Disabilities and concerns brought to our attention throughout the cycle.

Priority #1 – Person Centered Planning (PCP)

Applications shall provide detailed information about the PCP process used by the applicant to develop a cogent service and support plan predicated on and specific to CCDDDB funding. To the extent possible, CCDDDB dollars will follow individuals rather than programs and will focus on PCP-driven services and supports tied to the individual. In addition, the PCP process shall promote self-directed and culturally appropriate individualized service plans which include measurable desired outcomes. Individuals

should have the opportunity to make informed choices, based on access to complete information about services and financial supports available in integrated settings, exposure to integrated settings and individuals who work and live in them, and exploration of any concerns they may have about integrated settings.

Priority #2 – Employment Services and Supports

Applications which focus on vocational services and supports which are predicated on efficacious PCP processes and which incorporate Employment First Act principles shall be prioritized, with an emphasis on full or part time work in integrated, community settings, consistent with industry standards, based on a person's interests and abilities, and, when indicated and chosen, supported by individually designed services. Further, all employment/vocational related applications must warrant that CCDDDB funding shall not supplement services funded by Medicaid. The following are examples of ES services and supports:

- assessment, exploration, and enhancement of vocational interests and abilities
- support for the acquisition of job tasks and problem-solving skills
- assistance in establishing a vocational direction/objective consistent with preferences
- access to supported and/or customized employment opportunities
- promotion of competitive employment outcomes
- blended and/or transitional programs incorporating increased community integration

Priority #3 – Comprehensive Services and Supports for Young Children

Applications with a focus on services and supports for young children with developmental delays not covered by the State's Early Intervention program(s) or under the School Code shall be prioritized. Examples of services and supports include:

- an array of Early Intervention services addressing all areas of development

- coordinated, home-based, and taking into consideration the needs of the entire family
- early identification of developmental delays through consultation with child care providers, pre-school educators, and medical professionals

Priority #4 – Flexible Family Support

Applications which focus on flexible, PCP-driven, family support for people with ID/DD and their families, which are designed to enhance stability and their ability to live together, shall be prioritized. Examples of flexible family support include:

- family respite, recreational activities, mutual support options, transportation assistance
- assistive technology, home modification/accessibility supports, information and education
- other diverse supports which allow consumers and their families to determine care and treatment

Priority #5 – Adult Day Programming and Social and Community Integration

Applications for PCP-driven adult day programming for people with ID/DD who may also have behavioral support needs and/or significant physical limitations shall be prioritized.

Examples of services include:

- speech therapy, occupational therapy, fitness training, personal care support
- support for the development of independent living skills, social skills, communication skills, and functional academics skills
- community integration and vocational training, per consumer preferences
- facilitation of social, friendship, and volunteering opportunities
- access to community education programs, fitness and health promotion activities, mentoring opportunities, and by other creative means

Priority #6 – Consumer Advocacy and Family Support Organizations

Applications highlighting an improved understanding of ID/DD through support of sustainable consumer advocacy and family support organizations, especially those comprising persons who have ID/DD, their parents, and others in their networks of support, shall be prioritized.

Priority #7 – Inclusion and Anti-Stigma Programs and Supports

Applications that support efforts to reduce stigma associated with ID/DD may describe various approaches which share the goals of increasing community awareness and challenging negative attitudes and discriminatory practices.

Priority #8 – Individualized Residential Service Options

Applications which focus on residential service and support options predicated on efficacious PCP processes and not funded by the Department of Human Services shall be prioritized. CCDDDB funding for residential (and other) services and supports can potentially disqualify people from Medicaid and other State funding options.

Overarching Decision Support Considerations

The FY15 CCDDDB allocation process will require all applications to address the overarching criteria listed below. Assessment of all FY15 applications will focus on alignment with these overarching criteria.

1. **Underserved Populations** - Programs and services that promote access for underserved populations identified in the Surgeon General's Report on Mental Health: Culture, Race, and Ethnicity and the consultation with Carl Bell, M.D.
2. **Countywide Access** - Programs and services that promote county-wide access for all people in Champaign County. Zip code data is mandated.
3. **Medicaid Anti-Supplementation** - Programs and services eligible for Medicaid reimbursement for eligible people with intellectual disabilities and developmental disabilities shall not receive CCDDDB funding.

4. **Budget and Program Connectedness** - Applications must clearly explain the relationship between budgeted costs and program components. “What is the Board buying?” is the salient question to be answered in the proposal, and clarity is required.

Secondary Decision Support and Priority Criteria

The process items included in this section will be used as important discriminating factors which influence final allocation decision recommendations.

Approach/Methods/Innovation: Applications proposing evidence-based or research-based approaches and addressing fidelity to the model cited. Applications demonstrating creative and/or innovative approaches to meet defined community need.

Evidence of Collaboration: Applications identifying collaborative efforts with other organizations serving or directed by individuals with ID/DD and members of their support networks, toward a more efficient, effective, inclusive system of care.

Staff Credentials: Applications highlighting staff credentials and specialized training.

Process Considerations

The criteria described in this memorandum are to be used as guidance by the Board in assessing applications for CCDDB funding. However, they are not the sole consideration taken into account in finalizing funding decisions. Other considerations would include the judgment of the Board and its staff, opinion about the provider's ability to implement the program and services proposed, the soundness of the proposed methodology, and the administrative and fiscal capacity of the agency. Further, to be eligible to receive CCDDB funds, applications must reflect the Board's stated goals and objectives as well as the operating principles and public policy positions taken by the Board. The final funding decisions rest with the CCDDB and their judgment concerning the most appropriate and efficacious use of available dollars based on assessment of

community needs, equitable distribution across disability areas, and decision-support match up.

The CCDDDB allocation of funding is a complex task predicated on multiple variables. It is important to remember that this allocation process is not a request for proposals (RFP). Applicants for funding are not responding to a common set of specifications but rather are seeking funding to address a wide variety of developmental disability service and support needs in our community. In many respects our job is significantly more difficult than simply conducting an RFP. Based on past experience, we can anticipate that the nature and scope of applications will vary significantly and will include treatment, early intervention, and prevention models. For these reasons, a numerical rating/selection methodology is not applicable or relevant to our particular circumstances. Our focus is on what constitutes a best value to our community, based on a combination of cost and non-cost factors, and will reflect an integrated assessment of the relative merits of applications using criteria and priorities approved by the CCDDDB.

Caveats and Application Process Requirements:

- Submission of an application does not commit the CCDDDB to award a contract or to pay any costs incurred in the preparation of an application or to pay for any other costs incurred prior to the execution of a formal contract.
- Technical assistance available to applicants will be limited to process questions concerning the use of the online registration and application system, application forms, budget forms, application instructions, and CCDDDB Funding Guidelines.
- Applications which include excessive information beyond the scope of the application format will not be reviewed and, at the discretion of staff, may be disqualified from consideration. Letters of support for applications are discouraged and, if submitted, will not be considered as part of the allocation and selection process.

- The CCDDDB retains the right to accept or reject any or all applications and reserves the right to refrain from making an award when that is deemed to be in the best interest of the county.
- The CCDDDB reserves the right to vary the provisions set forth herein at any time prior to the execution of a contract where the CCDDDB deems such variances to be in the best interest of Champaign County.
- Applications and submissions become the property of the CCDDDB and, as such, are public documents that may be copied and made available upon request after allocation decisions have been made. Materials submitted will not be returned or deleted from the online system.
- The CCDDDB reserves the right, but is under no obligation, to negotiate an extension of any contract funded under this allocation process for up to a period not to exceed two years with or without additional procurement.
- If selected for contract negotiations, the applicant may be required to prepare and submit additional information prior to final contract execution, in order to reach terms for the provision of services that are agreeable to both parties. Failure to submit required information may result in cancellation of the award of a contract.
- The execution of financial contracts resultant of this application process is dependent upon the availability of adequate funds and the needs of Champaign County.
- The CCDDDB reserves the right to further define and add application components as needed. Applicants selected as responsive to the intent of this online application process will be given equal opportunity to update proposals for the newly identified components.
- All proposals considered must be received on time and must be responsive to the application instructions. The CCDDDB is not responsible for lateness or non-delivery of mail or messenger. Late applications shall be rejected.
- The contents of a successful application will be developed into a formal contract, if selected for funding. Failure of the applicant to accept these obligations can

result in cancellation of the award for contract. The CCDDDB reserves the right to withdraw or reduce the amount of an award if there is misrepresentation of the applicant's ability to perform as stated in the application.

- The CCDDDB reserves the right to negotiate the final terms (i.e., best and final offer) of any or all contracts with the applicant selected, and any such terms negotiated as a result of this application process may be renegotiated and/or amended in order to meet the needs of Champaign County. The CCDDDB also reserves the right to require the submission of any revision to the application which results from negotiations conducted.
- The CCDDDB reserves the right to contact any individual, agency, or employee listed in the application or to contact others who may have experience and/or knowledge of the applicant's relevant performance and/or qualifications.

Final Decision Authority – The CCDDDB will make the final decision concerning all applications for funding, taking into consideration staff recommendations, defined decision support criteria, best value, and availability of funds.

13. E.

CCDDB 2013-2014 Meeting Schedule

Board Meetings

8:00 AM

Brookens Administrative Building, Lyle Shields Room
1776 East Washington Street, Urbana, IL

November 20, 2013 – 8:00 AM

December 18, 2013 – 8:00 AM

January 22, 2014 – 8:00 AM

February 19, 2014 – 8:00 AM

March 19, 2014 – 8:00 AM

April 30, 2014 – 8:00 AM

May 21, 2014 – 8:00 AM

June 18, 2014 – 8:00 AM

This schedule is subject to change due to unforeseen circumstances.

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

DRAFT
2013-2014 MEETING SCHEDULE WITH SUBJECT AND
ALLOCATION TIMELINE AND PROCESS

The schedule provides the dates of board meetings for the Champaign County Developmental Disabilities Board. The subjects are not exclusive to any given meeting as other matters requiring Board review or action may also be addressed or may replace the subject listed. Study sessions may be scheduled throughout the year with the presentation and discussion held during the meeting or in the afternoon, following a meeting of the Champaign County Mental Health Board. Included is a tentative schedule for the CCDDDB allocation process for Contract Year 2015 (July 1, 2014 – June 30, 2015).

<u>Timeline</u>	<u>Tasks</u>
9/18/13	Public Hearing on Developmental Disabilities, 4:30PM Champaign Public Library, Robeson Rooms A&B
10/23/13	Regular Board Meeting Release Draft Three Year Plan 2013-2015 with FY14 Objectives Release Draft Contract Year 2015 Allocation Criteria
11/20/13	Regular Board Meeting Approve Three Year Plan with One Year Objectives Allocation Decision Support – CY15 Allocation Criteria
12/15/13	Public Notice to be published on or before this date, giving at least 21 day notice of application period.
12/18/13	Regular Board Meeting
1/8/14	Open CCMHB/CCDDDB Online System access to CCDDDB CY 2015 Agency Program and Financial Plan Application forms.
1/22/14	Regular Board Meeting
2/14/14	Online System Application deadline – System suspends applications at 4:30PM (CCDDDB close of business).
2/19/14	Regular Board Meeting List of Requests for FY15 Funding
3/19/14	Regular Board Meeting

4/23/14	Program summaries released to Board, copies posted online with the CCDDDB April 30, 2014 Board meeting agenda.
4/30/14	Regular Board Meeting with review of program summaries.
5/21/14	Regular Board Meeting Allocation Decisions Authorize Contracts for CY15 Allocation recommendations released to Board, copies posted online with the CCDDDB May 21, 2014 Board meeting agenda.
6/18/14	Regular Board Meeting Approve Draft Budget
6/27/14	Contracts completed
7/23/14	Regular Board Meeting Election of Officers

14.B.

Documents from
September 18, 2013
Public Hearing
on Intellectual Disabilities and
Developmental Disabilities

Including:

Consolidated Statement of Priorities of Champaign County
Stakeholders

Court Reporter's Transcript

Power Point Presentation by Melissa Picciola,
"Developmental Disabilities and Intellectual Disabilities:
Overview of Current Issues"

Written Testimony of Citizens

September 18, 2013

Consolidated Statement of Priorities of Champaign County Stakeholders

In Champaign County, where taxpayers have twice demonstrated their values by establishing public trust funds to improve the quality of life for our most vulnerable residents, the system of supports and services for those with intellectual and developmental disabilities remains: *complicated*, even for its most expert users; *incomplete*, meeting some of the needs of many and none of the needs of others; and *fragmented*. Our efforts to balance the preservation of core services with the innovation of more effective, self-directed service models are hampered by the context of the State of Illinois' protracted financial crisis and inattention to system design flaws.

The symptoms of inadequate investment of resources – both funding and human - can be witnessed at every stage of life for individuals with ID/DD and their loved ones:

- For **young children**, early diagnosis and treatment can lead to better quality of life for them and their supporters and decreased need for costly (and often segregated) supports in adulthood. Families may receive evaluations by speech, occupational, and physical therapists but then find no therapists available to provide the services as recommended. Parents of children suspected of having an autism spectrum disorder learn they can be scheduled for diagnostic assessment in 2015. A core problem with provider recruitment and retention here, as in Illinois generally, is found in the administration of Medicaid in Illinois, with a tradition of slow payment and low reimbursement rates for these valued services.
- Similar services and supports also appear difficult for **school age children** to access with the frequency and intensity known to facilitate greater gains. For example, there is now some insurance coverage for specific services for children with autism, but this is available only to families working for certain employers and not available to those with Medicaid.
- **Young adults** transitioning out of public school, for whom the promises of the Ligas Consent Decree and Employment First Act offer some hope, face long waiting lists for traditional services and supports. The critical role of the Pre-Admission Screening (PAS) Agent in helping people navigate the system is undermined by inadequate funding of PAS program activities and by state practices we do not understand, such as whether there are selection criteria for state awards from the PUNS (Prioritization for Urgency of Need for Services) list and why a person with a documented Developmental Disability, but IQ above 70, can no longer qualify for these awards. Families are urged to enroll in PUNS, but in the last three years only a very few children, all designated as "emergency," have received funding, leaving many uninvolved, with their important needs unaddressed.
- The shortages in supports available to **adults** with ID/DD have harmed our community deeply and for too long. The effects of waiting for any support at all are felt by all involved in the lives of these individuals; all deserve a more accessible system of care, and all deserve to direct and design the care. Housing, employment, volunteer, recreational, and social options for adults should include flexibility, greater integration in the community, and least restrictive environments for all. The high turnover, low compensation, and insufficient professional

development of direct service staff do *not* reflect our values as a community and do *not* foster the empowerment of individuals participating in services.

- Other persistent system gaps may require action beyond 'fixing' Medicaid (rates, service categories, payment practices) and adequately funding the Department of Human Services: individuals who have ID/DD and mental health needs are not well-served by either system; individuals with Autism Spectrum Disorders may benefit from supports not currently offered; many **older adults** currently participating in programs at the state's lowest rates have increased support needs associated with aging, no increased funding to address the changing needs, and little or no family left. It is critical that funding for individuals outside the Ligas class continues and that the supports those people receive are also adequate, to avoid creating new service gaps or deepening the current ones.

Illinois ranks near the bottom nationwide in providing community-based services and supports to individuals with developmental disabilities. We need adequate, flexible, and on-time funding. We want to unbind ourselves from the state's budgetary woes and to manifest the values Champaign County voters have twice expressed, to move this system into the 21st century with innovative, culturally responsive, and self-directed options enjoyed by other citizens.

CHAMPAIGN COUNTY DEVELOPMENTAL DISABILITIES BOARD
CHAMPAIGN COUNTY MENTAL HEALTH BOARD

PUBLIC HEARING ON
INTELLECTUAL & DEVELOPMENTAL DISABILITIES

September 18th, 2013
Champaign Public Library
200 West Green Street
Champaign, IL
4:45 PM

Ann K. Parkinson: CSR 84-002089

Area Wide Reporting & Video Conferencing
301 West White
Champaign, Illinois 61820
(800) 747-6789

(Welcome and introductions by Susan Suter.)

(Statement of priorities of stakeholders by Elaine Palencia.)

KEYNOTE PRESENTATION BY MELISSA PICCIOLA:

MS. PICCIOLA: Good evening. I just want to say it's a pleasure to be here, and thank you so much for having me. My name is Melissa Picciola, and I am from Equip For Equality. And I think I won't adequately address the issue that I stated on my first slide here, but I will do my best to hit the main points.

But I just want to say it's a pleasure to be in a roomful of people who care about this issue, and I hope that we can all work together to find solutions to some of the issues that I raise here today.

Let's get started. The first slide I just want to talk about, Equip For Equality; who we are and what we do, for those of you who may not be familiar with us.

We are the statewide, independent not-for-profit designated to administer the federally-mandated protection advocacy system for people with disabilities in Illinois.

And that mouthful basically means we provide legal services as well as advocacy services, ~~process ability~~ statewide. And we are part of a national network of places just like us.

So, I'm going to draw on that network as I talk about sort of some of the issues, and where we should be going as a state.

The main issues I want to talk about today are community integration, systems transformation, employment and abuse/neglect. I'm just going to touch on all of them because time is short, and I think it's most important that we hear from all of you. That's what the board has expressed, but I do want to sort of lay out some of those issues in each area.

So, the first one is community integration. We'll sort of start at the top by pointing out that Illinois is at the bottom,

Cross-
disability

right? So, this is where we need the biggest change, I think, in terms of where our services are and where they should be.

It was mentioned that Illinois ranks near the bottom. Illinois ranks 48th compared to how much nationwide, compared to how much spending is spent on home and community-based services. And we've been there for some time, which is discouraging. And I think as advocates, it sort of means that we need to do better.

The thing about it that I want to emphasize is that choice is paramount in this discussion. And it's something that we don't want to lose sight of. We want to listen to people with disabilities, and listen to where they want to live and with whom and provide them that choice.

And the last thing I want to point out about this is when I say smaller, smaller is generally considered to be four people or less. But definitely eight people or less. So when we say the right to live in the least restrictive settings, and we talk about smaller, we're typically talking about eight or less.

So, Illinois is sort of trying to catch up to the rest of the country on this front. But it's a long road and it's a hard road. We started to rebalance the system, and one of the ways we've started to do that, when I say "we", I mean royal "we", Illinois, not "we", like me. I'm a little self absorbed, but not that much.

The closure of state-operated developmental centers, including the closure of the Jacksonville Developmental Center and the closure process that has begun with the Murray Developmental Center. At least 13 states, and it keeps getting larger, that number, have no state-operated developmental centers. That is large facilities that are state run for people with disabilities.

But the main thing that I want to emphasize here is we need to make sure we're providing adequate services to people as we move them out.

The other thing that the state is doing on the DD side is the implementation of the Ligas consent decree, which provides that people who are either living in ICF/DD, which are larger nursing

homes for people with developmental disabilities, or who are on the waiting list that was mentioned before for home and community-based services, start to move off that waiting list and are offered home community-based services.

So, that's sort of one of the things that we're doing as we -- two of the things that we're doing.

And the next slide is issues in community integration. So, sort of what we've come up with so far, and what has been shown. This is not a comprehensive list, by any means. But it is some of the things that we've seen come up, and some of the ways that we should probably be doing better.

The first issue is adequacy of the provider network. And this includes how many providers there are to provide these services in the community. But also where the services are. We repeatedly hear about people who want to live in a particular section of the state, but providers aren't available. We also hear about the availability of qualified DSPs, or direct service personnel, to serve those individuals in the communities that they wish to live.

The other thing that was mentioned, and I would like to highlight as well, is the ability to care for individuals with dual diagnoses; and that means a DD diagnosis, as well as a mental health diagnosis. But this would include, I think, those who have significant behaviors that may or may not be tied to an official diagnosis. The service, the system as structured currently struggles with how to provide services adequately to those individuals, which leads me directly into the issue of the safety net, or lack thereof.

If an individual struggles in the community, and is struggling in their community placement, what happens next? And I think that as we move forward and we possibly downsize or go away from a larger institutional model, the question becomes, if you're not succeeding in your current placement, what do we do next?

And I think one of the things that we should start to think about is enhancing what's the current process, which is the SST process, the support services team process that's called in when someone is struggling.

And the most important thing that I would like to emphasize as we see the issues is the need for flexibility when designing service plans and also delivering those service plans.

What we recognize now, but we need to start to build a service around, is that each person is unique and they need unique services. And we need to start designing a system that can adequately serve those individuals.

This slide is related to our issues list. But I just want to talk a little bit about system transportation. That is what else is going on, other things that we're doing in the state.

The change of these things equal big changes, including the transition from a fee-for-service system, to a capitated rates, or otherwise known as a managed-care system.

Here's the bottom line. Any time you change the payment structure, the services are going to change. The thing is, this can be good, and it can be bad. And we're still sort of in this experimentation phase in Illinois.

It's like we're in college, that we're sort of trying to figure out how to do this and how to do this right. But we need to continue to be vigilant about how we deliver those services in this changed payment structure.

The other thing that I wanted to mention is the idea of individualized budgets versus predetermined rates. So, like I was talking about flexibility and individualization. We're starting to move with saying, okay, not here is the rate for this individual, but here is this individual. What do they need, and how much will it cost to serve them?

This move that we're starting to see from the Ligas consent decree and other ideas is really important, and can help us a lot with delivering those individualized services.

Decreasing waiting list was mentioned before, about how this being on a waiting list damages an individual. But also that if we decrease them, we can help.

The other thing I wanted to touch on was the collapsing silos of state government and benefit systems. Some of this is coming from the Affordable Care Act, including a unified eligibility system for public benefits. But, also

other framework and global budgeting solutions.

When we collapse budgets between agencies, what we find is the ability to stop worrying, okay, you're a person with DD, you receive services from this particular agency, and we don't have any ability to draw funds from any other places. If we can do a global budgeting, we can really start to break down those silos and serve people better.

The next issue I want to touch on is employment. And as was mentioned, Illinois recently launched an Employment First initiative and passed legislation. And Employment First, for those of you who are not familiar, or just tangentially familiar, what we're talking about is the first option for people with disabilities should be competitive and integrated employment.

So, what that means is that we have to decrease reliance on nonwork activities and sheltered workshops. And I say "and", and not "such as", because I also think because competitive-integrated employment will cause us to have to go away from day programs where we currently serve people, where people are not paid and they're not employed.

Sheltered workshops are something that have been in existence for a long time, but nationwide we see a movement towards decreasing reliance on them and getting rid of them all together.

In Oregon, for example, the state recently reached a settlement with a group of individuals who brought a class action saying that the state over relied on the use of sheltered workshops and that this was a form of segregation under Olmstead and violated the ADA.

So, Oregon is becoming this interesting national model where we're being forced to offer people more employment services as a result of this litigation. What would be great is if Illinois could avoid litigation, and move towards employment in an integrated setting on its own.

But the last thing I want to mention about, I have this last slide here about addressing employment discrimination and emphasizing creativity and flexibility. Obviously I think that one of the challenges will be we can't just take people with disabilities out of

where they are currently spending their days and plop them into a job and say work. We have to think about a creative way of working with the business community to create the appropriate incentives. But also finding ways to support people in those opportunities. And this is another way for us to touch on individualized and flexible services.

Sometimes we think that the service system is very ingrained in what it's doing. Often if we dig deeper what we find is that the funding system is causing them to be that way. And if we are insensitizing people by the way we're funding services, and causing them to keep people in one place and not be flexible about where they provide those services, maybe we need to take a step back and look at the way we're funding those opportunities.

The last thing I want to touch on, the last main issue is the issue of preventing abuse and neglect. Recently we're launching what's known as an Adult Protective Service System for people with disabilities, meaning we're moving the domestic abuse investigation program for people with disabilities, domestic in this sense means anyone who is living at home, and we're moving it into the department on aging, the AAA system. They'll be doing the investigation.

The idea here is that we're going to use a different model of adult protective services so that instead of saying, being very strict about where we investigate, how we investigate and what kind of solutions we can provide, we start to dig a little bit deeper into the situation and try to help people as much as we can if there's an issue that is abusive. This redesign could really change things for people, as well as provide real solutions when someone is in a not great situation.

The other thing is the implementation of a robust mortality review process. The state is just beginning to start to really review all deaths that occur in all settings that receive services from the Department of Human Services. So, this includes mental health settings, and DD settings, and it also includes community providers as well as state-based providers.

So that's important to note. This will

really allow for identification of patterns and trends among things that are happening. And hopefully, we hope, get prevention so if we can see a pattern, then we can start to think about how to prevent it.

One thing that I do want to point out is this best practice of mortality reviews occurs in other states, but the real best practice would be to investigate and talk about all incidences of abuse, or serious incidence of abuse, not just deaths. Because the best practice can extend to those other incidents as well.

So it's something to think about for the future in Illinois, if we can create a robust mortality review process, perhaps we can extend it to other types of abuse.

So rather than just talk about problems, I wanted to take a few minutes to talk about ways to move forward, or at least ideas that have been thrown out for ways to move forward.

One of the key things will be an increase of housing options. And this is especially true for accessible housing. It's a shortage that we see in this state, and it's a problem that we continue to come up against, is that there's simply not enough housing stock for people with developmental disabilities or other disabilities to live in.

And we need to get creative again about where those are located and how the services are designed. One of the national trends that I wanted to hit on is that many states, and at least at the federal level they're encouraging a disconnection between the services and the housing. So right now in order to get housing, for the most part you have to get services from that particular provider as well. Other states are moving away from this, and providing housing separate from the services. And this is another best practice that can be emphasized.

I've sort of touched on it, I don't know, maybe five times now, flexibility in programs and services in both the design of the services, as well as the funding of the services. Again, to get people to try to be creative when we're thinking about an individual and the best way to serve them.

I also think one of the keys here in

terms of flexibility is investment in the work force, as well as expansion of that work force. So, more DSPs, but also better training, better pay to decrease turnover and really solve some of those issues that we're seeing.

The last thing is employment opportunities. And I just want to point out that when someone is employed, they're more likely to be successful in the community. And so we can really start there in some ways, though it's a big dream and we have to take a lot of steps to get there. But if we can provide someone with meaningful employment, it really can lead to success in their community placement. And it is one of the most common things that we hear from people who are transitioning, is their desire for a job and their desire to be competitively employed.

So, that's it. I just wanted to say thank you and put up my contact information, and I will leave it up here for a few minutes so people have time to write it down. But thank you very much.

(Public participation.)

VICKI NISWANDER: My name is Vicki Niswander. My family has lived in Mahomet for 25 years. I am also the director of the Illinois Association of Microboards and Cooperatives. And in short, we help people live the lives they choose to live, contributing to and living in the community of their choice. Community Choices, which is one of our local human services cooperatives, is part of that effort.

My oldest daughter, Annie, is a member of Community Choices. We are also forming a Microboard for her, which is a business whose sole purpose is to figure out a better way for her to live as independently as possible and improve the opportunities that she has in her life.

Her parents, brother and sister, extended family, friends and other community members are a part of the organization as well. And Annie's Microboard is one of 50 in Illinois, and her Microboard is as unique as she is.

Other Microboards are CILA providers, some assist with employment or self employment, and all put great effort into creating connections and personal relationships in the community. All of the ramifications of Microboards and cooperatives can not be explained in three minutes or less, so I'm more than happy to talk with you after the session today.

Annie has hopes and dreams for herself. And they are not dissimilar from dreams of many with and without disabilities; to make her own decisions about her life, where to live, how to spend her time, how to earn a living, and how she has fun. She does not need or want what is typically intended for people with her disabilities, specifically group homes, sheltered workshops or day programs.

Thanks to the efforts of Community Choices, Annie has had a job as an assistant teacher in a local day care center. She has worked there for almost three years and is a valued employee.

When not working, she volunteers at the Humane Society and the public schools and at her church. She also works out three days a week, attends class and goes out for dinner every Wednesday night with her friends, which is why she's not here. In a few short months we hope she will be moving into her own home. For all of these places and activities she needs some type of support, transportation, job coaching and personal assistance. When she moves to her own place she will need more.

Annie is fortunate to be a recipient of the home-based support services program. It's a great way to support a person for about 30 to 35 hours a week, but it's not enough.

Services in Illinois need to be based on the needs and wants of the person receiving them. They shouldn't have to make a choice between 24 hour-a-day care and facilities, or 30 to 35 hours a week of home-based care. Illinois and Champaign County need to fund flexible, innovative services that give people, to the greatest extent possible, control and choice in the way they live their lives. Thanks.

JANE WEBBER: I guess I'm number two. And I don't mean to be rude to the people out in the audience, but I'm going to turn my back to you because I really want to speak to the boards. My name is Jane Webber. And I wanted to attend today's public hearing to express my appreciation to the CCD board for the funds awarded to DSC for the employment services program.

I was hoping my son, Alex, would be with me here today, but he doesn't like to be the center of attention; and as you can tell, his mother loves it.

Anyway, I'm going to tell you a little story about Alex. Alex is 22. He graduated from Unit 4 School District in May, which meant transitioning into the working world.

Alex had a community job at Walgreen's working one day a week as a food stocker. He needed full-time placement as Alex can not be left home alone, unattended. He needs to be supervised, as he is autistic and has a disability that requires daily structure and also a routine. And anybody who is in the autism world knows that is very important.

As I'm sure you're aware, there are a few agencies in our community that supply Community Choice programs that identify jobs and place individuals with disabilities in these job positions.

Our needs for Alex were a little bit more complex as we needed daily support starting as soon as he transitioned out of the Unit 4 program, in addition to job placement.

After learning more about the programs supplied by these various agencies in the community, it was DSC who supplied us with the best solution for Alex. As he would tell you, if he were here, he thinks DSC is great. DSC has an in-house training program at the Clark facility that allows an individual to transition from the school environment into a work environment, which is challenging for us all, let alone a child with disabilities.

DSC was able to evaluate Alex's skills and put a program in place to teach basic work skills prior to identifying a position in the community that matches Alex's skills and interests.

Alex now has the daily support he requires, and learning how to function within a working environment. And this means such things as interacting with other co-workers, asking for time off, knowing when to take a break, knowing when to stop work on a daily basis. He did lose his job at Walgreen's because he has this habit of 15 minutes until the end of the day of saying I'm done. I'm going home. So, we weren't able to keep that position for very long. So again, the support and structure needs to be in place.

I know as funding resources become limited and more and more agencies are clamoring for these funds, I urge and recommend to the CCDDB board the continued support of DSC's employment services program. It's an excellent, excellent use of your funds. Thank you very much. Appreciate it.

ELIZABETH MCCOY: I guess I will stand here so I can address everybody. Good afternoon, ladies and gentlemen. My name is Elizabeth McCoy. I am a professor at the University of Illinois. I am here also to thank the board and to advocate continued funding for the Disabilities Services Center, and in fact to encourage not only a continuation of funding, but consideration of support to expand its services.

The DSC is performing a vital service to this community. Families with disabilities will be attracted to this area and will contribute to the local and state economy if they know their disabled child can receive support.

I came here to join the University of Illinois in 2008. It made a huge difference in my decision to move to know that my son, Allen, would have access to the services of the center, even if it meant waiting on the wait list.

The DSC is actually a model for the entire country. In many states, like Florida, where we came from, there is nothing comparable to serve the autism spectrum population.

I'd like to offer a glimpse at our personal history by way of illustration of how important DSC has been to us. Our son, Allen, who has Asperger's on the autism spectrum, grew up in Florida where services for children with

disabilities are practically nonexistent. We had to resort to medical services to fill our most pressing needs, but there was no social support available.

When we arrived in Illinois six years ago, Allen was 21 years old. He was living at home, socially isolated, depressed, and unable to find employment. The nuclear family was his only connection to the world. When we were able to get an appointment with DSC, our lives started to change dramatically. The meeting with Ron Rubiesco and his staff opened up possibilities that we had never imagined would come our way.

The first step was that Allen received social services to integrate him into the community. This process took about a year.

The second step was to receive family services, including assistance with managing his SSI income, budgeting and living independently. This resulted in successful transition from living at home to living in an apartment with two other roommates. The third step was to introduce vocational services. Allen is now employed and doing very well at his job.

He has also moved into an apartment where he is living on his own and doing extremely well in managing his own affairs.

Allen's transition to a normal adult life has freed me to do my work at the University of Illinois. Allen is no longer dependent on me and the family for his every need. It has been the greatest joy of our lives to witness his growth and development since DSC initiated services for him.

I'm extremely proud of him, and what he has accomplished using these resources. The adage that it takes a community to raise a child is even more true for people with any kind of disability. Autism spectrum is a very complex condition requiring expert intervention, patience and sensitivity. DSC has provided this for us, and we are very grateful. Please do continue your support for this important organization. Thank you.

CARL WEBBER: Hello, I'm Carl Webber. I have resided in Champaign-Urbana, except for a

time in the Navy, for all my life. And I have been fortunate to be on the board of DSC for quite a while, but I'm here as a parent.

Thanks to DSC, my daughter got a job working at the YMCA taking care of kids while their parents worked out. There were six or seven kids every day, and all of a sudden the YMCA moved. We thought great, that will be great, new place that has up to 160 kids now every time, every day. So that was too much for her. DSC stepped in, and within just a few weeks she was back working at a day care center, and is doing tremendously well, and in a month will move into her own apartment.

So, I've got to say, everybody talks about their child, and I've got to say that about my child; I'm pleased and I'm tremendously proud of DSC and the work they've done. But ten years ago or so we had another meeting like this, and several of the legislators were willing to come and join us, and at that time I said the biggest fear of anyone in my position is what happens when I die? What do you do? How can you plan for what happens when you die?

And we all think about it. I've seen a lot of heads nod in the room. One of the things that we can do is make sure that organizations and programs that are funded can continue that way. I hope we can come up with more and more programs throughout the state and throughout this county. And I hope there's things I can do to help them happen.

But we need to continue the support of the ones that are here so that those of us who plan on them, and put that in our plan for what happens when we're not here any more, can count on that. We have enough variables. Our variables include everything from the cost of living, to the interest rate, to what's going to happen to them, what's their medical situation going to be. We don't need any more.

So please, keep funding DSC and other organizations like it that you're funding, because that funding is very, very important to our planning. Thank you.

PATSY PETRIE: Good afternoon, and congratulations to all of you for coming this afternoon and showing your interest. I'm Patsy Petrie, and I'm a county board member.

And my purpose for being here this afternoon is to bring the focus of the money and funding to the county level. So far it has been focused on our state legislators, when funding can be coming to us from the state.

There are two very important things happening on the county level as we speak. One is next Tuesday, when the report concerning the jail issue will be given at six o'clock at Brookens. And the reason that is so important because part of that report focuses a great deal on mental health issues in relationship to people being put in jail and the funding for that.

The second is, overlaying over the jail report on the 1st of October will be a sole meeting of the committee as a whole focusing on the county budget. And this is an opportunity for everybody in this room, and all of your friends, to come to the county board and talk about how your tax dollars will be used on various programs. You generate with your tax dollars over seven million dollars, which get sent to the Developmental Disabilities Board and the Mental Health Board for them to distribute.

And it's very important to hear from everybody in the community that we are doing an appropriate job with that money, and how it gets used for funding. It is the county board's responsibility to make the final approval of both of these budgets. So we do need to hear from you at that meeting on the 1st of October again at Brookens at six PM. And I really encourage everybody to come.

My last point that I have discovered as I've been doing my own research on learning about the programs in the community, has two prongs to it. One prong is the difficulty of a centralized location listing of all of the various programs that exist in this community. They're scattered throughout the community. There are excellent programs, but you can't find them very easily.

And the second is, again, as I was doing my investigation of what's offered in our community, we have very little evaluation as to

the effectiveness of these programs. And that seems to be a really important thing for us to start focusing on, to make certain that at least I, as a county board member, where I have a fiduciary responsibility about your tax money, is to make certain that when we approve tax dollars for programs, that we know that they are very efficient and effective. Thank you.

KRISTEN PETERSON: My name is Kristen Peterson, and I am a direct service professional at the Developmental Services Center.

My main purpose for talking today is to talk about how important it is to me that the individuals that I serve continue to have a wide range of choices and just abilities and just things that they can choose to do with their lives. I actually personally work with individuals who are fairly -- who are lower functioning individuals who maybe are nonverbal or have accessibility things or maybe have significant behavioral issues. And it's important to me that those individuals also have a place where they can feel comfortable and safe and supported.

I really love what I do, and I feel like DSC does a great job at looking at the individual. I mean, every individual has a team of people to support them and to really help them grow in the area that they want to go to, just from basic things as to do you want to sit at this table or that table, to do you want to live here, where do you want to live, what do you want to work on, where do you want to eat dinner, which is a lot of times McDonald's.

Whatever choices they have, it's just really important to me that they continue to have those choices, and that people who are getting served can choose to stay where they are, and that the funding is still available for places like DSC and for others.

JENNIFER CARLSON: Hello, my name is Jennifer Carlson, and I'm the director of residential services at DSC. There are so many examples of how state funding has negatively

impacted lives with budgets cuts and inadequate rates, while local funding has made a tremendous difference for hundreds of families throughout Champaign County.

I want to quickly provide an example of how state funding can positively impact families and local funding when it works well.

Two gentlemen just recently received emergency CILA funding through the Ligas consent decree. Not only did this meet their immediate needs with new state funding, but it also opened up opportunities for others because these two gentlemen were previously served through local funding by the Champaign County Developmental Disabilities board.

Now after years on a waiting list, apartment services are being offered to others that currently reside at home with family. This will bridge a gap for families, empower a few people to leave their family home for the first time, enjoy a much more independent sense, and still receive desired support by qualified direct support staff.

These scenarios are wonderful examples of how state funding should positively impact local funding to support people that may otherwise go without services. Two Ligas awards led to four individuals and four different families receiving support and funding to meet their individual needs and personal goals. We need many more stories like this in Champaign County. Thank you.

CINDY CREIGHTON: Hi, I wanted to come and share the story about my son. My name is Cindy Creighton and I reside in Mahomet. Our son, Jimmy, is 18 and a half years old. His challenges include a right frontal lobe brain injury, which in turn have caused a visual impairment, cerebral palsy, a form of autism. He has a feeding tube and he also suffers from intermittent impulsive aggression due to brain injury. Our son has recently been placed in a residential school placement in Wisconsin until he was discharged from this program on March 18th of this year, at which time he returned home.

He remained in our home for 10 weeks while we awaited an adult CILA placement nearby to

serve him. In May he was temporarily transitioned to an adult group home in Rantoul until a more appropriate placement was found or created for him. We have recently received a discharge notice from this particular company due to their inability to serve his needs, and we are once again in search of a provider to serve him in a four person or less adult CILA. When we learned of our son's discharge in Wisconsin, we advocated on our son's behalf with the assistance of Senator Chapin Rose to secure the enhanced funding necessary for our son's needs to be met in an adult CILA close to our family.

Jimmy was awarded this enhanced funding. We have since been diligently searching for a local service provider to accept our son in a four person or less group home. Over the last three-and-a-half weeks, our son has been transported to the Carle emergency room via ambulance a total of seven times due to aggressive outbursts which the current group home is not equipped to handle. During these episodes when 9-1-1 was called due to the group home's inability to serve our son's population of disability, our son was handcuffed on several of these occasions.

He during the last episode experienced such anxiety from the situation he urinated in his clothing. With each trip to the ER, our son was discharged without any additional supports to assist him. While my husband and I have submitted countless e-mails to numerous individuals sharing and detailing the situation involving our son, we are determined to share that only one person receiving these e-mails, Senator Chapin Rose, has chosen to engage himself and offer to assist our family in the crisis situation that we are currently faced with.

My husband and I would like to say thank you to Senator Chapin Rose for his willingness to help us advocate and navigate the complex and inadequate human service system.

I implore all of you to please continue to help increase the capacity of the service system so that all individuals will have the ability to live safely and with dignity in their home communities. Thank you for listening.

DOROTHY FANNING: My name is Dorothy Fanning, and I'd like to share a story. My daughter, Ellen, was born in 1959. She was diagnosed with Downs Syndrome. There were no services. No public school. Lincoln State School or Dixon State School. Not knowing what to do, we put her name on a waiting list.

The best advice we got was from our physician. Take her home and love her. She is a part of your family. She joined her two older brothers, and we were a family.

Margaret Cunningham was the staff at the welfare service here in Champaign. She helped us get in touch with other families who had children who needed special care. Four mothers got together, we started what you would call a nursery program in space donated by the Presbyterian church. Dr. Marie Share at the University's sharing clinic gave us some advice. We gave our children a chance to be with others, to socialize in a structured setting. That was what was available.

Public Law 94-142, which mandated special education in public school was, I don't remember the year, it was somewhere in the sixties. So Ellen was able to go to school when she was seven years old. Ellen graduated from Marquette school in Champaign when she was 21. Then what? Fortunately we had DSC. The staff helped her transition to the vocational program. They taught her to take the city bus by herself. She had to walk two blocks to get on the bus. How proud she was. How proud we were.

When Ellen was 30, we had the opportunity for her to move into a group home that DSC was developing. Should we? Are we ready? Is she ready?

We took the chance and thought this was important. Transition was made. She would come home for the weekends. But she was getting involved, learning to be more responsible for herself. And one weekend I called and I said Ellen, what time shall I pick you up? She said mom, do you care if I don't come home? I said yes! We have finally found her right where she needs to be. She has learned to make decisions, to be more responsible, under supervision. She is not my little girl any more. She is a young lady.

She enjoys going to work at DSC. She loves her paycheck. She likes to tell me how much she earned. And she loves her friends, staff, she is in a caring environment that gives her the structure that she needs.

Ellen is now 54. I am 84. As the gentlemen said, what happens? We worry about if our daughter or child outlives us. And at this point she is probably likely that she will. So it's my hope that DSC will be there for her, the group home setting, the work setting, but most of all the staff cares. They care. She was seriously ill a week ago, or I'm sorry, a year ago, and they had to take her to the emergency room. The staff, Jennifer, her staff, spent time with her, time with her in the hospital.

She had to then have antibiotic therapy, and we found some space at the Champaign County Nursing Home. And they told me we're not licensed for developmentally disabled people. But, temporarily she can be here.

So, my hope is, as I say, that there will be services for her from DSC for her life when I'm no longer here. Thank you.

RANDY STEARNS: I'm Randy Stearns, I guess I'm one of those families that is kind of in limbo right now. My son, Travis, has autism. And just turned 22 right at the end of the school year. So, for the last year or so we've been kind of preparing for this. We hope that the transition would be a little bit smoother. But right now he's at home. He doesn't have services. We're on the list. He's on the emergency list. We're hoping that within the next few months something will open up and he will get funding, because I think he would very much benefit from the programs you have at DSC. I think that the group setting is very important for him. He had a lot of good services through the school district as far as job training and life skills. We would like for that to continue.

Again, right now we're trying the best we can at home. We're in the situation where my wife basically, because someone has to be with my son, she had to quit her job of 15 years. She worked at a facility with disabled children. But

she had to quit that job to be home with Travis. We're trying to do things during the day to keep him active and trying to do the best we can with education, and keep him socially active also.

But I guess our situation is, we're just hoping that something will come available. And I know there are others like us that Travis has gone to school with, that will soon follow. So I think they're probably looking at our situation, hoping that something moves with us because they will be in the same situation. Thank you very much.

DEBBIE CURTIN: My name is Debbie Curtin. I have a very long history with DSC. I guess my story, I'm not prepared so I will kind of wing it.

Thirty years ago we lost my mother. My sister was developmentally disabled, and she was taken into DSC on emergency. It's been great. I don't have to worry about her. I have two kids developmentally disabled, 23 and 26. Been working with DSC for the last several years to bring a group home to my community. Recently got the award letter from the state for CILA or ES funding. Talked to my PAS agent. Nobody had any information to give me. No information, misinformation. Just flat wrong information. I was given bad advice.

I talked to DSC because I knew them. They helped me, even accompanying me on a trip to Springfield to help straighten out the mess.

Currently working with them to get a home in Mahomet so I can keep them in my home community. My son is in a day program, my daughter is wait listed to be in the day program. She is an insulin-dependent diabetic, so because of Rule 116 it's nearly impossible to get her housing. But Dale is helping me work with the appropriate agencies to get that rule changed. If my husband and I drop dead tomorrow, the only choice for my very high functioning 23 year old daughter is go to a nursing home. That is unacceptable, and God knows where it would be. It probably would not be local.

Chapin Rose has helped us tremendously. We need to keep the funding going. We need these services for our children. I know there are

medical issues that there are no help for. I've heard the testimony here. The only way we're going to get them is if people get involved. And we need the organizations such as DSC to help us, because most of you look like you're about my age group, which means you're probably working full time. Those of you that are retired, it's a full-time job to traverse all this. I mean, we need help.

And the only way we're going to get the help is organizations such as that, that that's their job. I guess that's my story.

BABETTE LEEK: Good evening everyone. Sorry for my tardiness, but I drove a little fast coming out of Springfield this evening to get here.

But I am Babette Leek with the Champaign County Regional Planning Commission. We are one of the 18 PAS agencies in the State of Illinois.

I wanted to voice some of my concerns this evening. I know that we are currently funding people in the State of Illinois off of the PUNS data base, which is the prioritization of unmet needs in the State of Illinois, but I see greater needs. I get phone calls almost daily. There are three areas that I have major concerns about.

The first area is autism. There are families that have children or adults at home that actually, and a lot of times we get the brunt of the fault, but because of the state and where their cutoff is for autism, a lot of people we're not able to get services for, or even put them on the data base because of their IQ levels. And I really feel like it's time for the state to address that. Because there are families that are suffering greatly with their children or young adults living at home that need services. That's one of my first areas of concern.

Second area, children. There are no children being drawn off of our data bases for selection of services. And I have families call all the time, and I see pictures, documentation, that mothers and fathers are taking and recording of what's going on in their homes. So, that's another area of concern that I have.

The third area that is really popping up big, our calls are kind of getting off the chain now with families that have taken their children home to raise them after high school, and they -- and I always knew there was a population of people that were going to be aging, and they were going to one day call my office; they're calling now. Because either mom and dad are ill, or one has deceased, and there's mom who no longer can provide care, or both are gone.

So that's a major concern to me because I can not serve those people because a lot of times they don't have any proof of age of onset. So, parents have not, you know, you don't think to keep that kind of stuff when your child now is 60, 65; I'm getting those calls. And so that's a concern to me. Those are the three populations that I'm really concerned about and getting calls about now.

So I just wanted to voice my concerns. Let you know that our office is at the Brookens building. Our number is 328-3313. If we can help you, we are putting forth every effort to do so. Thank you.

JULIA WATSON: Hello, my name is Julia Watson, and I'm just going to read from my notes here. I'm here to speak on behalf of my son, Guy Watson. Guy recently joined DSC at the end of May, for which our family and friends were excited and proud. Guy also just recently graduated from Urbana High School on May 20th. An accomplishment that early on in Guy's life seemed almost unimaginable. But because of our family being introduced to children's services, and the services provided to Guy at DSC some 21 years ago, Guy's graduation date became a reality. With the guidance and foresight of children's services, we began the process of independent goal objectives for Guy, such as teaching Guy to sit up right, on his own, and to where he is standing with the aid of a walker.

These skills followed Guy through early childhood school to where he learned to walk with little assistance. Guy has received the best educational, occupational, physical and speech therapy services that CU school district has to

offer.

Through Guy's entire scholastic career, Guy has been provided with detailed IEP goals. For the last two years Guy attended the Urbana assist program. And his goals were directly related to Guy's transition to DSC. During the last couple of years there was a concern that DSC was experiencing cutbacks, and the possibility that there would be no opening for Guy once he graduated.

But because of the compassion and the help of his teacher, Victoria Gordon, for which we are so grateful for, Guy was accepted into the DSC family just two weeks before Guy graduated the last day of school. With the assistance of Guy's teachers and aids, Guy was able to climb up the stairs to the stage and walk to receive his high school diploma. The overhead screen showed a class picture of Guy, and the words below read, Guy Steven Watson, employed at Developmental Service Center, Champaign, Illinois.

All of the years of planning, goal setting and dedication from countless special need educators and service providers, not to mention Guy's own accomplishments, has made Guy's transition to DSC a reality. While Guy's fellow senior class members will have opportunities and access to 100 colleges and employers, Guy will have one. And that is DSC. DSC provides Guy with a variety of training skills, work activities, interpersonal skills, motor and academic skills that is essential for his well being and quality of life. Guy is one of the few people that we know that on Monday morning is so genuinely happy to go to work and high fives his co-workers along the way. It may sound petty to some, but DSC is really all that Guy has now.

I mean, shame on us that we had such a narrow vision of relying solely on the existence of DSC. Our home doesn't come close or even compare to this great facility and its employees. Guy's 22 years of continued progress and happiness and community involvement will be dramatically reduced without the services of DSC. DSC has been a household name to our family and friends and well known in our community and local businesses. When people ask what Guy is doing now, and we say he is working at DSC, they respond very positively

and happy for Guy. And they feel a sense of satisfaction that their community continues to meet Guy's needs and the needs of others. Thank you.

BARB PRITCHARD: Thank you. I missed some of the testimony because I was out. Peter asked me to go out to talk to the media, but my name is Barb Pritchard and I'm glad to be here tonight. I am a disability rights advocate and I worked in the social service system for more than 25 years now.

After I got done with, I was lucky enough to have the support of my family and friends and go through college here at the U of I. And after doing so, I was able to get a job at PACE Local Center for independent living. And then since I retired in 2002 did advocacy work with my husband around the state. I've been associated with the Illinois Council on Developmental Disabilities, and the Statewide Independent Living Council.

And I guess tonight the only point I want to leave is I think the parents have done an excellent job of saying many of the things that are needed in our community.

I would also like to encourage you to listen to the self advocates or the people with disabilities who have their own voice to say what they want to do. And I think I'd like to challenge everyone to think outside the box. And think about new ways to employ people, or to use somebody's skills and abilities.

A good friend of mine recently, he was employed at a shelter workshop of Northern Chicago. And he really wanted to be in a community. And I found out just last week that he had gotten a job delivering trays at the local -- food trays at the local hospital to patient rooms. And it's an excellent fit for him. He's very social. But he's also got the personality to know when not to disrupt someone. And I was truly glad to see that he got something in the community.

But I've also had another self advocate, or several actually tell me, but one in particular sticks out. She told me, you know, I'm really glad that your parents pushed toward changes and

got social services expanded. And they worked for many people your age and worked for a number of years. But, she said that's not the kind of work I want to do. I want to be in the community. I want real pay for a real job in the community with people with all abilities and inabilities. And she said I'm grateful for what your family and other families did. But, it's not what I want.

So I would challenge you all tonight to listen to the voices of self advocates as well. Maybe many couldn't be here tonight. But, they do have a voice, and they have really strong desires. And I think as well as the more traditional services that have been offered, I would challenge you to look up, think outside the box, and be creative and talk to actual folks with disabilities and see what they want for their lives. Thank you.

BRIAN RICHTER: Hi, my name is Brian Richter. I work at DSC. I'm reading a letter tonight for a family member who couldn't be here. Not my family member, a person we serve.

She writes, I'm the oldest of five children. Each of my four siblings was diagnosed early in life with developmental disabilities, and later with a significant degenerative medical issue.

Collectively my siblings have received an array of assistance and support from practically every service program offered by DSC, and I have worked with three of them, so I know that they are across our spectrum.

To help you understand what DSC has meant to me and my siblings, I share my brother, Tom's, story. Tom was linked to DSC after graduating from high school. He received vocational training through the employment program, and later with the help of a job coach, that was linked to plays and supported a variety of jobs in the community. During this time in his life he also began receiving case management services as he transitioned out of the family home and into more independent apartment living.

In 2001 Tom was diagnosed with a serious degenerative heart disease. Gradually over time he began to experience memory difficulties and

complex medical issues that impacted his ability to safely access the community and carry out day-to-day tasks. Apartment services were added. He transitioned from community employment to working at DSC, continued to do the janitorial work he loves with the modifications needed to accommodate his medical needs. A few years later home-based support services were needed on the weekends.

However, as time went on Tom required an even more supportive living arrangement, so he moved to CU Independence.

When Tom has his moments, when the reality of the situation comes crashing down and the tears begin to fall, he always voices some concern related to independence. DSC has made his emotional dynamic easier for Tom and me as a result of their ongoing monitoring of his current status and redefining programming to provide for the highest possible level of personal independence at any given time. So during the difficult times I'm able to cite to Tom an entire array of the very ways in which he continues to be independent; perhaps in a new way due to the creative planning and ongoing support of DSC.

Tom recently demonstrated the need for an even greater level of care due to him, forgetting to take his medication consistently, which on several occasions resulted in a medical crisis. In August he moved to a new CILA home with two men, resolved the issue, and allowed him to regain some of his independence.

I want to stress again he actually regained much of his independence. He is now able to participate in more activities due to having the daily 24 hour support of DSC staff. He is able to cook again and do his own laundry. He is able to access the community again and participate in social activities with peers.

I am forever grateful for DSC. They have helped me carry the load of responsibility I have had over the years while providing phenomenal day-to-day services to my brother honoring him with the dignity and respect he deserved. There are so many men and women like Tom that will have growing needs as they age, and I truly hope they have the same opportunities as my brother has been given. Signed sincerely, Lisa Dolman.

I had the opportunity to read this letter to Tom today. His sister told him it was going to happen, told him she had written it. But she hadn't read it to him. So he said well, that reminds me of what my mom used to say, if you don't have anything nice to say, keep talking.

And then he also said, it allowed him to do his own cooking and his own laundry. He said well, I could do without the laundry.

(Conclusion of public speakers.)

CHAPIN ROSE: First of all, thank you, Peter, and to the board members for hosting this, and certainly to the folks who came out tonight.

I would start, if I may, by telling you a little bit about myself, and some of you may know. My wife, Camille, has a Master's degree in occupational therapy. She is the OT for DSC. She's also the OT for the Urbana School District. And DDMI issues. And so in many respects for the last well more than a decade, through her we lived these issues on a day-to-day basis. In fact, many of your loved ones in this room she has probably seen in some capacity or another.

And probably because of that, and probably because of my friendship with some good folks in this room the last decade or so, we've tried to beat the drum and shake the bushes, so to speak. Sometimes it works, sometimes it doesn't work.

I want to just give you a few observations. The testimony is absolutely wonderful. You know, to Melissa, right? To your initial presentation, one of the things I've been very passionate about, and she put it in here, is the housing issue.

What we have, we've got a chicken or egg problem. No one wants to put up the housing unless you have the funds to qualify people. Without the funding to qualify people, nobody -- you know, you get the picture.

It's easy to say that. It's a little bit deeper. We had a bill, where did Cindy Creighton go? Thank you for your kind words, and the same thing for you, Cindy Creighton. We had a bill trying to get a pilot project going in

Mahomet for parents, several of them whose kids are aging out of the school system. And they wanted, as Mr. Webber's comment, they wanted to know they're safe before the parents move on to their next adventure. And what stopped that was the Federal Government. No pilot projects allowed.

Here you have a group of dedicated parents. We have willing providers that were interested in providing a service. But we couldn't get past home base. And in fact, my bill never got out of rules because the department came in and said, ah, ah, ah, you can't do that; Federal Government.

This is a real issue, and every time you come to one of these you learn a lot. And I really appreciate the invitation. I learned a lot tonight. One of the things I put on my list is the issue of people whose IQs are over 70, but have a clear diagnosis of DDMI, but they're not eligible. Prior to today, I didn't realize that. I've been doing this for 10 years now. My wife is in the field. So, you always learn something.

Earlier today I was at Macon County Resources. We talk about Employment First, which is the new state initiative. Macon County Resources, for those of you who don't know, is the Decatur equivalent of DSC here. And by the way, if you ever wonder where your license plates come from, that's where they manufacture license plates as part of their VT program and their job programs and their Voc Tech program.

And I make it a point to go, I've been to DSC, I've been to all of them, Shelby County, today was my tour of Macon County. During the tour, I never really thought about it, this is interesting, the Federal Medicaid rules, so if you're DDMI and you've got a job, whatever the job is, you love the job, you want to work there, who said their kid was excited about getting a paycheck. Was that you? Somebody said it.

You love the job. You can't work more than a certain number of hours a week or you lose your health benefit. Well, in many respects the health benefit is worth more than the job. And so these are take-aways, every time I do one of these things, it's put on the list as something I need to get around to fixing. In that case we're going

to need federal help as well.

But let's talk about some things we've done right. I am a positive person by nature, and there's plenty of negative, we know that. So let's talk about a few good things.

First of all, the management improvement initiative. This was something that came out of folks in this room, Dale Morrissey from DSC, Mark Clause before Dennis was at CTF. You talk about silos in your presentation. There is no place that has more silos in this than the DDMI system in the State of Illinois. Peter, you know that from having worked there. Management Improvement Initiative is aimed at limiting these silos, condensing the bureaucracy so that you can get back to taking care of a human being.

And what am I talking about? I will give you two quick examples. I don't want to bore you. But I was at CCAR in Charleston. CCAR says every year on our audit they ask us for everybody's diplomas from high school. They didn't un-graduate since last year on the audit, so why do you keep asking us for the same data? I get it, a current CPR card that has to be renewed every year. I get that. But diplomas, the amount of bureaucracy and paperwork that these providers have to put out on a daily basis just to help your loved one is amazing.

Well, as a result of the Management Improvement Initiative, we now have a central document depository where everything goes in one time.

One we're working on in the echelon is the financial audits. Financial audits are extremely expensive. The feds require it, states require it, depending on what program you have, you might have three or four different audits. Each audit is 10 to 15 thousand dollars potentially. As taxpayers we want to make sure that people are using and expending your dollars wisely, so we're going to have an audit, correct? But do we have to have three or four of the same things? Wouldn't that be better spent treating your loved ones for whatever it is they need? That's coming down the pike. Those are good things.

The big one on funding, and we've been dealing with this for a long time. You go back to

February and April, or February and March of this year, DDMI was seven months behind, five to seven months behind or so in payment. And Governor Quinn issued an edict that said we're not going to pay you for the rest of the year. I was honored to be appointed by my leader on my side of the aisle to be one of the negotiators in the room with the governor's office and all the other caucuses, \$225 million dollar program that wasn't near spending because we actually made a commensurate amount of cuts in other areas of the state budget. So \$225 million dollars to accelerate payments.

I checked in with our two big dogs here today, both of them, one of them had their payment cycle cut by three-fourths since then. They're down to only -- so I won't give you the numbers, but it's a marked, marked improvement as to where we were back earlier this year.

More importantly, for the long haul, we took away the governor's ability to hold, not just this governor, but any governor, the governor's ability to hold a bill without paying it; that he must send it within 30 days now to the comptroller for payment. So that expedites the cycle.

Now, I don't want you guys to go home and say Chapin Rose says everything is fine. I'm not saying that. I am saying there are some bright spots in an otherwise dreary day.

I would say one or two other things. Peter and I had a really interesting conversation today about Microboards. And Vicki, I'd love to talk to you more about that concept. I think there's a lot of improvement there.

The management improvement issue is not over. There's a six-month, one-year, three-year, five-year plan, some of it involves quite frankly very expensive computer systems that take time to come on-line. But we've done this three years ago now. I think it's time to revisit it and try to break down the silo some more.

Housing; and you have seen I think marked improvement. By the way, I thought this was a great world view of the history of DDMI issues, to go back to the 1950s on this. You know, over the last decade, and as recently as this year, you've seen closure of many of the State Ops. Something that everyone in this room

has been fighting for, for a long time.

Now unfortunately, it is unfortunate we're always going to have some amount of State Ops. There is people whose disabilities are so severe that we're going to have to have some facility. But as you move on, the concern I have, and Melissa alluded to it in her comment, is the transition out.

One of the most unfortunate things I've seen was when JDC closed the way in which the transition was handled without the capacity already in place to transition people out.

We had a bill on this a year ago, to say okay, we're going to start moving people out. Let's get the capacity going. Let's solve the chicken and egg problem. Again, nothing but fight and push back from the administration. So you don't go away. You don't quit. You fight back harder. But one of the most atrocious things I've seen was when the JDC transition plan was posted, and on of all things Craigslist, looking for a good home. That was the most disgusting, deplorable thing I've ever seen in state government. And that says a lot. I lived through the Blagojevich years. That was awful. That is not a transition plan.

And so I want to work with Equip For Equality on those issues as we go forward. Frankly, as a personal goal, although it may never happen, I'd love to see respite get back to where it was. I know everybody in this room is shaking their heads yes, but that was just such an important thing.

I do know with Ligas, we will be seeing more and more PUNS pulled. That's a good thing. I'm very -- the confusion, PUNS, PAS, this, that, somebody coming into the system, my gosh, it could go over their head. And there's all these acronyms, nobody know what it means; until five minutes ago I didn't know what PUNS stood for. I just knew you had to have one.

My point, I think that's a good thing for management improvement issue is to make it, where did Patti Petrie go, a one-stop shop type concept. Makes a lot of sense.

With that, I'm going to take some executive privilege here as I turn the microphone over. First of all, Chad Hays was here,

Representative Hays. He had another speaking engagement in Gifford that he had to run to, but he asked me to tell you that he was here for about 98 percent of the public comments. And he was listening and he wanted you to know that.

But my last bit of editorial license I'm going to take is my good friend, Naomi Jakobsson, is retiring at the end of this term. She has had a very, very honorable career in public service. And there is no person on this earth who has more compassion and more heart for the rest of this than her. And so we may be on opposite sides of the aisle, but you're my friend, and I hope as we welcome you up that everybody will give her a big round of applause.

NAOMI JAKOBSSON: Thank you. Chapin and I went in the house at the same time. And we did become friends. As he said, we're on opposite sides of the aisle, but often we were working on these same issues together, some that he brought forward, and sometimes I would talk to him about some.

But, I want to thank you for having this hearing this afternoon. And thank you everyone who presented. I know it's not always easy to get up in front of a group and be ready to talk to everybody else about what is so personal to you. But thank you, because we need that.

Many of you in this room know that Barb has been one of my leaders in just knowing what's right. And in fact, I upset her a couple months ago because she knew I visited Murray Center and I said I really wanted the governor to go there and meet some of the people. And the bottom line was the transition. And I think I helped her understand that was why I went there, because I truly believe that people do need to belong, need to be in the communities. And there are some people that are not going to be able to have a job, and we know that. But, there are so many people who are.

And we talked about having jobs that aren't just the ones that DSC can provide, but real workplace jobs, if I've got the right vocabulary on that. And I know that's a very difficult thing. In a previous job that I had, I

like to make sure that I have a good mix of people on my staff. And I hired somebody with disabilities. And when I left that job the person who succeeded me didn't keep him for very long because she didn't like how often he had to go to the bathroom. That was due to his medication. She didn't like that he wasn't as speedy as some of the other people. And I know that's what the community faces.

And it's time that we get over some of those things, and make sure that when we do have jobs in the community, that we hire the people that can do them. But once in a while we might have to look at that actual person and say, sure, you have some needs that we need to help you meet. Because they like a paycheck just like everybody else here.

And I know so much of this comes right down on funding. And here's a place that we don't agree. But, I'm going to say one of the things that we need to very closely look at is what's going to happen in 2015 when the five percent income tax starts going down.

And my solution to that is that we need to have a fair tax amendment, and that will bring more revenue to the state, and at the same time lower most peoples' income tax, state income tax.

So that's a solution I have, that we can talk about another time. But, I think we do need to understand that we're all working on some way or other, maybe it's not always the same way, of trying to find the appropriate funding for these very, very important community services. Thank you.

(Closing remarks.)

(Hearing adjourned at 6:24 p.m.)

Developmental Disabilities and Intellectual Disabilities: Overview of Current Issues

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Melissa O. Picciola,
Equip for Equality

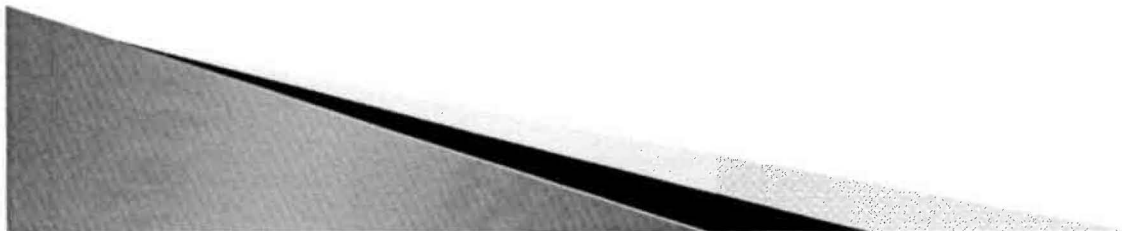
September 18, 2013

Equip for Equality:

Who we are and what we do

- ▶ Statewide, independent, not-for-profit designated to administer the federally-mandated protection and advocacy system for people with disabilities in Illinois
 - Offices in Chicago, Springfield, Moline, and Carbondale
 - Providing legal and advocacy services to advance the human and civil rights of people with disabilities

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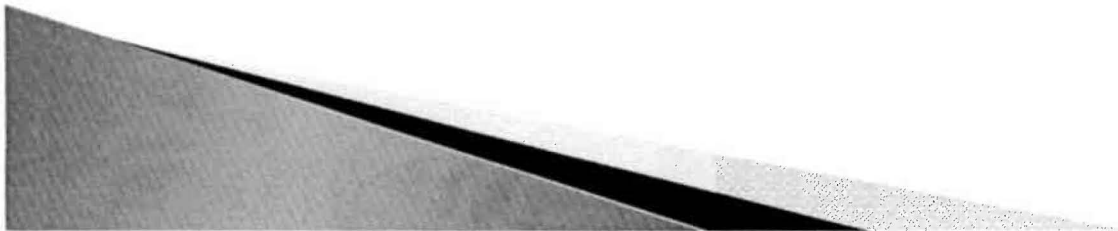
Current Issues for Individuals with ID/DD

- ▶ **Community Integration**
- ▶ **Systems Transformation**
- ▶ **Employment**
- ▶ **Abuse / Neglect**



Community Integration

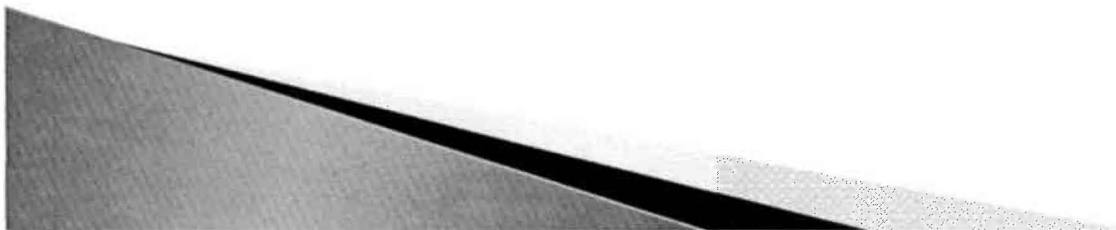
- ▶ The right to live in the least restrictive setting capable of meeting one's needs
 - May provide cost savings when compared with institutional living
 - Quality of life is shown to improve in smaller settings



Community Integration in Illinois

- ▶ Illinois is rebalancing the DD/ID service system
 - Closure of State Operated Developmental Centers
 - Ligas Consent Decree
 - ICF/DDs
 - Waiting List

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Issues in Community Integration

- ▶ Adequacy of the Provider Network
- ▶ Ability to care for individuals with dual diagnosis
- ▶ Safety Net
- ▶ Flexibility in housing options and services

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System Transformation

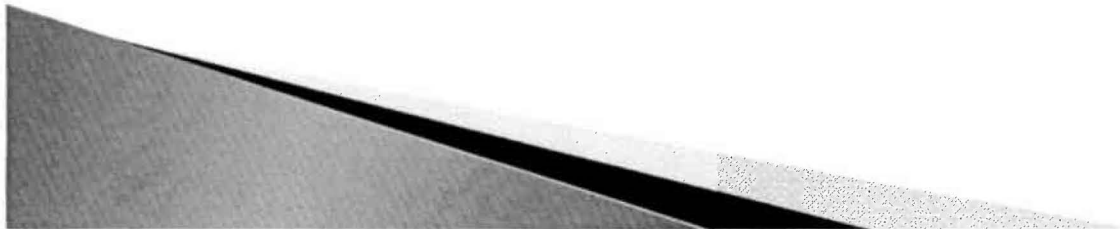
- ▶ Transition from Fee For Service System to Capitated Rates (aka Managed Care)
- ▶ Individualized Budgets vs. Pre-determined rates
- ▶ Decreasing Waiting lists
- ▶ Collapsing silos of state government and benefit systems



Employment

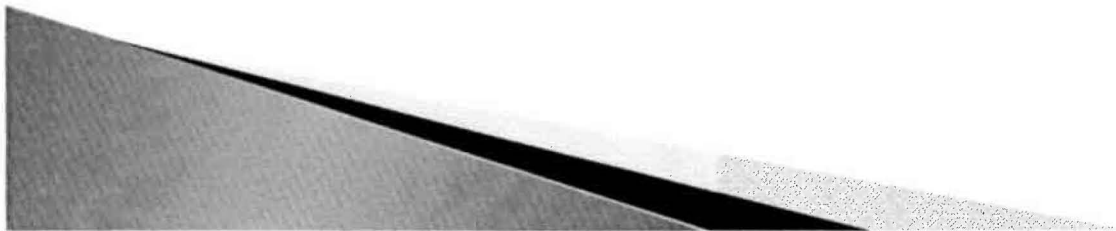
- ▶ Illinois recently launched “Employment First” Initiative
 - Change attitudes and programs of providers
- ▶ Strive to provide people with competitive, integrated employment
 - Decrease non-work activities and sheltered workshops
- ▶ Address Employment Discrimination
 - Creativity and Flexibility

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Preventing Abuse/Neglect

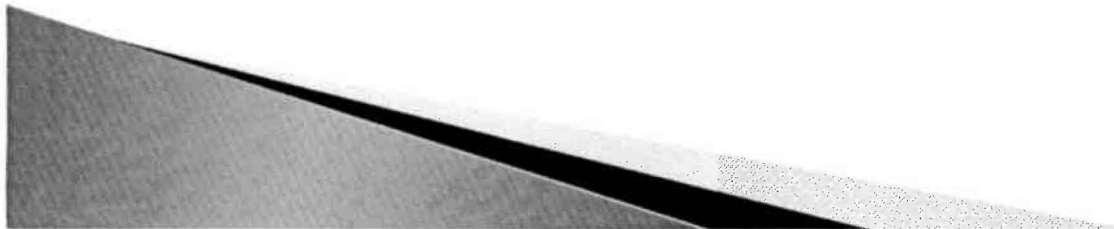
- ▶ Launch of Adult Protective Service System
 - Re-Design of Domestic Abuse Investigatory System
- ▶ Implementation of Robust Mortality Review Process
 - Allow for identification of patterns and trends



Ways to Move Forward

- ▶ Housing options increased
 - Especially accessible housing
- ▶ Flexibility in Programs and Services
 - Design and Funding
 - Investment and Expansion of workforce
- ▶ Employment opportunities
 - Including training programs and increased supports

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Thank You

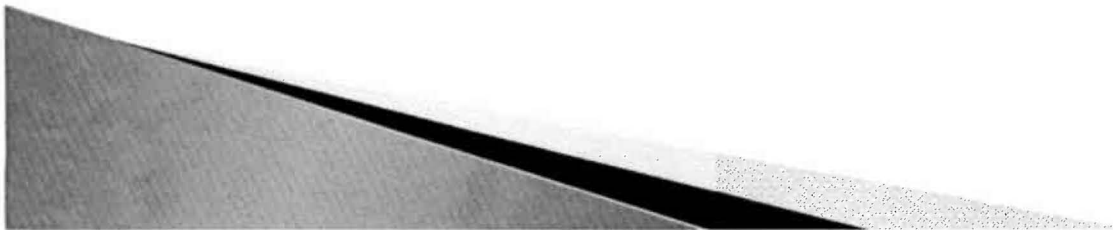
▶ Melissa Picciola
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Comments re: Public hearing for Champaign County Intellectual and Developmental Disabilities
Programs sponsored by CCDDDB/CCMHB

To: Lynn Canfield
c/o Brookens Administrative Center
CCDDDB/CCMHB
1776 E. Washington Street
Urbana, IL 61802

September 18, 2013

Two of my children were diagnosed in 2002 at 10 and 11 years of age with juvenile onset MLD—an incurable, regressive illness. So I have not been dealing with the disability sector since birth. Knowing what I know now, that would have been easier, as it's more difficult to get assistance as they age into adulthood.

I'll make this short, but that doesn't mean there aren't more issues!

There is so very much misinformation by all the agencies (and schools) that it makes it so difficult for parents to get any kind of guidance and assistance.

We can't make an informed decision because everyone—even all staff within the same office and agency—will give different information. Who do we believe/ trust? And then the problems when we're told differently later!!

Why isn't everyone on the same page??!!

Also, it would make our lives a little easier if agency staff would return phone calls or e-mails in a timely fashion or at all.

It is our choice to keep our children at home for as long as we're able to care for them. Talk about a huge savings for the state!! (my daughter is total care, my son is following) Just take a look at the numbers for what the waivers allow and what it costs to care for these kids in an ICFDD!!

We are trying to get a home modification (a one time fixed amount allowance) through DRS—which I've been told that we are allowed for our daughter. I had to do all the work to try to get the required bids. No business wants to give a bid and do work and then wait for 8 months to maybe get paid by the state. I wasted so much time making phone calls—time that should have been spent taking care of my children. Why does it have to be so gosh darn difficult??!! I can think of easier ways. Now I'm waiting and waiting until someone will maybe approve the project. During all this waiting time, my husband and I are struggling to not injure ourselves or our daughter as we care for her. As we're saving the state money by keeping the kids at home, I'd like to see a larger allowance to assist us in their care.

It would also be so wonderful if our home modifications didn't have to be done by a contractor—that could save all involved a lot of money and time. With some financial assistance for supplies, it's usually very easy to get family members or church groups (both who usually already have professional construction people in their groups) to volunteer the labor.

I'm grateful for the assistance we do get, but we need to get people who are living with all these issues to be involved in solving problems, we need to be taken seriously regarding how difficult and expensive it can be to care for our special needs "kids".

Thank you for your time,

A handwritten signature in cursive script that reads "Barb Maxstadt".

Barbara Maxstadt
2180 County Road 0 East
Mahomet, IL 61853
217-493-2166
Maxstadt6@yahoo.com

Legislative Forum
Champaign Public Library
September 18, 2013

Ladies and Gentlemen:

Thank you for the opportunity to speak to you on behalf of my own daughter, as well as other families in Illinois who see community inclusion and supports as critical to a good quality of life.

My name is Vicki Niswander. My family has lived in Mahomet for 25 years. I am also the director the Illinois Association of Microboards and Cooperatives. In short, we help people live the lives that they choose to live, contributing to and living in the community of their choice. Community Choices, one of our local human services cooperatives is part of that effort.

My oldest daughter, Annie, is a member of Community Choices. We are also forming a microboard for her, which is a business whose sole purpose is to figure out a better way for her to live as independently as possible and improve the opportunities that she has in her life. Her parents, brother and sister, extended family, friends and other community members are part of the organization as well. Annie's microboard is one of 50 in Illinois, and her microboard is as unique as she is. Other microboards are CILA providers, some assist with employment or self-employment, and all put great effort into creating connections and personal relationships in the community. All of the ramifications of microboards and cooperatives cannot be explained in three minutes or less, so I'm more than happy to talk with you after the session today.

Annie has hopes and dreams for herself, and they are not dissimilar from dreams of many with or without disabilities: to make her own decisions about her life; where to live, how to spend her time, how to earn a living, and how she has fun. She does not need or want what is typically intended for people with her disability – specifically group homes, sheltered workshops or day programs.

Thanks to the efforts of Community Choices, Annie has a job as an assistant teacher in a local day care center. She has worked there for almost 3 years, and is a valued employee. When not working, she volunteers at the humane society, in the public schools, and at her church. She also works out three days a week, attends a class, and goes out for dinner every Wednesday night with her friends. In a few short months we hope that she will be moving into her own home.

For all of these places and activities, she needs some type of support; transportation, job coaching, and personal assistance. When she moves to her own place she'll need more. Annie is fortunate to be a recipient of the Home-based support services program. It is a great way to support a person for about 30-35 hours a week, but is not enough.

Services in Illinois need to be based on the needs and wants of the person receiving them. They shouldn't have to make a choice between 24 hours-a-day care in facilities or 30-35 hours a week of

home-based care. Illinois and Champaign County need to fund flexible, innovative services that give people, to the greatest extent possible, control and choice in the way they live their lives.

Thank you,

Vicki Niswander
104 Woodcreek Ct.
Mahomet, IL 61853
217-778-1664
vniswander@gmail.com

October 12, 2013

Ms. Lynn Canfield
CCDDB
Brookens Administrative Center
1776 East Washington Street
Urbana, IL 61802

Dear Ms. Canfield:

“Choice is paramount.”

That is what Melissa Picciola from Equip for Equality said in her talk at the September 18th public hearing sponsored by the Champaign County Developmental Disabilities Board. Yet as my husband and I search for adult services for our 21 year-old developmentally disabled son we find choice non-existent in Champaign County. There are a slim number of group home providers and one agency (Developmental Service Center, or DSC) providing day programming. In a county with a population of more than 200,000 that is home to a prestigious university that boasts the country's first special education department at a university, this is a disgrace.

Our Story

Jason is 21 and has Down syndrome and autism. Although he talks a little bit, he is primarily non-verbal and communicates through a voice-output device and a picture-exchange communication system (PECS). He cannot be left alone, and also requires assistance with basic self-care tasks. Jason's a social guy and loves being in the community; with a companion/helper community employment, volunteering, and social outings are possible.

Since 2008 Jason has attended Heartspring, a residential school in Wichita, Kansas, as his unique individual educational needs could not be met locally, especially the intensive occupational therapy and speech therapy he required. Under an interstate compact agreement, Jason is not eligible for adult services in Kansas. So next May, when Jason ages out of this placement funded by the Illinois State Board of Education, he returns to Illinois.

But he faces a life drastically different from the one he now enjoys if he returns to Champaign County. That's why as we look for an appropriate adult placement for our son my husband and I are investigating agencies and programs around the state as well as some highly regarded programs in other states. What follows are the highlights of what we've learned, and how it compares to Jason's current situation.

HOUSING

- **Current:** At Heartspring, Jason lives in an 8-person co-ed group home with students of a similar age. Each person has his/her own room and a semi-private bath (one bathroom is shared by two bedrooms, i.e. two people). The dwelling is 15 years old.
- **Champaign County:** We find there are some agencies operating group homes, however, they are primarily shared bedrooms and shared bathrooms in homes occupied by middle-aged adults and senior citizens. Dwellings run the gamut in age and location, from new and ideal to older and questionable.
- **Other Illinois counties/other states:** Some offer private rooms with semi-private baths as their standard offering. Many are converting from shared rooms to private rooms and a shared bath as standard practice. Others will honor requests for private rooms on a case-by-case basis. The out-of-state programs offer private rooms with a shared or semi-private bath as their standard practice.

QUESTIONS: Why should a person with a developmental disability suffer lack of privacy and personal space by sharing a bedroom? Why should a person with reduced cognitive capability, who has never before shared a bedroom, suddenly find him/herself in a strange environment sharing a room? And if he or she is a young adult, why should he/she be expected to share a home with gray-haired residents who eat soft food and use walkers?

ACTION ITEM: We need to establish group homes in Champaign County specifically for young adults with developmental disabilities, as their needs, capabilities, and interests are vastly different from older adults. These homes should be 3 to 4-person homes to afford each individual dignity and respect by having his/her own room. It also reduces the number of residents sharing a bathroom. Staffing should be based on the level of care required by the residents. Homes should not have residents previously or currently diagnosed with a mental illness.

EMPLOYMENT

- **Current:** Jason currently has a community-based job delivering a free monthly neighborhood newspaper to distribution stands at 10 stores within a few miles of his school. On campus he performs a variety of delivery tasks for school staff. He also has two volunteer jobs: he is part of a group that shreds paper for use as animal bedding and delivers it weekly to the local Humane Society and he is also part of a group that delivers Meals on Wheels once a week. Jason is in a pre-vocational skills class where he explores and perfects a variety of job skills that could be used in a workshop or in the community. Packaging is his best (and preferred) task, so he's focusing on improving his packaging skills. He packages 4 diverse items together and is increasing his competency in packaging 5 or more items.

Heartspring has numerous contracts with local businesses that reliably and consistently provide workshop work. These include rolling silverware in napkins for

a local restaurant (the students roll 300 sets every weekday); copying, collating, and assembling new patient information packets for doctor and dentist offices; stuffing goody bags for the Wichita Convention and Visitor's Bureau to distribute at events; and assembling sprinkler heads for a local lawn-care company (used in their underground sprinkler system installations). In addition, the school operates a student business manufacturing and packaging dog treats that are sold through the school and at some local stores.

- Champaign County: I first visited DSC's day programming services 10 years ago. Their programs were lackluster and their facilities dreary and in need of modernization. On my recent visit to DSC I was unable to complete the tour of group homes and day programming prior to day program clients departing for the day. I was offered the opportunity to return to complete my tour so that I could see the day programs in action. When I accepted, noting that I'm sure many things had changed since my last visit, the response was "If you were here 10 years ago you won't see anything different. Everything's basically the same." Really?? In 10 years, despite an influx of millions of dollars from county taxpayers, nothing has changed? I find that very disturbing. And that raises the question: What has DSC done with the money granted them through CCDDDB?

Upon my return to DSC to complete my tour, I was pleasantly surprised to find 1:2 staffing for a select group of clients needing additional supports to perform packaging work. Overall, though, I found DSC's day programs still to be lackluster and not much different from what I had seen in 2003. At the Bradley Avenue location client employment was packaging work in a workshop setting, primarily for Horizon Hobby. If Horizon has no work for them, the clients have no job to do during their time at the center. Leisure facility capacity prohibits all clients from participating, so I was unclear what clients did when there was no packaging work. Staff prevaricated when asked about creating a varied schedule, with a personalized program that would meet Jason's diverse needs and interests. When pressed, they said that was not possible based on current staffing and funding.

I also found the Bradley Ave. DSC facilities still dreary and in need of modernization and/or replacement. What they call their McKinley Buildings are definitely in need of replacement. These Quonset huts can only be described as depressing. I would even label them dangerous. They lack adequate ventilation, smell of mildew and in some places had black mold visible on the walls. Bathroom facilities were inadequate for the number of people occupying the building. I was told that DSC had sold these buildings and now rents them back from the current owner. When I inquired if there were plans to use the money from the sale to build new facilities, the answer was "no."

I inquired about community employment opportunities for DSC clients. I was told DSC operates a warehouse at a different location where they package for Kraft. This is ***not*** community employment!

DSC's current capacity of serving 160 clients total in their day program offerings is the same as the figure they told me they served when I visited in 2003. In 10 years, despite an influx of millions of dollars from county taxpayers, DSC has not expanded their capability to serve more clients. Again, this begs the question: What has DSC done with the money granted them through CCDDDB? I cannot find financial information on the DSC website.

- Other counties/other states: In visiting other agencies around the state, where agencies have competition, I have encountered many agencies that are expanding capacity. These agencies have realized they cannot solely rely on donations and government funding for their survival and their ability to expand to meet the growing need. These agencies have all established independent revenue streams.

Enterprises I encountered at other agencies include bakeries, restaurants and tea rooms, aluminum can collection and recycling, catered box lunches, candy making businesses, gift shops selling crafts and artwork made by agency clients as well as local artists, packaging and selling gourmet coffee and/or client-made cookies locally and online, greenhouses with regularly scheduled public plant sales, and janitorial services.

Clients are involved in these offerings to the best of their ability. For instance, a client may not be able to bake the cookies or package the coffee but is capable of putting labels on the bags or folding down the top of a shipping box. A client not able to tend a plant can balance a tray of plants on their wheelchair and help transport it to a customer's car. At one agency, all but the most severely developmentally disabled clients worked in private businesses in the community—true community employment! A fourth agency I visited in Illinois offered a community-based post-transition educational program for highly-functioning young adults that combined classroom activities with community resources such as libraries, public transportation, and park district facilities so that young adults build their social skills as well as skills in employment and recreation areas. Clients not eligible for the education program worked in local businesses in community employment or in one of the agency's workshops.

Out of state programs offered employment in various local businesses as well as work opportunities in agency gift shops, coffee shops, greenhouses, and light industrial programs. One agency devotes itself to agricultural programs, growing vegetables in its outdoor gardens in spring and summer. Customers purchase a "share" of the produce and enjoy weekly deliveries of fresh vegetables. The same agency also worked with a university to establish an orchard and now offer apple shares in the fall. Winter finds the clients busy in the greenhouse tending seedlings.

QUESTIONS: With so many agencies that receive state funding for clients the same as DSC (but are in counties that do not have the county funding services the way Champaign County does) demonstrating creative ways to provide services to their clients that also supplement the agency's donations and government funding—

while continually expanding their offerings and the number of clients they serve— why does Champaign County continue to fund the status quo? Is expressed client satisfaction with the status quo truly satisfaction with current services? Or is it based on a lack of knowledge of other options because DSC is the extent of their experience? Do clients fear retaliation if they complain or demand other choices from DSC? Why are CCDDDB members reluctant to fund new programs offered by groups other than DSC?

ACTION ITEMS: The CCDDDB needs to thoroughly evaluate the effectiveness of programs offered in the county and thoroughly evaluate the effectiveness of programs the CCDDDB is funding, as recommended by County Board Member Patsy Pettrie during the September 18th hearing. (This may require the appointment of an independent review committee to maintain impartiality.) These findings should be made public. I could find no evidence of either of these evaluations on the CCDDDB website. In fact, I had to dig very hard to even find what CCDDDB is currently funding (it is in May 2013 board meeting minutes). There are no annual reports posted for CCDDDB on the website. Entries under the “Annual Reports” heading were labeled “Mental Health Board Annual Report.” These did contain vague information on CCDDDB, but had no information on dollar amounts dispersed and to whom, number of people served, or outcomes.

The Board should place an emphasis on CCDDDB funding new and innovative programs. In particular, CCDDDB should provide guidance, support, and significant funding to establish another agency in the county that offers day programs, group homes, and community employment. The CCDDDB’s information on unmet need in Champaign County that was included in the CCDDDB’s July meeting agenda that is posted on the website shows that there are 583 people in emergency/crisis need of services. They are in immediate need, yet must ask where are they to live? Where are they to get day services? In addition, the county has 156 recent or coming grads—what are these young adults, including my son, to do during the day when the school bus stops coming? There are a number of families in the county who are struggling financially because a parent had no choice but to quit his/her job and stay home with the young adult due to lack of services in the county. An unemployed person has no income to spend in the county, thus does not contribute to revenue generation, which impacts the county in myriad ways.

I along with hundreds of other residents voted “yes” to create the CCDDDB because we believed it would expand opportunities for county residents with developmental disabilities and that new opportunities would be created. Where are these opportunities?

I find it interesting that the MHB & DDB website’s home page lists the Board’s duties as:

The CCMHB is responsible for planning, coordinating, evaluating and allocating funds for the comprehensive local system of mental health,

developmental disabilities and substance abuse services for Champaign County. The CCDDDB has essentially the same functions, but is limited to developmental disabilities.

and the CCDDDB's mission statement as "the promotion of a local system of services."

Perhaps it is this vagueness of having "essentially" the same function as the MHB rather than having the duties explicitly spelled out that is responsible for the "promoting local services", i.e. funding the lone existing agency rather than helping new providers begin service in the county?

The CCDDDB should also consider ways the board can fund leisure, transportation, exercise, and social opportunities for adults. Per federal regulations, adults receiving SSI who reside in a group home are allowed to keep \$50 per month; those in other care facilities may keep \$25 per month. The rest of their monthly SSI check must be turned over to their group home or facility provider. One cannot pay for transportation, recreation, and social outings like movies and dining out and still buy shoes, clothing, soap, toothpaste and food not covered by government food assistance on \$50 a month. Could CCDDDB provide money for bus passes for DD adults and children? Help establish a countywide van transportation service for those without access to public transportation? Could CCDDDB underwrite the cost of Y memberships? Provide special recreation scholarships?

In the information that I found on the CCDDDB website I saw nothing that would preclude the Board from issuing a call for proposals for areas where they identify a specific need. Therefore I urge the CCDDDB staff and board members to be more creative, more innovative. Adults with developmental disabilities in Champaign County would be better served, especially young adults.

Sincerely,



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Cc:
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State Sen. Chapin Rose
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