PLEASE REMEMBER this meeting is being audio recorded.
Speak clearly into the microphone during the meeting.

Champaign County Developmental Disabilities Board (CCDDB) AGENDA

Wednesday, March 21, 2018
Brookens Administrative Building, Lyle Shields Room
1776 E. Washington St., Urbana, IL 61802
8AM
(Members of the Champaign County Mental Health Board are invited to sit in as special guests)

1. Call to Order
2. Roll Call – Stephanie Howard-Gallo
3. Approval of Agenda*
4. Citizen Input/Public Participation
   At the chairperson's discretion, public participation may be limited to five minutes per person.
5. President's Comments – Ms. Deb Ruesch
6. Approval of CCDDB Board Meeting Minutes* **(pages 3-9)**
   Minutes from 1/24/18 and 2/21/18 are included. Board action is requested.
7. Financial Information* **(pages 10-13)**
   A copy of the claims report is included in the packet. Action is requested.
8. New Business
   A. Board Direction
      This item supports board discussion of planning and funding. No action is requested.
   B. CCRPC Independent Service Coordination Presentation **(pages 14-23)**
      Representatives of the Independent Service Coordination Team will present on the new Transition Consultant Services available through the FY18 funded ID/DD program. No action is requested.
   C. Update on Legislative and Policy Conferences **(pages 24-62)**

A Briefing Memorandum summarizing activities of the March 2018 NACBHDD and NACO Legislative and Policy Conferences is included in the packet for information only.

D. Successes and Other Agency Information

Funded program providers and self-advocates are invited to give oral reports on individuals' successes. At the chairperson's discretion, other agency information may be limited to five minutes per agency.

9. Old Business
   A. Meeting Schedules **(pages 63-66)**

      Copies of CCDDB and CCMHB meeting schedules and CCDDB allocation process timeline are included in the packet for information.

   B. Acronyms **(pages 67-68)**

      A list of useful acronyms, compiled and published by the Ligas Family Advocacy Program, is included for information.
10. CCMHB Input
11. Executive Director's Report – Lynn Canfield
12. Staff/Consultant Reports **(pages 69-71)**

    Reports from Chris Wilson and Barbara Bressner are included for information.
13. Board Announcements
14. Adjournment

**Board action requested*

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

Minutes –January 24, 2018

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

8 a.m.

DRAFT

MEMBERS PRESENT:	Joyce Dill, David Happ, Mike Smith
MEMBERS EXCUSED:	Cheryl Hanley-Maxwell, Deb Ruesch
STAFF PRESENT:	Kim Bowdry, Mark Driscoll, Stephanie Howard-Gallo, Shandra Summerville, Chris Wilson
OTHERS PRESENT:	Danielle Matthews, Annette Becherer, Laura Bennett, Ron Bribrisco, Vicki Tolf, Developmental Services Center (DSC); Kathy Kessler, Rosecrance; Amy Slagell, Diane Gordon, Meredith Barnes, CU Able/IAMC; Kyla Chantos, Reagan Carey, CTF Illinois; Sheila Krein, Parent; Becca Obuchowski, Community Choices; Katie Harmon, Regional Planning Commission (RPC); Mark Scott, Down Syndrome Network (DSN)

CALL TO ORDER:

Mr. David Happ, CCDDB Vice-President/Secretary called the meeting to order at 8:00 a.m.

ROLL CALL:

Roll call was taken and a quorum was present.

APPROVAL OF AGENDA:

The agenda was approved as submitted.

CITIZEN INPUT:

None.

PRESIDENT'S COMMENTS:

None.

APPROVAL OF CCDDB MINUTES:

Minutes from the December 13, 2017 Board meeting were included in the Board packet.

MOTION: Ms. Dill moved to approve the minutes from the December 13, 2017 CCDDB meeting as presented in the Board packet. Mr. Smith seconded the motion. A voice vote was taken and the motion passed.

FINANCIAL INFORMATION:

The claims report was included in the packet.

MOTION: Mr. Smith moved to accept the claims report. Ms. Dill seconded the motion. A voice vote was taken and the motion passed.

NEW BUSINESS:

Board Direction:
Deferred.

Mid-Year Progress Report:
Meredith Barnes and Diane Gordon reported on the first 6 months of CU Able's Community Outreach program. A copy of their Powerpoint presentation was distributed. Board members were given an opportunity to make comments following the presentation.

CCMHB/CCDDB Personnel Policy:
A Decision Memorandum and Draft CCMHB/CCDDB Personnel Policy with proposed changes highlighted was included in the Board packet. Ms. Howard-Gallo explained the Policy had been presented to the CCMHB on January 17, 2018 and the document was approved with the following proposed change: CCMHB Member Dr. Julian Rappaport requested in addition to the proposed changes, to strikethrough reference to the defunct Executive Committee in the Intergovernmental Agreement (on Page 66, #9 of the MHB packet) and replace "Executive Committee" with "CCMHB and CCDDB Board Presidents".

MOTION: Mr. Smith moved to approve the CCMHB/CCDDB Personnel Policy with all revisions described in the memorandum and at the meeting. Ms. Dill seconded the motion. A voice vote was taken. The motion passed unanimously.

IDHS-DDD Person Centered Planning Process:
A Briefing Memorandum was included in the Board packet. There was no discussion.

Successes:
Becca Obuchowski from Community Choices (CC) and Annette Becherer from DSC reported on their trainings with area businesses.

OLD BUSINESS:

Meeting Schedules:
Copies of the CCDDB and CCMHB meeting schedules were included in the packet for information only.

Ligas Family Advocate Program Acronym Sheet:
A list of useful acronyms, compiled and published by the Ligas Family Advocacy Program was included for information only.

CCMHB Input:

None.

EXECUTIVE DIRECTOR'S REPORT:

None.

STAFF REPORTS:

Staff reports from Kim Bowdry, Stephanie Howard-Gallo, Shandra Summerville, and Chris Wilson were included in the packet for review.

CONSULTANT REPORT:

A report from Barb Bressner was included in the Board packet.

AGENCY INFORMATION:

None.

BOARD ANNOUNCEMENTS:

None.

ADJOURNMENT:

The meeting adjourned at 8:33 a.m.
Respectfully Submitted by: Stephanie Howard-Gallo

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

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

Minutes –February 21, 2018

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

8 a.m.

MEMBERS PRESENT:	Cheryl Hanley-Maxwell, Deb Ruesch
MEMBERS EXCUSED:	Joyce Dill, David Happ, Mike Smith
STAFF PRESENT:	Kim Bowdry, Mark Driscoll, Stephanie Howard-Gallo, Shandra Summerville, Chris Wilson
OTHERS PRESENT:	Pius Wiebel, Champaign County Board, Annette Becherer, Laura Bennett, Ron Bribriesco, Patty Walters, Danielle Matthews, Vicki Tolf, Developmental Services Center (DSC); Kathy Kessler, Rosecrance; Amy Slagell, Diane Gordon, Meredith Barnes, CU Able; Kyla Chantos, Tracy Waverly, CTF Illinois; Sheila Krein, Parent; Becca Obuchowski, Community Choices; Katie Harmon, Regional Planning Commission (RPC); Barb Bressner, Consultant; Dylan Boot, PACE; Kentrell Graham, Dianna Defoi, Kim Harris, Charlie Osterbur, Advocates in Motion

CALL TO ORDER:

Ms. Deb Ruesch, CCDDB President called the meeting to order at 8:00 a.m.

ROLL CALL:

Roll call was taken and a quorum was not present.

7

APPROVAL OF AGENDA:

Deferred.

CITIZEN INPUT:

None.

PRESIDENT'S COMMENTS:

None.

APPROVAL OF CCDDB MINUTES:

Minutes from the January 24, 2018 Board meeting were included in the Board packet. There was not a quorum. Action was deferred.

FINANCIAL INFORMATION:

The claims report was included in the packet. There was not a quorum. Action was deferred.

NEW BUSINESS:

Board Direction:
There was no discussion.

Self-Advocates Presentation:
Representatives of Advocates in Motion presented their work. A copy of their Powerpoint presentation was included in the packet. Board members were given an opportunity to ask questions following the presentation.

Online Needs Assessment Surveys:
A Briefing Memorandum describing the needs assessment survey project was included in the packet.

Online Service-Level Data Reporting System:
A Briefing Memorandum was included in the Board packet. A listing of service activity categories per program and sample data analysis was included in the packet as well.

Successes:
Becca Obuchowski from Community Choices (CC) provided an update on recent successes.

OLD BUSINESS:

Meeting Schedules:
Copies of the CCDDB and CCMHB meeting schedules were included in the packet for information only.

Ligas Family Advocate Program Acronym Sheet:
A list of useful acronyms, compiled and published by the Ligas Family Advocacy Program was included for information only.

CCMHB Input:

The CCMHB will meet later today. Ms. Canfield reviewed the agenda items they will be discussing. A study session is scheduled for February 28, 2018.

EXECUTIVE DIRECTOR'S REPORT:

Ms. Canfield will be traveling to Washington D.C. next week for National Association of Counties (NACO) and National Association of County Behavioral Health and Developmental Disabilities Directors (NACBHDD) Legislative and Policy Conferences.

STAFF REPORTS:

Staff reports from Kim Bowdry, Stephanie Howard-Gallo, and Shandra Summerville were included in the packet for review.

CONSULTANT REPORT:

A report from Barb Bressner was included in the Board packet.

AGENCY INFORMATION:

None.

BOARD ANNOUNCEMENTS:

None.

ADJOURNMENT:

The meeting adjourned at 9:24 a.m.
Respectfully Submitted by: Stephanie Howard-Gallo

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

VENDOR NO	VENDOR NAME	TRN DTE	B N	TR 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 DEVLMNTL DISABILITY BOARD												
90	CHAMPAIGN COUNTY TREASURER									MENT HLTH BD FND 090		
		1/26/18	02	VR	108- 22		571154	1/31/18	108-050-533.07-00	PROFESSIONAL SERVICES	FEB ADMIN FEE	28,210.00
											VENDOR TOTAL	28,210.00 *
161	CHAMPAIGN COUNTY TREASURER									REG PLAN COMM FND075		
		1/26/18	02	VR	108- 13		571159	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB DECISION SUPPOR	7,205.00
											VENDOR TOTAL	7,205.00 *
11587	CU ABLE											
		1/26/18	02	VR	108- 16		571187	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB COMM OUTREACH	1,150.00
											VENDOR TOTAL	1,150.00 *
18203	COMMUNITY CHOICE, INC									SUITE 419		
		1/26/18	02	VR	108- 17		571201	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB CUSTOM EMPLOY	6,175.00
											VENDOR TOTAL	6,175.00 *
19900	CTF ILLINOIS											
		1/26/18	02	VR	108- 14		571210	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB NURSING	500.00
		1/26/18	02	VR	108- 14		571210	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB ADVOCACY CENTER	5,000.00
											VENDOR TOTAL	5,500.00 *
22300	DEVELOPMENTAL SERVICES CENTER OF									CHAMPAIGN COUNTY INC		
		1/26/18	02	VR	108- 18		571213	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB APARTMENT SVCS	34,778.00
		1/26/18	02	VR	108- 18		571213	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB CLINICAL SVCS	14,500.00
		1/26/18	02	VR	108- 18		571213	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB COMMUNITY EMPLO	30,114.00
		1/26/18	02	VR	108- 18		571213	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB CONNECTIONS	7,083.00
		1/26/18	02	VR	108- 18		571213	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB EMPLOYMENT 1ST	6,667.00
		1/26/18	02	VR	108- 18		571213	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB FAM DEV CENTER	46,857.00
		1/26/18	02	VR	108- 18		571213	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB INT SITE SVCS	66,591.00
		1/26/18	02	VR	108- 18		571213	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB SERVICE COORD	34,237.00
											VENDOR TOTAL	240,827.00 *

CHAMPAIGN COUNTY

EXPENDITURE APPROVAL LIST

2/09/18 PAGE 9

VENDOR NO	VENDOR NAME	TRN DTE	B N	TR CD	TRANS NO	PO NO	CHECK NUMBER	CHECK DATE	ACCOUNT NUMBER	ACCOUNT DESCRIPTION	ITEM DESCRIPTION	EXPENDITURE AMOUNT
*** FUND NO. 108 DEVLPMNTL DISABILITY FUND												
22816	DOWN SYNDROME NETWORK											
		1/26/18	02	VR	108- 15		571217	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB DOWN SYNDROME	1,250.00
											VENDOR TOTAL	1,250.00 *
35550	IL ASSOC OF MICROBOARDS & COOPERATIVES											
		1/26/18	02	VR	108- 19		571240	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB BUILD INCLSV CO	4,396.00
											VENDOR TOTAL	4,396.00 *
54930	PERSONS ASSUMING CONTROL OF THEIR ENVIROMENT, INC											
		1/26/18	02	VR	108- 20		571263	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB OP FOR INDEPEND	3,379.00
											VENDOR TOTAL	3,379.00 *
61780	ROSECRANCE, INC.											
		1/26/18	02	VR	108- 21		571272	1/31/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB COORD OF SERVIC	2,844.00
											VENDOR TOTAL	2,844.00 *
										DEVLMNTL DISABILITY BOARD	DEPARTMENT TOTAL	300,936.00 *
										DEVLPMNTL DISABILITY FUND	FUND TOTAL	300,936.00 *
											REPORT TOTAL *****	619,957.12 *

VENDOR NO	VENDOR NAME	TRN DTE	B N	TR 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 DEVLMNTL DISABILITY BOARD												
90	CHAMPAIGN COUNTY TREASURER							MENT HLTH BD FND 090				
		2/23/18	03	VR 108-	33		572206	2/28/18	108-050-533.07-00	PROFESSIONAL SERVICES	MAR ADMIN FEE	28,210.00
											VENDOR TOTAL	28,210.00 *
161	CHAMPAIGN COUNTY TREASURER							REG PLAN COMM FND075				
		2/23/18	03	VR 108-	23		572211	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR DECISION SUPPOR	7,205.00
											VENDOR TOTAL	7,205.00 *
11587	CU ABLE											
		2/23/18	03	VR 108-	26		572228	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR COMM OUTREACH	1,150.00
											VENDOR TOTAL	1,150.00 *
18203	COMMUNITY CHOICE, INC							SUITE 419				
		2/23/18	03	VR 108-	27		572238	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR CUSTOM EMPLOY	6,175.00
											VENDOR TOTAL	6,175.00 *
19900	CTF ILLINOIS											
		2/23/18	03	VR 108-	24		572245	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR NURSING	500.00
		2/23/18	03	VR 108-	24		572245	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR ADVOCACY CENTER	5,000.00
											VENDOR TOTAL	5,500.00 *
22300	DEVELOPMENTAL SERVICES CENTER OF							CHAMPAIGN COUNTY INC				
		2/23/18	03	VR 108-	28		572248	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR APARTMENT SVCS	34,778.00
		2/23/18	03	VR 108-	28		572248	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR CLINICAL SVCS	14,500.00
		2/23/18	03	VR 108-	28		572248	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR COMMUNITY EMPLO	30,114.00
		2/23/18	03	VR 108-	28		572248	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR CONNECTIONS	7,083.00
		2/23/18	03	VR 108-	28		572248	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR EMPLOYMENT 1ST	6,667.00
		2/23/18	03	VR 108-	28		572248	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR FAM DEV CENTER	46,857.00
		2/23/18	03	VR 108-	28		572248	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR INT SITE SVCS	66,591.00
		2/23/18	03	VR 108-	28		572248	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR SERVICE COORD	34,237.00
											VENDOR TOTAL	240,827.00 *

VENDOR NO	VENDOR NAME	TRN DTE	B N	TR CD	TRANS NO	PO NO	CHECK NUMBER	CHECK DATE	ACCOUNT NUMBER	ACCOUNT DESCRIPTION	ITEM DESCRIPTION	EXPENDITURE AMOUNT
*** FUND NO. 108 DEVLPMNTL DISABILITY FUND												
22816	DOWN SYNDROME NETWORK											
		2/23/18	03	VR	108- 25		572250	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR DOWN SYNDROME	1,250.00
											VENDOR TOTAL	1,250.00 *
35550	IL ASSOC OF MICROBOARDS & COOPERATIVES											
		2/23/18	03	VR	108- 29		572275	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR BUILD INCLSV CO	4,396.00
											VENDOR TOTAL	4,396.00 *
54930	PERSONS ASSUMING CONTROL OF THEIR ENVIROMENT, INC											
		2/23/18	03	VR	108- 30		572306	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR OP FOR INDEPEND	3,379.00
											VENDOR TOTAL	3,379.00 *
61780	ROSECRANCE, INC.											
		2/23/18	03	VR	108- 31		572316	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR COORD OF SERVIC	2,844.00
											VENDOR TOTAL	2,844.00 *
76107	UNITED CEREBRAL PALSY LAND OF LINCOLN											
		2/23/18	03	VR	108- 32		572332	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	FEB VOCATIONAL SVCS	2,883.00
		2/23/18	03	VR	108- 32		572332	2/28/18	108-050-533.92-00	CONTRIBUTIONS & GRANTS	MAR VOCATIONAL SVCS	2,883.00
											VENDOR TOTAL	5,766.00 *
										DEVLMNTL DISABILITY BOARD	DEPARTMENT TOTAL	306,702.00 *
										DEVLPMNTL DISABILITY FUND	FUND TOTAL	306,702.00 *
											REPORT TOTAL *****	666,614.32 *

Are you an individual or family member of a person with an intellectual or developmental disability graduating in the next 6-12 months?

Let Champaign County Regional Planning Commission's Transition Consultant Services help you.

Our Transition Consultants seek to:

- **Assist** with transition planning to adult services for students with intellectual and developmental disabilities who are nearing graduation from secondary education
- **Provide** linkage and referral services to community supports
- **Attend** Individualized Education Plan (IEP) meetings to assist with transition planning
- **Support** individuals and families in learning about the Prioritization for Urgency of Need for Services (PUNS) and registering for services

Need more information?

Please contact:

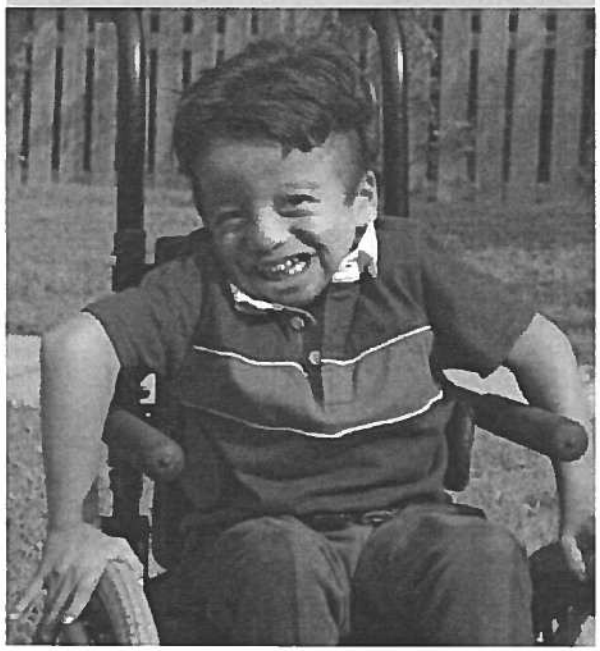
Sara Wilham
(217.493.8892 / swilham@ccrpc.org)
or **Sheila Krein**
(217.800.1479 / skrein@ccrpc.org)

rpc

CHAMPAIGN COUNTY REGIONAL PLANNING COMMISSION

About the Illinois Department of Human Services' Division of Developmental Disabilities

The Illinois Department of Human Services, Division of Developmental Disabilities provides leadership for the effective management of the design and delivery of quality outcome-based, person-centered services and supports for individuals who have developmental disabilities. These services and supports will be appropriate to their needs, gifts, talents and strengths; accessible; life-spanning; based on informed choice; and monitored to ensure individual progress, quality of life, and safety.



Contact the Illinois Department of Human Services' (IDHS)
24 hour automated helpline:
1-800-843-6154 or
1-800-447-6404 (TTY)

You may speak with a representative between:
8:00 am – 5:30 pm
Monday – Friday (except state holidays)

The following is an automated number directing the caller to local DD service information:
1-888-337-5267 or
1-866-376-8446 (TTY)

Contact us via mail at:
Illinois Department of Human Services
319 East Madison, 4N
Springfield, IL 62701

Visit our web site at:
www.dhs.state.il.us

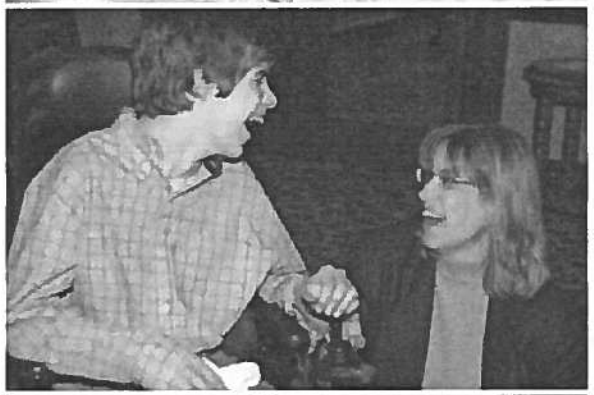
IDHS
Illinois Department of Human Services

DHS 4313 (R-01-16) Understanding PUNS 1,250 copies
Printed by the Authority of the State of Illinois PO #16-0892

State of Illinois
Department of Human Services

Understanding PUNS

A Guide to Prioritization for Urgency of Need for Services



IDHS
Illinois Department of Human Services

Enroll in PUNS to Apply for the Services You Need

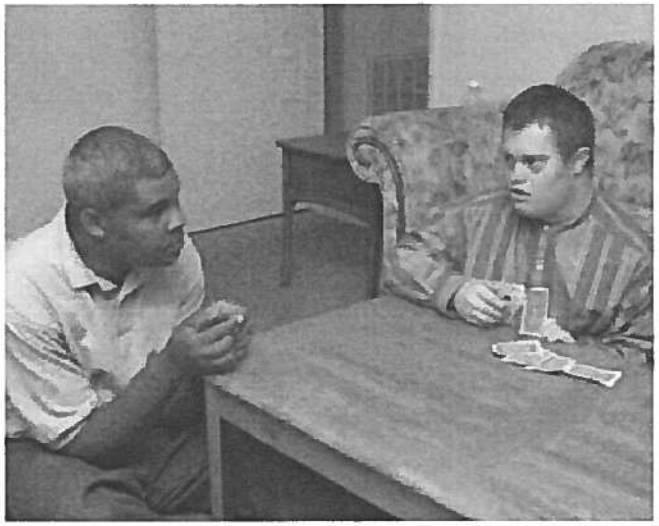
Frequently Asked Questions

WHAT IS PUNS AND HOW IS IT USED?

- PUNS (Prioritization for Urgency of Need for Services) is a statewide database that records information about individuals who have developmental disabilities who are potentially in need of services
- The State uses the data to select individuals for services as funding becomes available, to develop proposals and materials for budgeting, and to plan for future needs

WHY ENROLL IN PUNS?

- To assist with identifying service needs and, if necessary, to enroll on a waiting list



WHO CAN ENROLL IN PUNS?

- Children, teens, and adults who have developmental disabilities and need services or supports

WHAT CAN FAMILIES EXPECT DURING THE PUNS ENROLLMENT PROCESS?

- The individual, along with guardian, caregiver and family, meets face-to-face with an Independent Service Coordination Agent (ISC)
- The ISC Agent will work with the individual and their family to identify the need for services, explain services and identify the urgency of need

WHEN DOES PUNS INFORMATION GET UPDATED?

- At least annually the ISC Agency will contact families
- Anytime a need for service changes
- When contact information changes, such as address or telephone number
- When caregiver information changes

HOW DOES THE PUNS SELECTION WORK?

- The selection is an open and fair process using criteria such as length of time on database, urgency of need and geographic area of the state

WHEN WILL AN INDIVIDUAL BE SELECTED?

- PUNS selections are based upon funding availability

HOW DO PEOPLE KNOW IF THEY GET SELECTED?

- Individuals selected from the database will receive a letter directly from the Department of Human Services announcing their selection and inviting them to apply for services by contacting their ISC Agency

WHAT DO FAMILIES DO IF A CRISIS EMERGES WHILE ENROLLED IN PUNS?

- Families should contact their ISC Agency immediately for available options in their area
- Individuals who meet the crisis criteria do not have to wait on PUNS

Please Note: Enrolling in PUNS does not confirm that you are eligible for services nor guarantee that services will be provided. It does ensure that the IDHS' Division of Developmental Disabilities knows about an individual's need for services.

ISC - Preference Assessment

Background / Social Summary

1. Personal Background and Social Summary (Provide a one-paragraph overview of the individual including a brief summary of the person's background, skills, and abilities, personal likes and dislikes current and future vision/hopes, relationships with family members and support staff) - Answers documented and on file.

Housing Preferences

2. What is your preferred living arrangement?

- [ ] Live with Family
- [ ] Live Alone
- [ ] Live with Roommates
- [ ] 24-hour Supervised Group Home (CILA) - Single Bedroom
- [ ] 24-hour Supervised Group Home (CILA) - Shared Bedroom
- [ ] 24-hour Supervised Group Home (CILA)
- [ ] Community Living Facility (CLF)
- [ ] Intermediate Care Facility (ICF/DD)
- [ ] Host Family CILA
- [ ] SODC

Preferred Number of Housemates

3. Where do you want to live? (City, county, or geographic region)

- Ludlow
- Urbana
- Bondville
- Broadlands
- Champaign
- Dewey
- Fisher
- Foosland
- Gifford
- Homer
- Ivesdale
- Longview
- Mahomet
- Ogden
- Penfield
- Pesotum
- Philo
- Rantoul
- Royal
- Sadorus
- St. Joseph
- Seymour
- Sidney
- Thomasboro
- Tolono
- Champaign-Urbana-Savoy
- Champaign County
- Outside of Champaign County

Day Activities

4. Employment or Volunteer

- [ ] Office
- [ ] Retail
- [ ] Restaurant/Food Services
- [ ] Factory
- [ ] Outdoors
- [ ] Construction
- [ ] Automotive
- [ ] Service Industry
- [ ] Recreation
- [ ] Public Services
- [ ] Education/Childcare
- [ ] Agriculture
- [ ] With Animals
- [ ] The Arts
- [ ] Trade Work
- [ ] Health Services
- [ ] Finances
- [ ] Other (please specify)

5. Community Opportunities

- [ ] Continuing Education
- [ ] Champaign Urbana Special Recreation (CUSR)
- [ ] Best Buddies
- [ ] Special Olympics
- [ ] Church
- [ ] Groups and/or Clubs
- [ ] Gardening
- [ ] Health & Wellness
- [ ] Other (please specify)

6. Leisure

- [ ] Movies
- [ ] Theatre/Arts/Museums
- [ ] Shopping
- [ ] Zoo/Aquariums
- [ ] Parks
- [ ] Recreation/Sports
- [ ] Swimming
- [ ] Sporting Events
- [ ] Concerts
- [ ] Festivals
- [ ] Eating Out
- [ ] Other (please specify)

ISC - Preference Assessment

Supports Needed

7. What kind of supports do you need?

- [ ] Independent/Daily Living
- [ ] Medical
- [ ] Financial
- [ ] Transportation
- [ ] Vocational
- [ ] Assistive Technology
- [ ] Socialization
- [ ] Behavioral Therapy/Counseling
- [ ] PT/OT/Speech
- [ ] None

8. Are you currently receiving case management services? If so, where?

- [ ] Not currently receiving services
- [ ] Current ISSA
- [ ] CCMHB / CCRPC Independent Service Coordination
- [ ] Developmental Services Center (DSC)
- [ ] Rosecrance
- [ ] PACE Center for Independent Living
- [ ] Community Choices
- [ ] Other (please specify)

* 9. Client's Full Name

* 10. Age Group

* 11. Gender

* 12. Race

* 13. Ethnicity

* 14. Zip Code

Other (please specify)

* 15. ISC Coordinator/Surveyor

* 16. Client's Current Preference Assessment Status

- New
- Annual Update

8.C.

BRIEFING MEMORANDUM

DATE: March 21, 2018
TO: Members, Champaign County Developmental Disabilities Board (CCDDB)
FROM: Lynn Canfield, Executive Director
SUBJECT: Legislative Conferences of NACBHDD and NACO

Background:
From March 3 through March 7, I attended the Legislative Conferences of the National Association of Counties (NACo) and the National Association of County Behavioral Health and Developmental Disability Directors (NACBHDD) in Washington, DC. I serve on the Health Committee of NACo, as Vice Chair of its Behavioral Health Subcommittee, and on the I/DD and Justice Committees of NACBHDD. My notes are in regard to related sessions and events, several general sessions, and some on Early Childhood, which is of interest to the CCMHB, CCDDB, the Champaign County Board, and the Association of Community Mental Health Authorities of Illinois (ACMHAI).

NACo Health Steering Committee, Joint Subcommittee Meeting:

- Broward County Commissioner Barbara Sharief commented on the recent shootings in her community. Following one at an airport, they now serve as a model for TSA safety. She called for mental health legislation in response to the Parkland tragedy.
- NACo program directors described conference events of interest, gave overviews of new (Children's Impact Network, e.g.) and ongoing (Stepping Up, e.g.) initiatives, and identified several upcoming opportunities.

"Poverty and Early Childhood Development: What's Health Got to Do with It?"

- Kelly Whitener of Georgetown University emphasized the critical importance of the Children's Health Insurance Program (CHIP, reauthorized for ten years) and Medicaid. Insurance and health care are critical investments in our future workforce and toward making life better for people. See https://ccf.georgetown.edu. As parents increasingly enrolled in coverage, their own improved health and ability to navigate the system improved their children's outcomes as well. CHIP is important, but Medicaid offers the lion's share of coverage. Its Pediatric Benefit helps children succeed (lifts attendance, performance, graduation, and wages) and provides economic security for families.
- Comments: medical provider shortages; mental health and substance use disorder treatment parity enforcement; managed care; reimbursement rates; barriers to early services; war between insurance and drug companies; make home visits (Nurse Family Partnership, aka McVee) a Medicaid benefit; and maximize Medicaid to address the social determinants of health.

"Counties' Health Response to the Opioid Epidemic: The Landscape of Federal Substance Use Treatment and Prevention Resources and Informing NACo's Future Efforts"

- 175 US adults die each day due to substance use disorders, 100 due to opioid use. Of 150,000 people in US jails, half have substance use disorders, and 10% have I/DDs.
- Dr. Manderscheid, Executive Director of NACBHDD and National Association of Rural Mental Health (NARMH) attended a White House Summit on the opioid epidemic. He stressed prevention and positive health promotion, not just treatment and recovery services.

- Of the $6b appropriated to address this crisis, he recommends distribution through existing programs, each successful and with established procurement processes: $2b through SAMHSA, to expand the Certified Community Behavioral Health Center program from the current 8 pilot states to all states; $2b through CDC to enhance local public health programs and collaborate with behavioral health; and $2b through HRSA for the Federally Qualifying Health Centers to include a continuum of substance use disorder services in their integrated care settings.
- Rob Morrison, National Association of State and Alcohol Drug Abuse Directors (NASADAD), would also distribute the $6b to existing programs, stressed using Substance Abuse Prevention and Treatment block grants and keeping SAMHSA central. Although many federal agencies are involved with addiction, not much money is out there; DOJ invests only $14m across the country for drug courts and residential treatment. Opioid issues impact our communities in different ways; keep the prevention programs states currently receive and expand Medication Assisted Treatment (MAT) plus counseling, Naloxone treatment training, offender re-entry training in addiction, recovery coaches, and prescriber education.
- Comments: engage with Public Health and VAs; large legal firms are pushing communities to sue; system of care which includes MATs, integration with health partners; need for affordable housing; 1115 waivers; and prescription reporting systems.

NACo Lunch Roundtable:

"Combating Multigenerational Poverty in our Nation's Counties"

- A two-generation approach, to address disparities in access to employment, healthcare, education, and housing, and to increase economic status of families so that children and communities thrive. Most programs are siloed, serving children or youth or adults. Core components of a 'whole family' approach include early childhood education, post-secondary pathways, health and well-being, and social capital (those in poverty are often socially isolated). Provide space, meals, childcare so that families come together, learn about, and bridge to programs.
- Examples of Two-Generation progress and challenges in Arapahoe County, CO (collaborating with neighboring counties and a faith-based group), Weber County, UT (focused on socio-economic and racial equity and resiliency), and Garrett County, MD (very rural Appalachian, with high poverty and unemployment, now dropping).
- Common themes: fostering confidence, autonomy, and belonging; collaboration; innovations can create disharmony, so understand the end goal; hard to get federal government programs/agencies to streamline.

NACo Health Steering Committee, Business Meeting:

- The committee approved a Proposed Resolution in support of the Veteran's Choice Accountability Act (H.R. 1797).
- How the Committee's priorities relate to those of NACo: support policies to promote mental health; protect Medicaid; ensure federal funding for safety net programs and core local public health and prevention; eliminate Medicaid exclusions in county jails; provide targeted funding and administrative changes to combat addiction; ensure investments in healthcare for older adults; combat intergenerational poverty; protect counties' ability to provide health benefits to their employees (3.6m people).

"Taking the Pulse of Congress: Prognosis for Health Legislation"

- Katie Weider and Rodney Whitlock of ML Strategies, and Brian Bowden, NACo: 2017 showed that advocacy matters; Affordable Care Act (ACA) stabilization will happen by March 23, or it won't; legislation is passed in even-numbered years; 2019 holds great uncertainty for insurers, who hedge against uncertainty by raising premiums; drug pricing, mental health, and opioids are focus; healthcare's future is all about cost.

"Roundtable Discussion: Medicaid and Counties: Where Do We Go from Here?"

- Discussion of 1915b, 1915c, and 1115 waivers, with emphasis on the latter, as research and demonstration projects. Budget-neutral, five years with three-year renewal.
- Trends include: work requirements; time limits; restructuring prescription prices (if one state gets approval, many will request; expect pushback from drug companies); removal of IMD exclusion; premiums and cost-sharing; and waiver of non-emergency medical transport. KY has an approved 1115, MA and WI pending.
- Move the focus to wellness and systems of care, as CA did successfully after trying to address stigma of poverty and mental illness.

NACO Early Childhood Meet & Greet:

- With a private foundation and two research partners, NACo will identify eight communities from among applicants: to strengthen Early Childhood systems with quality care, early learning, and healthy beginnings, and to accelerate collaborative efforts on behalf of children 0-3 and their families.
- Overview of the project's goals and roundtable on communities' early childhood systems. Details on trainings and announcement of successful applicants are pending.

NACO Resilient and Healthy Counties Lunch:

"Strengthening Counties' Resilience by Addressing the Public Health Impacts of Natural Disasters"

- Responses to previous disasters; system/community changes to mitigate future impacts; unprecedented disasters are the new norm; preparing for distinct events (e.g., Hurricane Sandy, Boston bombing, severe pandemic); marginalized, disadvantaged, and medically fragile people bear the brunt.
- Examples from Oklahoma City-County Health Department and Harris County, TX.

NACBHDD Spring Board Meeting:

- Brief Updates on Opioid Appropriations, NACo Legislative priorities, 1115 waiver opportunities and trends, (see notes from sessions, above) and Homeland Security interdiction with China and Mexico, on fentanyl and other synthetic opioids.
- Reports from: NACBHDD President - outreach to non-member states rather than corporate partners, shift our focus to policy and social policy; Treasurer - 2018 budget approved; National Association for Rural Mental Health - conference theme will be rural resilience; State Association Directors committee - planning the policy agenda and position papers, with help from the Communications committee; Behavioral Healthcare committee - focus on outcomes, logic model, measures of well-being, which will also be developed for the Healthy People 2030 committee; Justice Committee - re-forming, with co-chairs; I/DD Committee - focus on Hill Briefing, will survey membership for Annual I/DD Summit topics for July; Communications/Outreach committee - position papers will be on the member page of NACBHDD website, social media under construction; and Executive Director - overview of topics and events.

- Items for Summer Board Meeting: opioid related state and county lawsuits, now encouraged by the Department of Justice (attorneys to present on these and what kind of data counties will need to produce); abuse of people with I/DD; school safety, gun violence versus mental health, the roles of stigma and bullying; data on those held while 'incompetent to stand trial'; strategies for recruiting new members.
- State Updates: IL, OR, TX, MD, MI, CA, MO, VA, and KS; all commented on Medicaid and waivers, workforce shortage, and homelessness; many on opioid epidemic, justice involvement, parity, early intervention, Managed Care, MAT, and political scandals.

NACBHDD Reception for NACo Board, Health Committee, and Justice Committee:
We presented recognition awards to NACo President Roy Charles Brooks of Tarrant County, TX and Commissioner Toni Carter of Ramsey County, MN.

NACBHDD Spring Meeting:
Mitch Anderson, President, asked us to think of policy issues, pay more attention to 'upstream' and underlying causes, and consider whether the services currently offered are the solutions. "Humans are infinities who try to turn each other into totalities."

Dr. Manderscheid read the 1998 NACBHDD meeting agenda: Managed Care, Parity, SAMHSA, Quality and Accountability, focus of the MH/SUD office, County Behavioral Health Institute, and CMS outcome measures, on which he was the guest speaker.

"Progress on Value-Based Purchasing (VBP)"

- Josh Rubin, of Health Management Associates, reviewed the evolution of payment systems: change the payment system to change the services; difficult to manage the system and an illness; increase value only by increasing quality or decreasing cost; promoting wellness can put a provider out of business, so incentives need to be aligned; while almost every state is moving toward VBP, the ACA's future is uncertain, and block grant Medicaid will hurt people in a few years.
- Key concepts: benchmarking, risk adjustment, attribution, predictive modeling, and stop loss. VBP is good in that how people behave and their circumstances (the social determinants/influencers) have the greatest impacts on health, compared to genetics at 30%. Behavioral healthcare is inexpensive but has high impact, is only 7% of national healthcare spending, helps with jobs, school, and housing, and keeps people out of jails and hospitals. The downside is that what gets measured is what gets paid for, and what gets measured is very political and contested.
- Examples from MN, CO, MA, NY, VT, VA, KS, and OR. Protect the role of county behavioral health, pay for things Medicaid can't (social determinants or 'influencers', enhanced services) or for those not eligible.

NACo Session:
"The Impacts of Adverse Childhood Experiences and Childhood Poverty"

- Uma Ahluwalia, Director of DHHS, Montgomery County, MD, introduced Dr. Brenda Jones-Harden, Chair of Committee of the Board at ZERO TO THREE, who presented on a theoretical framework for trauma informed care.
- Highlights: language as predictor of behavioral and physical health; early stress and early death; plasticity of early childhood; value of earliest intervention; sensitive periods of

development; disrupting the impact of toxic stress, mediated by positive caregiving; universal Pre-K; impact not as much about poverty as all the other stuff ('poverty plus').
- Examples from Buncombe County, NC (having implemented these principles over the past five years) and Deschutes County, OR (getting started with a regional effort).

NACBHDD Spring Meeting:

"Update on Federal Mental Health and Substance Use Initiatives"

- Elinor McCance-Katz, Assistant Secretary for Mental Health and Substance Use at SAMHSA, reviewed her responsibilities, data, initiatives, and what's next (her slides have been distributed by email).
- Highlights: collaborate on care to veterans and the homeless; focus on Severe Mental Illness; establish online resources on Evidence Based Practices and disseminate findings (especially peer services and MAT); need to recruit workforce; follow high risk youth with integrated physical and behavioral healthcare, 24 hour crisis intervention, community recovery services, and peer supports; "Zero Suicide" project; criminal justice related programs; practitioner training; a five point opioid strategy; guidance for telehealth; coming guidance about marijuana, not a safe drug.

"Key Developments in the Medicaid Program"

- Kirsten Beronio, Center for Medicare and Medicaid Services, and Lindsey Browning, National Association of Medicaid Directors, on Medicaid, what it doesn't pay for, and 1115 waiver trends.
- Highlights: state and local funds are also critical. 9.8m adult Medicaid recipients have MI, great unmet need for mental health treatment, high rates of comorbid physical conditions. CMS informational bulletins on MAT, youth with SUD, opioid and pharmacy benefits, evidence-based practices for first-episode psychosis, maternal depression, etc. They post annual reports on drug utilization review programs. Optional benefits include health home with linkage to social services. In implementation of parity, Medicaid is not doing as well as private coverage. Use 1115 waivers to do full continuum of SUD treatment. Trends include IMD exclusions (for jail population), work requirements, IT, etc. Counties can partner to design innovative programs.

"Addressing Our Human Resource Crisis"

- Panel presentation on areas of workforce shortage/crisis. Not even counting I/DD, the workforce shortfall is ¼ million providers.
- Rural workforce challenges: stigma is strong; 90% of psychiatrists and psychologists and 80% of social workers live in urban areas; 85% of behavioral health shortage areas are rural; access to equipment limits access to telehealth services; broadband and peer support are needed; use cooperative extension.
- Identifying what we need of more workforce: change the culture, act early, close treatment gaps, partner with communities, improve the use of data, position government to lead, break out of underperforming treatment systems.
- Examples from Olmsted County, MN (one FQHC serves 27 counties, large Somali refugee population, 90% of clients skip meals) and New York City (details on advances such as social spaces, self-care apps, 24/7 center at https://thrivenyc.cityofnewyork.us/)
- I/DD workforce: 'supported employment systems change' grants made progress but then stopped; see http://statedata.info; CMS improved the priority and definitions in 2011, then

approved the settings rule; WIOA similarly challenges the use of sheltered workshops and encourages more early work experiences. 30 "Employment First" states but still only 13% of employment services are in community, people work 13 hrs/week, and support staff do not fade. We need expert workforce, agency policy to support training, and state support for training and TA. Engage family and friends in the employment process; move away from cold calls and want ad searches; provide outreach and TA to the community; and improve reimbursement rates, especially group.

"Moving the Parity Agenda to Address Mental Health and Opioid Care"

- Representative Joseph Kennedy, MA: framing gun violence as a mental health issue is stigmatizing but creates an opportunity to recast the debate and fix the mental health services infrastructure; continue with reforms to make a parity rule that works, is enforceable; build a continuum of care of behavioral health services and supports through Medicaid; even in MA the safety net is the criminal justice system, with law enforcement becoming advocates for an effective behavioral health system.

"National Update on Parity Developments"

- Tim Clement of The Kennedy Forum: for full compliance with the law, the number 1 issue is non-quantifiable treatment limitations, very complex definition; medical management practices are not working, and these protocols are to be implemented in the same way as for medical; regulators need a standard tool for compliance work; opioid epidemic but also a suicide epidemic; the "sentinel effect" of auditing, so no less than 12 randomized audits per year; see http://paritytrack.org, bundle data so regulators can analyze it; there is model parity legislation for states (e.g., eliminate barriers to MAT); see http://parityregistry.org; more optimistic about parity than about Medicaid.

"Bringing the Parity Agenda to States and Counties: Panel Dialogue"

- Examples from OR (90% coverage due to Medicaid expansion, care coordination, good system coordination), MI (autism coverage strong thanks to a family member in power, MI and DD systems are still public), and Orange County, CA (behavioral health is carved out, strong state parity law).
- Panelists from states, The Kennedy Forum, and Department of Labor. DOL is looking at a package of deliverables (IL has strong parity rules!); re psychiatric shortage, you'd solve any other kind of shortage by raising the rates.

"Discussion of '18 NACBHDD Legislative Agenda"

- Preserve Medicaid (oppose block grant); youth opioid treatment; integrated care with social supports; I/DD service system management; parity enforcement; behavioral health and I/DD workforce development; smart decarceration; etc.

"Final Preparations for Capitol Hill"

- NACo passed a resolution supporting the Veteran's Choice Accountability Act and one regarding those in jail without adjudication, due to not making bail; support reauthorization of the Juvenile Justice Delinquency Act and Second Chance Act; legislative staff who will receive awards from us are excited, as this is unusual; focus on early intervention and comprehensive services; review of priorities.

NACBHDD Hill Briefing:
"When a Good Life is Dependent on Federal Policy: For Individuals with Intellectual and Developmental Disabilities (I/DD)"

- Our I/DD committee organized this event and developed the four "leave-behind" fact sheets with NACBHDD Communications Committee and Optum Health.
- Speakers: Cheryl Dougan, parent and Director of National Alliance for Direct Support Professionals; Mary Lee Fay, Executive Director of National Association of State Directors of Developmental Disabilities Services; John Butterworth, Director of Employment System Change and Evaluation, Institute for Community Inclusion, UMass Boston; and Les Wagner, Executive Director of Missouri Association of County Developmental Disabilities Services.

NACo Hill Briefing:
"Improving Lives and Outcomes at the Local Level: How Counties are Tackling Multigenerational Cycles of Poverty"

- Examples from counties working with federal and state partners on innovative anti-poverty programs, to break the cycles and help people thrive.
- Speakers: Representative Bobby Scott, VA; Senator Martin Heinrich, NM; Representative Adrian Smith, NE; NACo President Roy Brooks; Commissioner James Ebert, Weber County, UT; Commissioner Merceria Ludgood, Mobile County, AL; and Charles Rudelitch, Executive Director, Sunrise County, Maine Economic Council.

NACBHDD Capitol Hill Reception:
We presented recognition awards to legislators and congressional staff. Among recipients who then spoke were: Grace Napolitano, CA; John Katko, NY; Katherine Clark, MA; and Ileana Ros-Lehtinen, FL.

NACBHDD Spring Meeting:
"Recovery Oriented Systems and Peer Support"

- Harvey Rosenthal and Elena Kravitz of NYAPRS: disclosure is the best anti-stigma campaign; history of the peer support movement (On Our Own, Conspiracy of Hope, Wellness Recovery Action Plans, 8 Dimensions of Wellness, Dignity of Risk); the power of peer support is in the quality and power of relationships, trauma-informed, strengths-based, and self-directed; see the world through a person's eyes rather than illness, deficit, diagnosis, and HEDIS outcomes; models – respite center, recovery center, crisis warm lines, peer-run housing and employment, peer bridger services; well-trained peer specialists in a variety of settings (including with primary care physicians); evidence from various studies, including forensic program outcomes and homeless outreach and linkage; nothing about us without us.

"Decarcerating Our City and County Jails"

- David Morrisset of SAMHSA described the GAINS sequential intercept model (SIM) and introduced our decarceration pilot project.
- Mentors Leon Evans and Mark Refowitz provided history from their own communities (Bexar County, TX, and Orange County, CA) and overview of our projects' goals and process; our people are the most expensive, and we will have impact through non-traditional services

- Examples from IL, MN, and TX. Each of us had completed SIM maps and examples of innovations, with some successes. All stressed the critical importance of collaborations.
- Charlie Curry, former Administrator of SAMHSA, joined us unexpectedly: community based mental health has NOT been a disaster but rather a success; counties are where the access and successes are, pathways to stabilization; champion recovery; we do have people living successfully in the community ("From Exclusion to Belonging").
- Centene will announce funding availability for 'social determinants of health' projects.

"Issues in Child Welfare and Services"

- Kim Dvorchak, National Association of Councils for Children: child welfare and juvenile justice systems can be pipelines to jail; inadequate systems of care; neuroscience research; we are funding our failures, so reverse the course; Every Student Succeeds Act (ESSA) has a toolkit on implementation; 75% of children change schools at first foster placement; 75% of youth in the JJ system have mental health issues, 60% also have SUD; 26,000 youth age out of care each year; 20% of homeless youth are LGBTQ; racial and ethnic disparities (e.g. perception of an offender's age); alternatives to jail (triage centers in Cook County, 24/7 psychiatry at Charleston MH center); include non-traditional stakeholders, collaborative councils, access to legal services.
- Examples from Johnson County, KS (develop supportive transitional housing and crisis stabilization/triage units for youth, map the child welfare system as a SIM) and State of CA (child welfare reform, protect children from stressors and prepare them with independent living skills).

From President Mitch Anderson's Closing Comments:
"Rather than saying a person needs treatment, say they need understanding, hope, and support."

Please Join Us!

The **National Association of County Behavioral Health and Developmental Disability Directors (NACBHDD)** and the **National Association for Rural Mental Health (NARMH)** invite you to a Congressional policy briefing:

WHEN A GOOD LIFE IS DEPENDENT ON FEDERAL POLICY FOR INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES(I/DD)

Tuesday, March 6, 2018
2:00 to 3:00 PM
Room SV209, US Capitol Visitors Center
OPEN to Hill Staff and The Public

Congressional Sponsors:

Senator Robert Casey – Pennsylvania
Representative Ryan Costello – Pennsylvania
Representative Lynn Jenkins – Kansas
Representative Grace Napolitano – California

(To attend, all persons other than Members and Staff must RSVP to Neche Nelson at nnelson@nacbhd.org by Sunday, March 4. If you are not on the list of attendees, you won't be able to get into the room.)

Hear from a parent and experts in the I/DD field about the importance of personal independence and the key role of Medicaid funding for services, the need for a strong workforce supporting individuals, and the essential role employment plays for individuals with disabilities.

SPEAKERS:

- Cheryl Dougan – Advocate, parent and National Alliance for Direct Support Professionals (NADSP) Director at Large, Board of Directors
- Mary Lee Fay - Executive Director, National Association of State Directors of Developmental Disabilities Services (NASDDDS)
- John Butterworth, Ph. D – Director of Employment System Change and Evaluation, Institute for Community Inclusion, University of Massachusetts, Boston
- Moderator: Les Wagner – NACBHDD Board Member and Executive Director, Missouri Association of County Developmental Disabilities Services

Sponsors: **Optum, ANCOR, Autism Society, National Alliance for Direct Support Professionals, NACo, NACBHDD, and NARMH**

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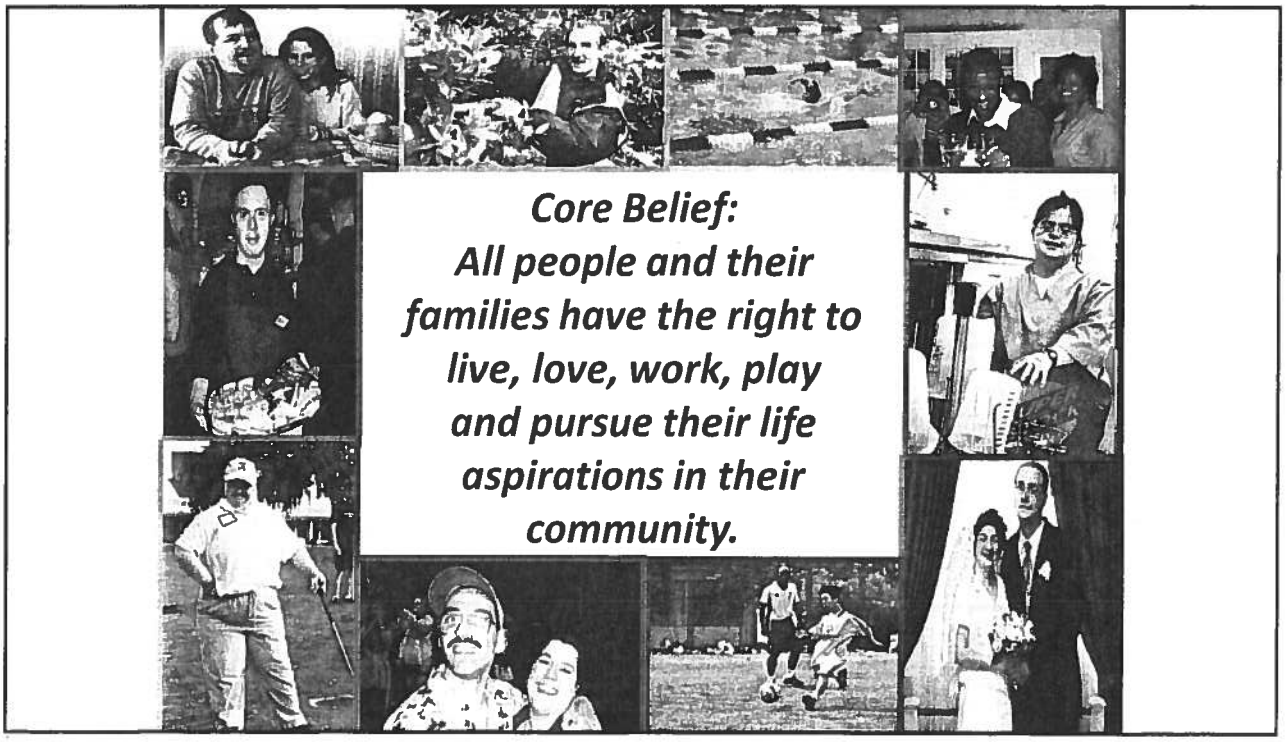
WHEN A GOOD LIFE DEPENDS ON FEDERAL POLICY

Medicaid: Home and Community Based Services What does it look like

Mary Lee Fay

National Association of State Directors of Developmental Disabilities



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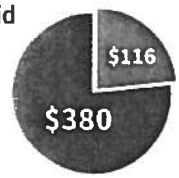
Medicaid – a Key Consideration for State I/DD Systems

2014 Total Medicaid Spending

Total federal and state Medicaid spending was $496.6 Billion.

Almost 25% was on Long-Term Care Services.

Source: 2015 CMS Actuarial Report



Total expenditures for programs targeting people with I/DD were $41.8 billion in FY 2014 – with 75% going to HCBS.

Elken, S., et. al., *Medicaid Expenditures for Long-Term Services and Supports (LTSS) In FY 2014: Managed LTSS Reached 15 Percent of LTSS Spending. April 2016*

NASDDDS
National Association of State Directors of Developmental Disabilities Services

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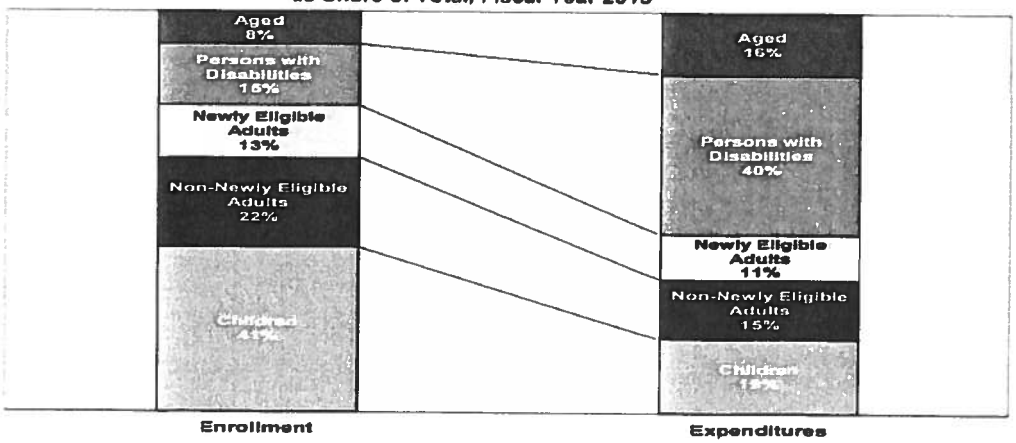
Medicaid Enrollment and Expenditures

Figure 1—Estimated Medicaid Enrollment and Expenditures by Enrollment Group, as Share of Total, Fiscal Year 2015



Note: Totals and components exclude DSH expenditures. Territorial enrollees and expenditures, and adjustments. Totals may not add to 100 percent due to rounding.

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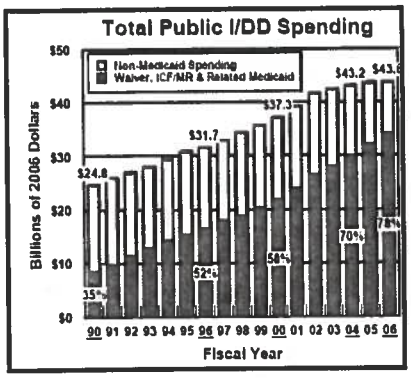
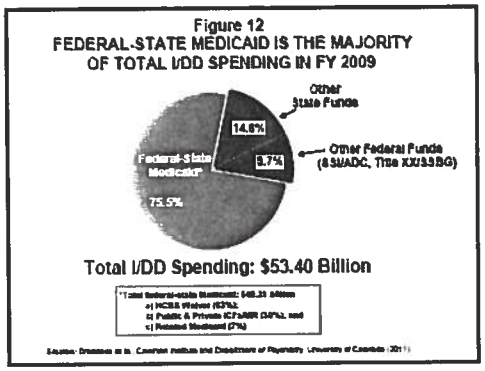
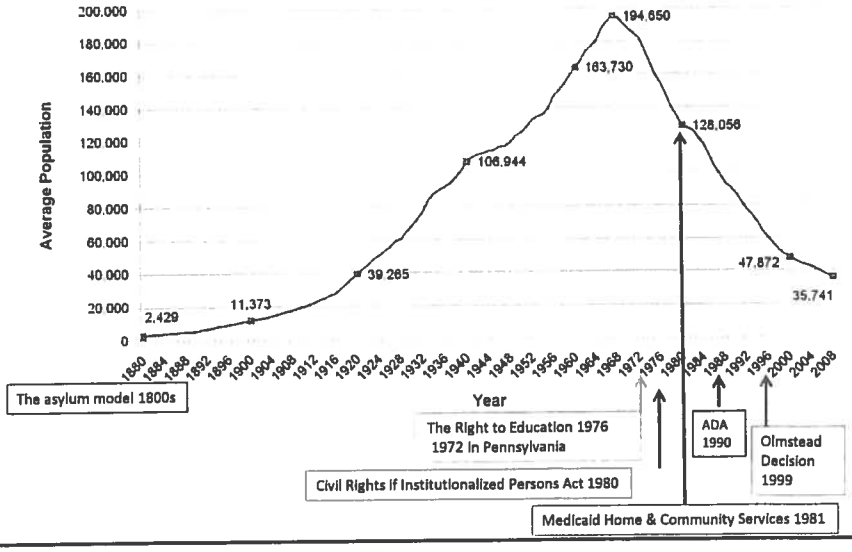
Without Medicaid, There Would Be No Services





NASDDDS
National Association of State Directors of Developmental Disabilities Service

The Impact of Public Policy on Institutional Census



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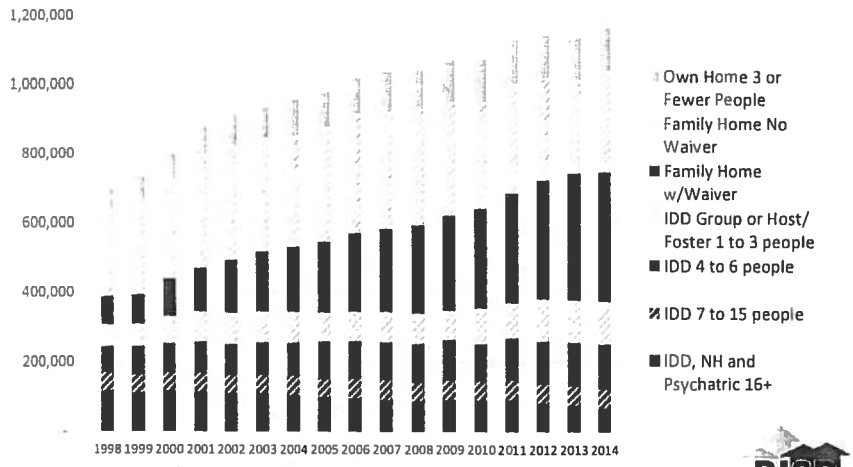
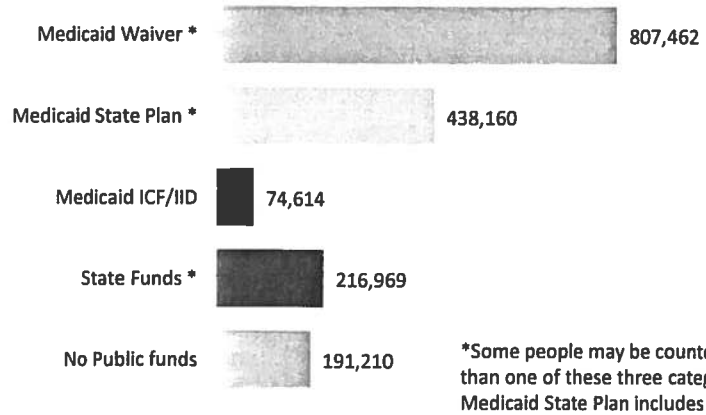
Change in Residence Type for People Served by State IDD Agencies 1998 to 2014



Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Fay, M.L. (2017). In-home and residential long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2014. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

Estimated Long Term Supports and Services (LTSS) Recipients with IDD by Funding Authority on June 30, 2016



*Some people may be counted in more than one of these three categories. Medicaid State Plan includes Targeted Case Management, 1915(i) and 1915(k).

risp.umn.edu

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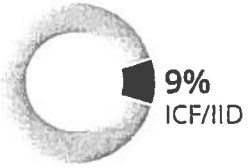
Medicaid Long-Term Supports and Services

EXPENDITURES

PEOPLE

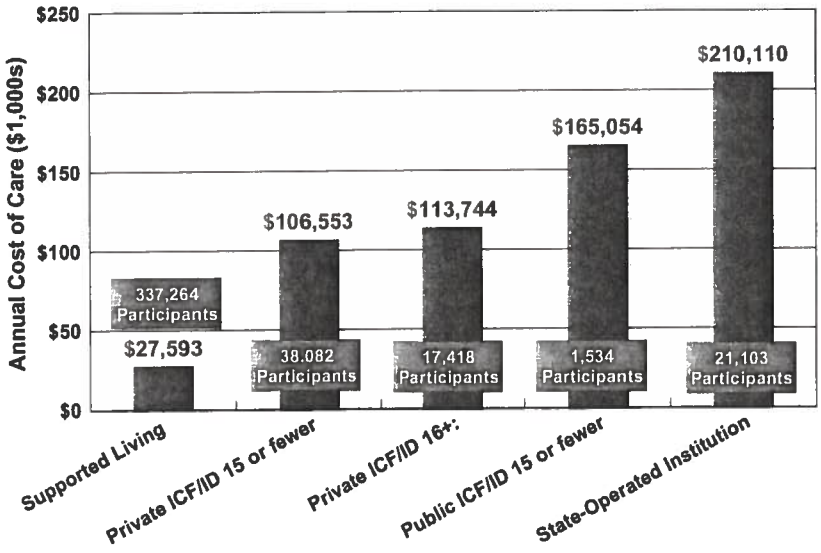


People Waiting for Medicaid Waiver

23% increase in Medicaid needed to serve all waiting Medicaid Waivers

RISP
risp.umn.edu

Annual Residential Cost of Care Per Participant, and Number of Participants



Source: Braddock, et. al., (2017). *The State of the States in Intellectual and Developmental Disabilities*

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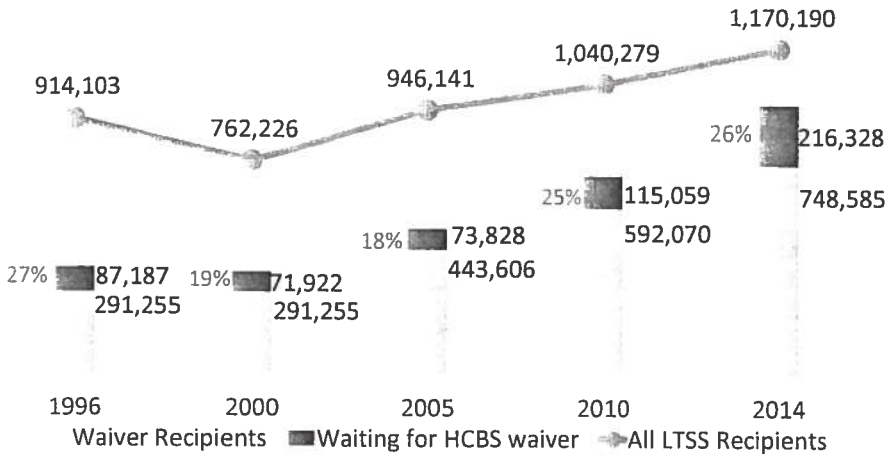
People With IDD Receiving or Waiting for HCBS Waiver Services…



How have Community Settings Changed over Time

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Home and Community Based Services What does Medicaid Buy

Residential

- Group Homes (people with I/DD live together with 24 hour staff)
- Shared Living
  - Apartments with roommates – staff comes as needed
  - Living with a host family
  - Living with family – may have staff, respite and/or day/employment program

Day Services

Competitive Employment (Person with I/DD works in at a local business with some ongoing staff support

Enclave/Group: (Several people, up to 8, work in the same local business with some ongoing staff)

Sheltered Work (people come to a DD agency run building and work)

Community Inclusion – People participate and/or volunteer

Home and Community Based Services What does Medicaid Buy

In addition to the "staffing" type services, HCBS Medicaid also pays for:

- Transportation (for non-Medical needs such as access to employment)
- Technology needs (for communication and health and safety)
- Home adaptations (for health and safety)
- Habilitative therapies (to maintain physical condition)

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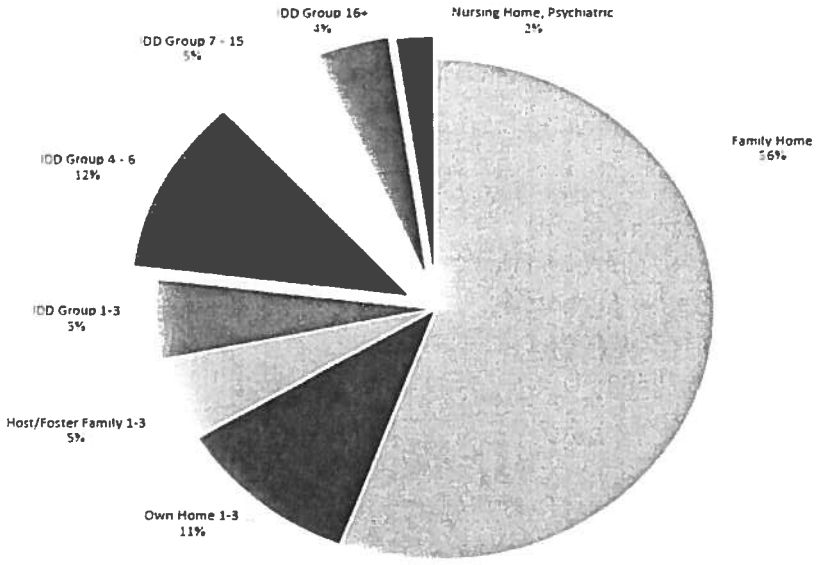
Figure 1.1 Residence Type and Size for People with IDD Known to State IDD Agencies on June 30, 2013 (Estimated Totals)



Institute on Community Integration (UCEDD), University of Minnesota | NASDDDS | National Residential Information Systems Project | 17

Focusing on Supporting Families

- ✓ Support Families to Envision a Good Life
- ✓ Support Family and Peer Networks
- ✓ Provide Information and Navigation
- ✓ Design supports to be flexible and responsive
- ✓ Understand the impact on policies and practices for ALL families

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Service Examples

One state building a supports program is incorporating the following types of services:

- Family Caregiving Supports –

- Respite
- Family Caregiver Stipend
- Community Support, and Navigation
- Family-to-Family Support
- Self-Advocacy Supports
- Peer-to-Peer Support
- In Home staffing
- Day/employment support
- Family Caregiver Training
- Individual Education and Training

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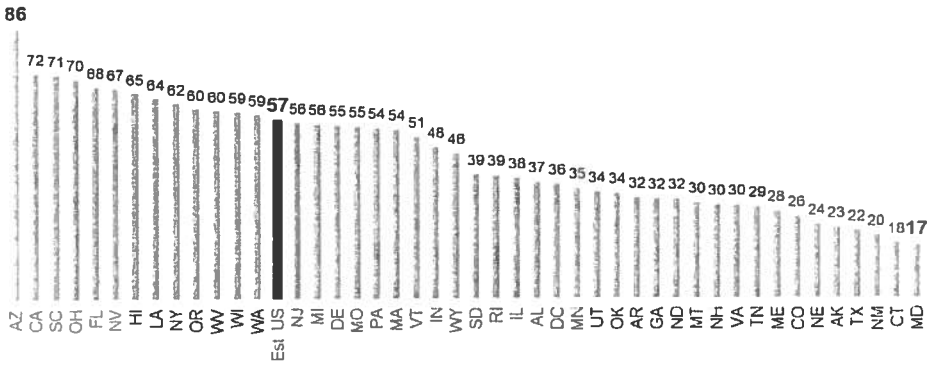
Percent of Service Recipients with IDD Living with a Family Member in 2014



57% of the people served by state IDD agencies in 2014 lived with a family member. The proportion by state ranged from 17% in MD to 86% in AZ

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Many Household Incomes Are Less Than $25,000*

2015-16 Adult Family Survey

2015-16 Child Family Survey

■ No earned income ■ Below $15,000
■ $15,001–$25,000 ■ $25,001–$50,000
$50,001–$75,000 Over $75,000

2016 HHS Poverty Guidelines for a family of four: $24,300

Data are from 2015-16 National Core Indicators Adult and Child Family Surveys

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And What Do People Do During the Day?...

New Possibilities and the Road Ahead- employment and community life engagement

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What do People Do During the day

- **Day Services**
- Competitive Employment (Person with I/DD works in at a local business with some ongoing staff support
- Enclave/Group: (Several people, up to 8, work in the same local business with some ongoing staff)
- Sheltered Work (people come to a DD agency run building and work)
- Community Inclusion – People participate and/or volunteer

Why Employment?

- Get out of poverty
- More independence
- Make Friends
- Make a contribution to the community
- Positive image and valued role within the family and community
- Opportunities for learning and expanding relationships
- Because people want to work

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When People Aren't Working: Community Life Engagement

- Individualized
- Leading to community membership and contribution
- Fostering independence
- Related to employment goals & activities
- Based on community partnerships
- Goal oriented and regularly monitored
- Well-supported by state definitions, funding, and monitoring

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What Does Medicaid Pay for

- STAFF – provide support throughout the day to help with skills, communication, activities of daily living
  - In a community job, staff – Is often intermittent, may fade over time, may use other co-workers as paid staff fade
- Transportation
- Technology

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MEASURING OUTCOMES

NCI
NASDDDS & HSRI™

NATIONAL CORE INDICATORS

NATIONAL CORE INDICATORS (NCI)

- NASDDDS – HSRI Collaboration since 1997
- Measures **performance** of **public systems** for **people with intellectual and developmental disabilities**
- **Performance domains** include:
  Employment, Community inclusion, Choice, Rights, Health and Safety
- Revisions in 2015-16
- Expanded tool set / protocols through the **NCI-AD (Aging and Disability)**

National Core Indicators (NCI)

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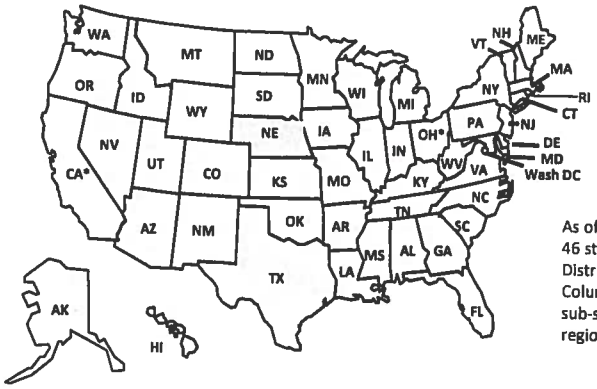
NCI State Participation



As of 2016-17: 46 states, the District of Columbia and 22 sub-state regions

NCI is a Person-Centered Tool that Provides Information on:

- Individual characteristics of people receiving services
- The locations where people live
- The activities they engage in during the day including whether they are working
- The nature of their experiences with the supports that they receive (e.g., with case managers, ability to make choices, self-direction)
- The context of their lives – friends, community involvement, safety
- Health and well-being, access to healthcare

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NCI Survey Tools

Adult Consumer Survey

(in-person)

Family Surveys (mail)

Staff Stability Survey

(providers → info on DSP stability)

National Core Indicators (NCI)

How Do States Use NCI Data?

NCI states use data in a number of ways to inform their **quality management** processes and **to improve the delivery of services and supports** to people with intellectual and other developmental disabilities.

To **inform legislators** and others on the **outcomes of supports** and to highlight particular areas of **policy focus.**

States use their NCI data for:

- Document CMS waiver assurances
- Assess system-level compliance with HCBS rule
- Conduct topic specific quality assurance/improvement (safety, medications, work) initiatives
- Make state-by-state (regional) comparisons
- Monitor outcomes as states transition to different service models/approaches (new waivers, managed care)
- Provide information for planning to Developmental Disabilities Councils and Quality Councils

National Core Indicators (NCI)

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Paid Community Job--2013-14 (N=14,479)

States can see where they fall in comparison to other states to identify areas for improvement.

National Core Indicators (NCI)

Family National Report

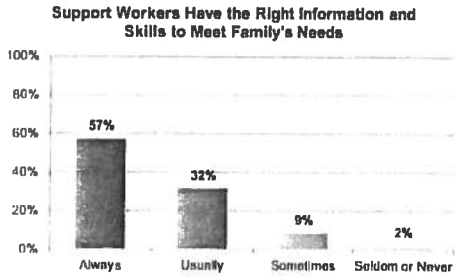

Table Q24. Do support workers have the right information and skills to meet your family's needs?

State	Always	Usually	Sometimes	Seldom or Never	N
Significantly Above Average					
LA	72%	22%	5%	1%	347
FL	69%	24%	5%	2%	382
AZ	65%	27%	5%	2%	297
MS	64%	27%	8%	1%	444
Within Average Range					
PA	61%	32%	6%	1%	389
NC	60%	31%	8%	0%	217
DC	59%	25%	13%	3%	214
OK	58%	35%	6%	1%	410
NH	55%	31%	10%	4%	357
HI	55%	34%	10%	2%	185
VA	52%	34%	10%	4%	141
GA	51%	33%	12%	4%	356
WA	50%	39%	7%	4%	284
Significantly Below Average					
MD	48%	38%	10%	3%	553
AK	42%	41%	14%	2%	132
NCI Average	57%	32%	9%	2%	4,708

National Core Indicators (NCI)

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Family National Report

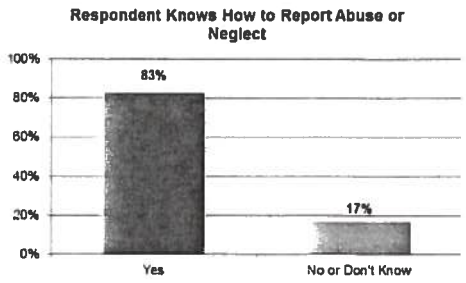
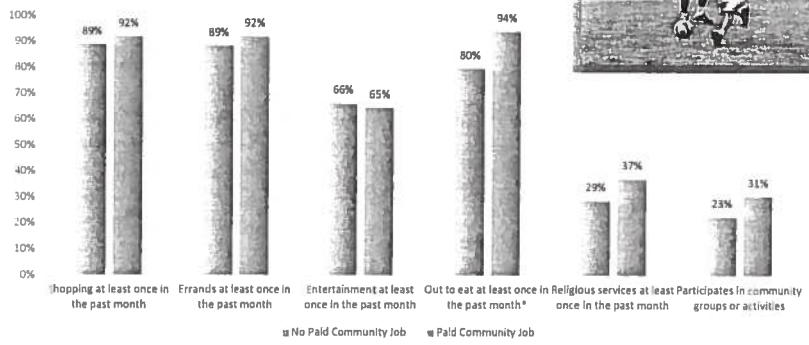


Table Q50. Do you know how to report abuse or neglect related to your family member?[4]

State	Yes	No or Don't Know	N
Significantly Above Average			
OK	93%	7%	469
FL	91%	9%	425
LA	90%	10%	386
Within Average Range			
NC	88%	12%	251
AK	88%	12%	137
PA	87%	13%	436
DC	87%	13%	233
MS	86%	14%	493
VA	84%	16%	164
NH	83%	17%	445
WA	81%	19%	426
AZ	77%	23%	320
Significantly Below Average			
HI	73%	27%	217
GA	69%	31%	432
MD	67%	33%	721
NCI Average	**83%**	**17%**	**5,555**

National Core Indicators (NCI)

Working people are more active in the community



* p<.01 **p<.001

National Core Indicators Project 2015-2016

3/5/2018

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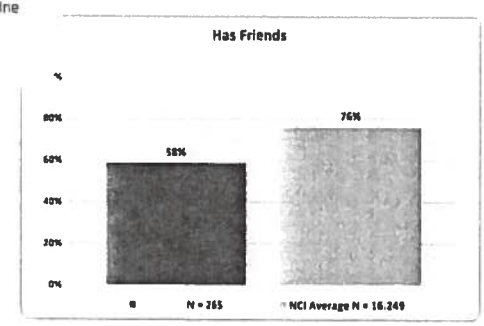
Identify areas of opportunity for quality improvement initiatives

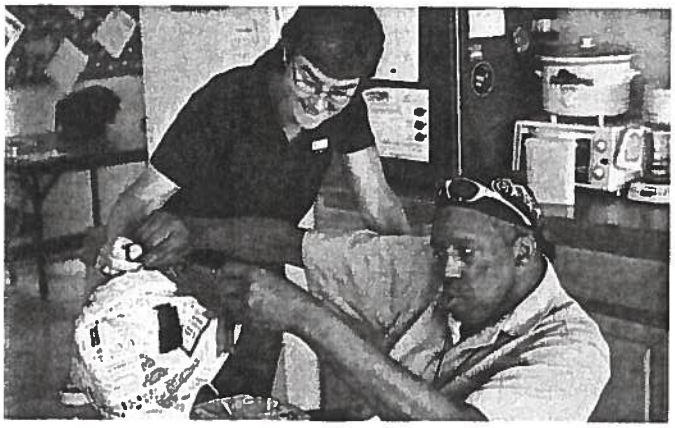
Do you have friends you like to talk to or do things with?

- ☐ 2 Yes, has friends who are not staff or family
- ☐ 3 Yes, all friends are staff or family, or cannot determine
- ☐ 1 No, does not have friends
- ☐ 99 Don't know, no response, unclear response



National Core Indicators (NCI)

Issues with Workforce shortage



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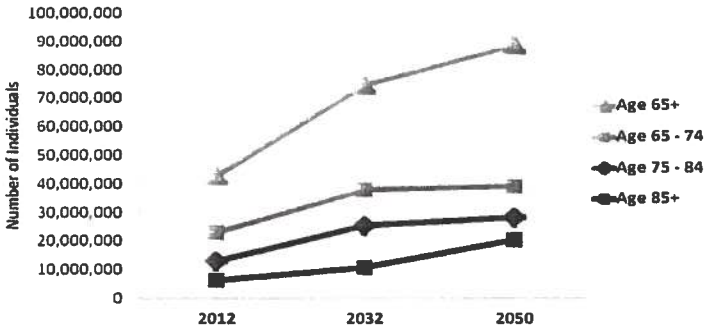
Demographics: Demand for DSPs is changing

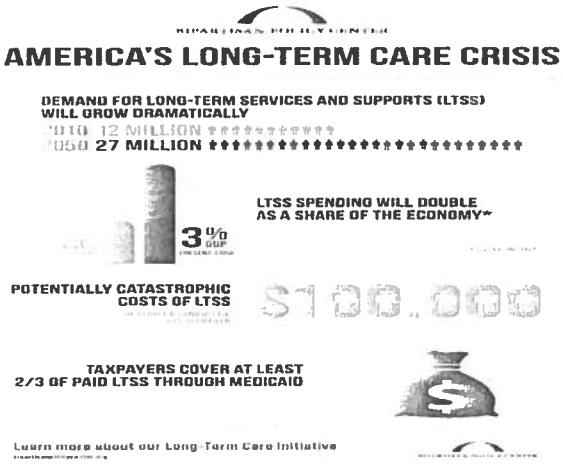
Figure 1

The 65 and Over Population Will More Than Double and the 85 and Over Population Will More Than Triple by 2050



SOURCE: A. Houser, W. Fox-Grage, and K. Gibson, *Across the States 2012: Profiles of Long-Term Services and Supports* (Washington, DC: AARP Public Policy Institute, September 2012), http://www.aarp.org/ppi/laws-politics/state-policy/articles/across-the-states-2012-profiles-report.html.

Demographics: Demand, cont'd



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Demographics: Supply

Quick Facts: Personal Care Aides	
2015 Median Pay	$20,980 per year $10.09 per hour
Typical Entry-Level Education	No formal educational credential
Work Experience in a Related Occupation	None
On-the-job Training	Short-term on-the-job training
Number of Jobs, 2014	1,768,400
Job Outlook, 2014-24	26% (Much faster than average)
Employment Change, 2014-24	458,100

Demand for New Direct-Care Workers Outstrips Number of Women Entering Labor Force (aged 25-54)

The projected percent change in employment from 2014 to 2024. The average growth rate for all occupations is 7 percent.

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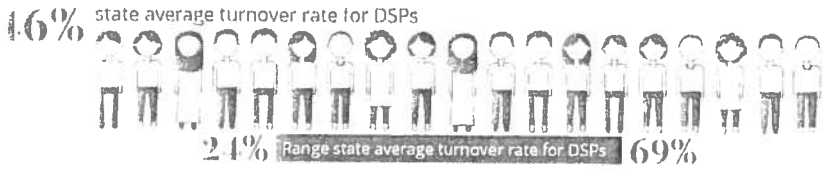
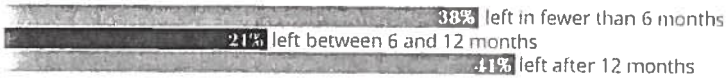
Bureau of Labor Statistics, U.S. Department of Labor, *Occupational Outlook Handbook, 2016-17 Edition*, Personal Care Aides, on the Internet at http://www.bls.gov/ooh/personal-care-and-service/personal-care-aides.htm (visited *November 29, 2016*).

National Core Indicators - Staff Stability Survey Turnover Rates



Of DSPs who left positions in calendar year 2016:



States: AL, AZ, CT, DC, GA, HI, IL, IN, MD, MO, NE, NY, OH, OR, PA, SC, SD, TN, TX, UT, VT

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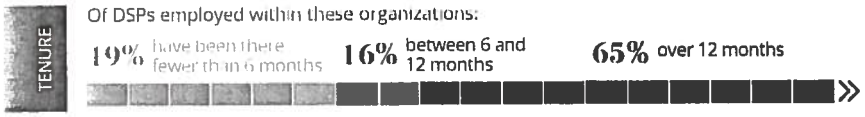
National Core Indicators - Staff Stability Survey Tenure



Length of employment of DSPs employed as of 12/31/26			
	<6 months	6-12 Months	12+ Months
State Ranges	12% to 31%	11% to 23%	50% to 75%

The Bottom Line

- To prepare for the future, states and Medicaid must work together and will be well positioned if they:
  - Keep the individuals they serve at the center of the decision-making
  - Are open to growing new and innovative approaches to meeting people's needs, in the context of their families, friends and communities
  - Develop necessary acumen to meet the data, reporting and quality requirements that are emerging

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Rich Data Resources Available

- National Core Indicators: Outcomes, Family Perspectives, and Staff Stability
- https://www.nationalcoreindicators.org/
- State of the States financial and programmatic data for intellectual/ developmental disabilities
- http://www.stateofthestates.org/
- State Employment Data trends and data reports on individual state performance in work, pulled from several national data sources.
- https://www.communityinclusion.org/topic.php?topic_id=5
- Residential Information System: residential service setting types, setting sizes, funding authorities, and expenditures
- https://risp.umn.edu/

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STATE OF THE STATES
IN DEVELOPMENTAL DISABILITIES

FISP **Supporting Individuals and Families Information Systems Project**

Questions

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www.nasddds.org

NACBHDD National Association of County Behavioral Health & Developmental Disability Directors

The voice of local authorities in the nation's capital

The importance of work for individuals with intellectual/ developmental disabilities

Calls to action

Individuals with intellectual and developmental disabilities (I/DD) should have the opportunity to work in their community.

- Reforms to Medicaid and balancing the federal budget should not fall disproportionately on the backs of individuals with I/DD.
- Federal programs, including Medicaid, need to be configured to make this possible and encourage opportunities for work for individuals with I/DD.
- Continue to support the Workforce Incentive Opportunity Act, which helps keep individuals with I/DD employed.

Work gives individuals a sense of purpose and self-worth. For many, it defines who we are and is a source of justifiable pride. Work helps improve individual and family finances, and it helps us connect socially. All individuals, regardless of disability, deserve the opportunity to be full members of their community where they can live, learn, work and play through all stages of life.

Recent legislation and regulation governing Medicaid Home and Community-Based Services (HCBS), the Workforce Innovation and Opportunity Act of 2014 (WIOA), and settlement agreements between states and the U.S. Department of Justice are clarifying federal intent and paving the way to support opportunities for individuals with disabilities to have meaningful jobs in their communities. With an increasing emphasis on integrated employment and an Employment First philosophy, the nation is poised for transformation that could put Americans with disabilities on a path out of poverty and toward self-sufficiency.[1]

Individuals with I/DD need to be supported to make informed choices about their work and career options and have the resources to seek, obtain and be successful in community employment. They may need varying degrees of support to reach personal goals and increase satisfaction with their lives. These goals often include being employed in the community alongside individuals without disabilities and earning competitive wages.

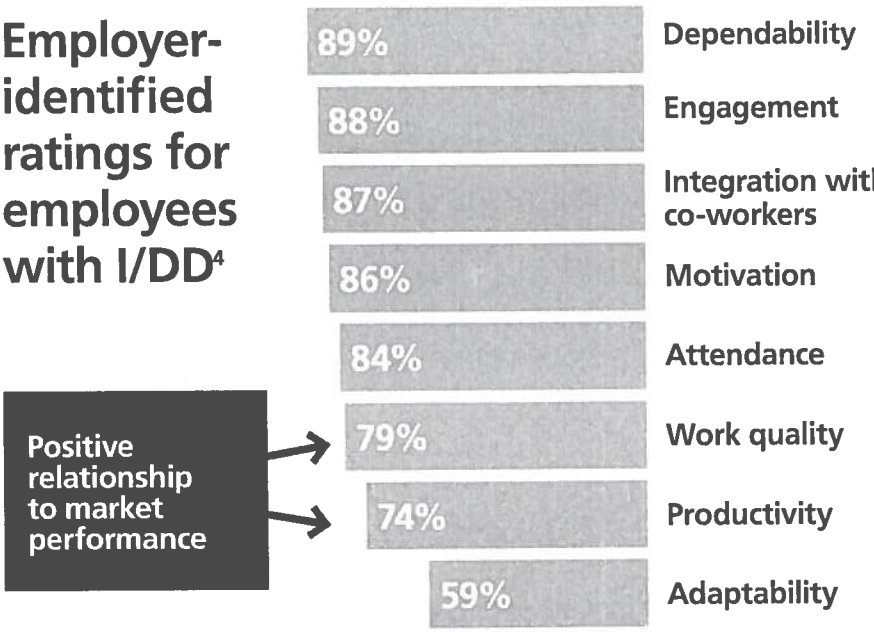
Yet there is a significant gap in the employment rate for working-age adults depending on whether they have a disability: 71.4% of adults without disabilities are employed, while only 32.5% of adults with disabilities are employed. For individuals with I/DD, the gap is even wider: only 14.7% of adults with I/DD are employed.[2]

Low societal expectations of individuals with I/DD fosters job discrimination. Lack of other services like transportation or accommodations and assistive technology can also hinder success. Other challenges for individuals with I/DD include a lack of work experience prior to leaving school. They may need long-term supports that aren't available, and have difficulty navigating the service delivery system. Requirements related to employment include:

- Opportunities for post-secondary education, including college and vocational training, to gain knowledge and skills to allow people to get better jobs
- Ongoing planning to promote job advancement and career development
- Fair and reasonable wages and benefits
- Opportunities for self-employment and business ownership
- Ability to explore new career directions over time
- Opportunities to work and increase earnings and build assets without losing eligibility for needed public benefits

Family caregivers report that 20% of individuals with I/DD have no source of paid income. They report low levels of employment (85% of individuals with I/DD did not have a job), decreases in employment services and unmet needs in the areas of job support. For individuals who had jobs, family caregivers reported that the individual liked what they did (82%), were satisfied with their work hours (78%), were satisfied with their wages (69%), and earned at least minimum wages (57%).[3] In addition, employers often value individuals with I/DD for their job performance.

Employer-identified ratings for employees with I/DD[4]



Individuals with I/DD must have training and information on how to access supports needed to find and keep jobs. Ancillary services like transportation and accommodations like assistive technology should be available to individuals and support agencies. Additional public policy changes should encourage employers to hire individuals with I/DD, such as a tax credit per I/DD individual who stays on the job for a defined period of time.

Using support strategies such as supported employment and customized employment, there are individual competitive integrated employment options for nearly everyone with I/DD. In addition to competitive, integrated employment with no formal paid supports, other options include supported and customized employment (competitive, integrated employment with formal paid supports), customized employment, social enterprise or self-employment, and volunteer work.

A significant amount of evidence indicates that integrated employment options improve consumer employment outcomes by moving an I/DD individual's daily focus away from formal, paid supports and toward an integrated, self-sustaining life alongside individuals without disabilities.

SOURCES

1. Winsor J, Timmons JC, Butterworth J et al. StateData 2016: The National Report on Employment Services and Outcomes. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion; 2017.
2. National Core Indicators. Adult Consumer Survey, 2015–2016 Final Report; 2017. nationalcoreindicators.org/upload/core-indicators/2015-16_ACS_Report_Part_1_0623.pdf.
3. Anderson LL, Larson SA, Wuorio A. 2010 FINDS National Survey Technical Report Part 1: Family Caregiver Survey. Minneapolis: University of Minnesota, Research and Training Center on Community Living; 2011.
4. Institute for Corporate Productivity, i4cp.com.

NACBHDD would like to thank the I/DD Subcommittee of NACBHDD as well as Optum, our corporate partner, and ANCOR for help in developing content for this informational sheet.

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Medicaid, the Affordable Care Act and impact of repeal efforts on individuals with intellectual/developmental disabilities (I/DD)

Calls to action

- We urge you to preserve access to community living and healthcare for individuals with I/DD, some of the most vulnerable individuals in society.
- Don't reduce funding to states that support housing, employment, training, case management and the health of individuals with disabilities, including individuals with I/DD.
- Don't block grant these federal programs.

Medicaid is an often invisible source of government funding for many different programs that help millions of individuals with disabilities and their families. Medicaid provides government-funded health insurance for children and adults who do not have much money and who have a disability. This means that Medicaid services are critically important to the quality of life of these individuals, as well as the quality of life of the families who care for them.

Background

The various proposals to repeal the Affordable Care Act (ACA) include funding cuts that are putting Medicaid's "optional" and "waiver" benefits at risk. Medicaid law requires that all states provide services such as doctor visits, hospitalization and nursing home care, among others. Other critical services for individuals with disabilities are not required by law (i.e., optional benefits), but are allowed if a state chooses to provide them and follows federal requirements. Once a state includes an optional service as part of its state plan, benefits must be about the same, available throughout the state, and individuals get to choose their providers and plans.

States provide many different services and supports as optional benefits. Examples of some of the optional benefits include: prescription drugs; clinic services; physical therapy; occupational therapy; speech, hearing and language disorder services; diagnostic, screening, preventive and rehabilitative services; dental services; prosthetics; eyeglasses; personal assistance services; case management; state plan home- and community-based services; and **Community First Choice Option**, allowing states to provide home- and community-based services and supports under the state plan as an alternative to facility-based care and receive increased federal matching funds.

Medicaid for adults with disabilities

According to the Kaiser Family Foundation, in the 32 states (including D.C.) that have adopted the ACA's Medicaid expansion, some adults with disabilities are eligible for Medicaid based solely on their low income. The ACA expands Medicaid eligibility to nearly all adults with income up to 138% FPL ($16,643/year for an individual in 2017) without an asset limit. It provides enhanced federal matching funds for states to cover this group. Thirty-five percent of adults on Medicaid who are not working report they have a disability or illness. Some expansion efforts for adults with disabilities have been effective. A recent study found that working-age adults with disabilities are significantly more likely to be employed if their state has adopted the Medicaid expansion, compared to states that have not expanded.[1]

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Home and Community-Based Services Waiver.

The most important waiver for individuals with I/DD is the 1915(c) Home and Community-Based Services Waiver. This waiver helps states provide long-term supports and services in home and community settings rather than in institutions. Waiver services include providing direct-support professionals to assist with meals and other activities of daily living. Waiver services also include habilitation, communication support, assistive technology, supported employment, behavioral supports and services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and communities.

For many individuals with I/DD, Medicaid generally is the only source of funds that allows them to live and work in the community and avoid more costly and segregated nursing homes or institutions. Nationwide, state and federal Medicaid together provide more than 75% of the funding for services for individuals with I/DD.

Example of a beneficiary receiving Medicaid community-based services:

Curtis, age 20, Kansas

Curtis lives with his mother and is diagnosed with autism, intellectual disabilities and sensory integration issues. He functions on the level of a 2nd or 3rd grader and recently has started to read. While he has a very easygoing personality, he cannot be left alone and needs help with shaving, bathing and taking medication. Medicaid provides attendant care services that help him to learn basic life skills at home, such as making his bed and dusting his room, while his mother is at work. His attendant also accompanies him to the library, to get his hair cut, to community events and to the book store, where his favorite activity is looking at picture books. Source: kff.org

What's at stake?

Optional and waiver services would be under attack if Congress deeply cuts and caps Medicaid funding. There would be real-life consequences for individuals with I/DD. They would lose services and supports. Waiting lists would quickly grow, creating a crisis for more than 730,000 individuals with I/DD living with aging caregivers. Individuals could lose critical services such as personal care, prescription drugs and rehabilitative services. States may decide to stop providing these services altogether. Individuals would lose the supports for community-based services and could be forced into more expensive, inappropriate residential settings. Returning to the days of institutionalization and of "warehousing" individuals with disabilities is unacceptable and a human rights violation.

The costs of providing healthcare and long-term services and supports will not go away. They would be shifted to individuals, parents, states and providers. States will not be able to make up the difference from the deep cuts under per-capita caps. States will be focused on keeping Medicaid spending under the cap, or face penalties.

SOURCE

1. Henry J. Kaiser Family Foundation. Medicaid Restructuring Under the American Health Care Act and Nonelderly Adults with Disabilities, March 16, 2017. kff.org/medicaid/issue-brief/medicaid-restructuring-under-the-american-health-care-act-and-nonelderly-adults-with-disabilities/view/footnotes/%20-%20footnote-211797-3/

NACBHDD would like to thank the I/DD Subcommittee of NACBHDD as well as Optum, our corporate partner, and ANCOR for help in developing content for this informational sheet.

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What is an intellectual/developmental disability?

The definition of developmental disability has changed over the last 75 years. Today, individuals with developmental disabilities live, work and play in the community, with self-determination and supports needed to live full lives. Housing options can range from living with family members, in group homes or in their own homes. Individuals may receive help with daily living skills from family or a personal support worker, or one-to-one supports with the goal of becoming as independent as possible.

The effects of an intellectual/developmental disability (I/DD) vary considerably. Children may take longer to learn to speak, walk and take care of personal needs. Students may take longer to learn in school. As adults, some can live independently without supports. Others need significant supports throughout their lives. A small percentage have serious, lifelong limitations. With early intervention, education and supports, an individual with I/DD can lead a satisfying life in the community.

Intellectual disability is characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior (a range of everyday social and practical skills). This disability originates before age 18. The levels of an intellectual disability range from mild (IQ 55–70), moderate (IQ 40–55), severe (IQ 25–40) and profound (IQ<25).

"Developmental disabilities" is a term that includes intellectual disability and other disabilities such as autism or fetal alcohol syndrome that are apparent during childhood. Developmental disabilities are severe chronic disabilities that can be cognitive or physical or both and will last indefinitely.

The Centers for Disease Control and Prevention estimates that, in the U.S., about one in six (about 15%) children age 3–17 years has one or more developmental disabilities. Across the nation, at least 4.7 million individuals have an intellectual or other developmental disability.

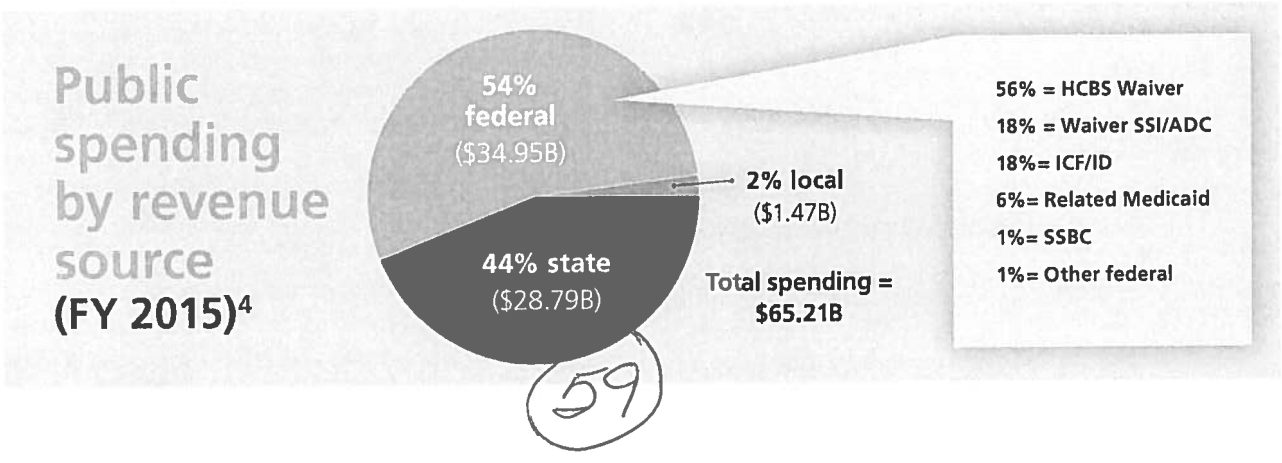
Of the 4.7 million with I/DD, only 1.4 million (30%) were known to or served by state I/DD agencies. Of that 1.4 million: 57% live in the home of a family member, 11% live in their own home, 5% in a host home, 25% in a group setting, and 2% live in a psychiatric facility.[1] In 2009, an estimated 1.8 million children age 6–21 with I/DD received special education services.[2]

Services and supports

Services and supports are funded by federal Medicaid dollars, as well as state and local dollars. The average costs vary, based on the needs of the individual, with the less expensive services being provided in integrated community settings.

On average, the cost of services per person per year is:[3]

- Intermediate care facilities (ICF) = $128,275
- Home- and community-based services (HCBS) (24-hour staffed) = $70,133
- Shared living = $44,122
- Supports in family home = $25,072



National Core Indicators (NCI)™ is a voluntary effort by developmental disabilities agencies to measure and track their performance. The NCI database is supported by Centers for Medicare and Medicaid Services. Many states have adopted their measures. Here's a sample of key NCI indicators and outcomes reporting for 2014–2015, showing what is important to and for people with I/DD.

Work – 92% like their paid community job
Choice – 45% have input/make decisions on home choice
Self-determination – 88% of those self directing who have help deciding how to use their individual budget/services
Community inclusion – 70% went out for entertainment in the past month
Relationships – 70% feel they can go out on a date if they want to
Access – 84% report having adequate transportation when they want to go somewhere
Gaps – 82% do not get services they need

Role and perspective of family caregivers

Family caregivers play critically important roles in supporting the well-being of individuals with I/DD. The following statistics are from the 2010 Arc Family and Individual Needs for Disability Supports (FINDS) Survey, as reported by family caregivers.

- 20% of those with I/DD had no source of income.
- Overall, 62% experience decreases in services; 32% were waiting for government-funded services, most for 5+ years.
- 58% provide 40+ hours of care per week (including 40% who provide 80+ hours of care per week). This interferes with their work (71%) and causes physical (88%) and financial strain (81%).
- 20% report that someone in their family had to quit work to provide care.
- 62% are paying for some care out of pocket.
- They struggle to find afterschool care (80%), reliable home care providers (84%) and community-based care (82%).

Current I/DD system challenges

The I/DD population is expected to grow. Prevalence increased 17% during 2006–2008, compared to a decade earlier. Individuals with I/DD are living longer. The number of adults with I/DD over 60 is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030. As parents and other caregivers become less able to care for I/DD individuals and begin to require their own supports, more will need Medicaid-funded long-term supports and services as well as state plan services (not funded by Medicaid).

The workforce that provides support services to individuals with I/DD are the same workers who support and care for other long-term services and supports (LTSS) populations. The services provided to individuals with I/DD are different than services provided to the general LTSS population. All LTSS populations have direct services providers who are underpaid, and the number of providers is not growing as fast as the need for support staff. Current fee-for-service payment models do not encourage or promote effective use of direct service provider time. With diminishing resources, we need to create additional community capacity, increase use of smart technology and work toward achieving full healthcare integration — while focusing on quality.

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For more information, contact: Ron Manderscheid, PhD, Executive Director, NACBHDD

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SOURCES
1. 2014 RISP Report – Institute on Community Integration, University of Minnesota.
2. Lakin KC, Larson SA, Salmi P, Webster A. (2010). Residential services for persons with developmental disabilities. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.
3. Mathematica
4. Stateofthestates.org

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Provider workforce challenges to serving individuals with intellectual and developmental disabilities

Calls to action

In order for individuals with intellectual and developmental disabilities (I/DD) to have a full life in the community, a trained workforce needs to be available to provide essential support services.

- We encourage support for the Workforce Innovation and Opportunity Act.
- We encourage that training through the National Health Service Corp include at least 1,000 positions for persons who will become providers serving those with I/DD.
- We recommend ensuring that Medicaid provides opportunities for the EMPOWER Care Act S2227, which reauthorizes Money Follows the Person (MFP), a Medicaid program providing funding to move individuals out of institutions and into the community.

The provider industry for home- and community-based services has been alerting policymakers about the growing crisis in the pool of workers for individuals with intellectual and developmental disabilities for a number of years. The national attention to workforce shortages, as well as the realization of the impact of the aging of the baby boom generation, has helped bring this growing crisis to the forefront in many states. Among the challenges are:

The workforce is shrinking. This is because of shifting demographics, lack of workers due to low unemployment rates and a mismatch between the skills of workers and job requirements.

Lack of workers. Slower growth in the number of new workers entering the labor force and greater competition for those workers are two factors negatively affecting the supply of workers.

Inability to find people who have "work-readiness" skills. Employers hiring for entry-level positions are increasingly unable to find workers with soft skills, or work-readiness skills, such as understanding the importance of reliability, self-direction, promptness, proper attire, workplace etiquette and appropriate language. Furthermore, because many workers no longer have direct supervision by professionals, it is more difficult to develop these soft skills. Increasingly, they work with minimal supervision and peer supports, and need greater technical and problem-solving skills and initiative.

Anecdotes that illustrate the challenges of this workforce shortage include:

> *Due to recent staff shortages, a mother of a consumer had to leave her job. The family is experiencing financial difficulties, and the mother does not have any other people to help provide support.*
>
> *A home care agency reported having to make difficult decisions when faced with limited staff. The agency is being forced to provide services to older adults who live alone instead of children who have family support in the home.*

If current trends persist, individuals will live alone and will have fewer children available to provide care. As these caregivers age beyond their caregiving capacities, formal living arrangements must be established to support their relatives with disabilities. The aging of our society, the increasing longevity of individuals with I/DD and growing waiting lists are stretching state service delivery systems well beyond their capacity to meet current and projected demands for residential, vocational and family support services for individuals with I/DD.

What are the most common jobs in the industry?

The most common jobs in the industry are **direct support professionals (DSPs), personal support workers and job coaches.** These professionals are the backbone of the field. They represent the core and vast majority of the workforce. They may work in a person's home, in day programs, schools or elsewhere in the community. DSPs and professional support workers aim to help individuals integrate into their communities and advocate for their needs and goals. The responsibilities are substantial, and the job is increasingly complex, requiring good communication and social skills. Typically, these jobs require a high school diploma or equivalent. In residential settings, with the need for 24-hour coverage, DSPs work a variety of shifts. In either community residences or day programs, they assist individuals with day-to-day tasks. They may prepare and provide meals. They may teach hygiene or academic skills. They may accompany individuals to the doctor, to the bank, or on leisure or recreation activities. They may guide activities in a day program. They are teachers and companions.

Job coaches, sometimes called employment specialists, provide employment supports or build "natural supports" in the workplace. Often, job coaches or employment specialists have responsibility for reaching out to employers to develop jobs. Job coaches may help individuals find employment, prepare for their jobs or offer on-site support to help individuals adjust to the routine of getting to and from work. Once the person becomes acclimated to his or her job and environment, job coaches spend less time on site but continue to evaluate, monitor and offer support when needed. A job coach may be a "circuit rider" and have responsibility for a number of people at different job sites. Sometimes job coaches work for the employers as their on-site agents. Job coaches earn more than DSPs and usually have a bachelor's or associate's degree. As the emphasis on employment for individuals with I/DD increases, the demand for job coaches is expected to grow.

Current workforce issues

The transformation of the field has brought with it the need to transform the workforce. The major workforce issues are discussed below.

Low pay rates in the face of increasingly complex responsibilities. Many DSPs work multiple jobs or extra shifts to earn extra income. One employer noted: "The DSPs who stay love what they do but can't live on the salary." Although pay has increased slightly in the past few years (2%), it is not likely to change very much in the next few years. In general, nonprofit organizations can only afford to pay DSPs more if they have endowments or if they raise dedicated funds from private sources. While reducing administrative costs is another option, this is not realistic for most agencies. In many states, DSP wages have stagnated over the last decade due to tighter Medicaid budgets and caps on rates.

High rates of staff turnover (or retention challenges). The DSP turnover rate can be as high as 50–70% within the first 12 to 18 months. Turnover is disruptive to agency operations and to relationships with the individuals with I/DD. It is also expensive, as agencies are constantly in recruitment, screening and training mode.

Need to expand labor pool. Many organizations struggle to find enough suitable candidates, and some are in constant recruitment mode. Non-profit organizations recruit through their websites, go to job fairs, have relationships with colleges, rely on word-of-mouth and sometimes give bonuses to existing staff for referrals. Some have internship arrangements with local colleges. The competition for labor will get even stiffer as the field competes for talent with elder care, home healthcare, and other healthcare and social service fields.

Lengthy hiring process. The screening and background checks required by states are time-consuming, often delaying the hiring process by four to eight weeks.

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9.A.

CCDDB 2017-2018 Meeting Schedule

Board Meetings
8:00AM except where noted
Brookens Administrative Building, Lyle Shields Room
1776 East Washington Street, Urbana, IL

September 20, 2017

October 25, 2017

~~November 15, 2017~~ cancelled

November 29, 2017 – Study Session, 5:30PM

December 13, 2017

January 24, 2018

February 21, 2018

March 21, 2018

April 25, 2018

May 23, 2018

June 27, 2018

This schedule is subject to change due to unforeseen circumstances.
Please call the CCMHB/CCDDB office to confirm all meetings.

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CCMHB 2017-2018 Meeting Schedule

First Wednesday after the third Monday of each month--5:30 p.m.
Brookens Administrative Center
Lyle Shields Room
1776 E. Washington St., Urbana, IL (unless noted otherwise)

September 20, 2017

September 27, 2017 – study session

October 18, 2017

October 25, 2017 – study session

November 15, 2017

November 29, 2017 – study session

~~***December 13, 2017 (tentative)***~~ ***cancelled***

January 17, 2018

January 24, 2018 – study session

February 21, 2018

February 28, 2018 – study session

March 21, 2018

March 28, 2018 – study session

April 18, 2018 – in John Dimit Conference Room

April 25, 2018 – study session

May 16, 2018 – study session

May 23, 2018

June 27, 2018

This schedule is subject to change due to unforeseen circumstances. Please call the CCMHB-CCDDB office to confirm all meetings.

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July 2018 to June 2019 Meeting Schedule with Subject and Allocation Timeline

The schedule provides the dates and subject matter of meetings of the Champaign County Developmental Disabilities Board through June 2019. 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; topics will be based on issues raised at meetings, brought by staff, or in conjunction with the Champaign County Mental Health Board. Regular meetings of the CCDDB are usually at 8AM; study sessions at 5:30PM. Included with meeting dates are tentative dates for steps in the funding allocation process for Program Year 2020 (July 1, 2019 – June 30, 2020) and deadlines related to current (PY2019) agency contracts.

07/18/18	**Regular Board Meeting** Election of Officers
08/24/18	*Agency PY2018 Fourth Quarter and Year End Reports Due*
09/19/18	**Regular Board Meeting**
10/17/18	**Regular Board Meeting** Draft Three Year Plan 2018-2020 with FY19 Objectives Release Draft Program Year 2020 Allocation Criteria
10/26/18	*Agency PY2019 First Quarter Reports Due*
10/31/18	*Agency Independent Audits Due*
11/14/18	**Regular Board Meeting**
11/28/18	**Study Session - tentative**
12/12/18	*Public Notice to be published on or before this date, giving at least 21-day notice of application period.*
12/19/18	**Regular Board Meeting** Approve Three Year Plan with One Year Objectives Allocation Decision Support – PY20 Allocation Criteria
01/04/19	*CCMHB/CCDDB Online System opens for Agency Registration and Applications for PY20 Funding.*
01/23/19	**Regular Board Meeting**
01/25/19	*Agency PY2019 Second Quarter Reports Due*
02/08/19	*Agency deadline for submission of applications for PY2020 funding. Online system will ~~not~~ accept forms after 4:30PM.*

02/20/19	**Regular Board Meeting** List of Requests for PY20 Funding
03/20/19	**Regular Board Meeting**
04/17/19	*Program summaries released to Board, copies posted online with the CCDDB April 24, 2019 Board meeting agenda*
04/24/19	**Regular Board Meeting** Program Summaries Review and Discussion
04/26/19	*Agency PY2019 Third Quarter Reports Due*
05/15/19	*Allocation recommendations released to Board, copies posted online with the CCDDB May 22, 2019 Board meeting agenda.*
05/22/19	**Regular Board Meeting** Allocation Decisions Authorize Contracts for PY2020
05/23/19-06/05/19	*Contract Negotiations*
06/19/19	**Regular Board Meeting** Approve FY2020 Draft Budget
06/27/19	*PY20 Contracts completed/First Payment Authorized*

9.B.

Ligas Family Advocate Program

ACRONYMS

ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
ASD	Autism Spectrum Disorders
CART	Clinical Administrative Review Team
CILA	Community Integrated Living Arrangement
CMS	Center for Medicaid & Medicare Services
DCFS	Department of Children and Family Services
DD	Developmental Disabilities
DDD	Division of Developmental Disabilities
DHS	Department of Human Services
DMH	Division of Mental Health
DPH	Department of Public Health
DRS	Division of Rehabilitation Services
DSCC	Division of Specialized Care for Children
DT	Developmental Training Day Program for adults
EI	Early Intervention (birth to 3)
HBS	Home Based Services
HFS	Department of Health Care and & Family Services (Public Aid)
HUD	Housing & Urban Development
ICAP	Inventory for Client and Agency Planning
ICF – DD	Intermediate Care Facility for Individuals with Developmental Disabilities
IDEA	Individual with Disabilities Education Act
IDPH	Illinois Department of Public Health
IEP	Individual Education Plan
ISBE	Illinois State Board of Education
ISC	Individual Service Coordination
ISP	Individual Support Plan
ISSA	Individual Service and Support Advocacy

OIG	Office of the Inspector General
PACKET	Information on paper going to Network Facilitator advocating your need for help
PAS	Pre-Admission Screening
PDD	Pervasive Developmental Disorder
POS	Purchase of Service funding method – fee for service
PUNS	Prioritization of Urgency of Need for Services (waiting list)
QA	Quality Assurance
QIDP	Qualified Intellectual Disabilities Professional
QSP	Qualified Support Professional
SEP	Supported Employment Program
SNAP	Supplemental Nutritional Assistance Program (food stamps)
SNT	Special Needs Trust
SODC	State Operated Developmental Center
SSA	Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
SST	Support Service Team
UCP	United Cerebral Palsy

Champaign County Mental Health Board

FY17 Revenues and Expenditures

Revenue		**FY 17 Final**		**Budget**	**% of Budget**
Property Tax Distributions	$	4,425,348.19	$	4,449,552.00	99.46%
From Developmental Disabilities Board	$	287,696.76	$	350,653.00	82.05%
Gifts & Donations	$	5,224.80	$	25,000.00	20.90%
Other Misc Revenue	$	135,668.72	$	500.00	>100%
TOTAL	**$**	**4,853,938.47**	**$**	**4,825,705.00**	**100.59%**

Expenditure		**FY 17 Final**		**Budget**	**% of Budget**
Personnel	$	449,220.17	$	509,225.00	88.22%
Commodities	$	6,262.83	$	17,922.00	34.94%
Contributions & Grants	$	3,593,417.51	$	3,733,794.00	96.24%
Professional Fees	$	333,523.64	$	368,213.00	90.58%
Transfer to CILA Fund	$	50,000.00	$	50,000.00	100.00%
Other Services	$	106,592.57	$	146,551.00	72.73%
TOTAL	**$**	**4,539,016.72**	**$**	**4,825,705.00**	**94.06%**

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Champaign County Developmental Disability Board

FY17 Revenues and Expenditures

Revenue		**FY 17 Final**		**Budget**	**% of Budget**
Property Tax Distributions	$	3,692,099.61	$	3,712,310.00	99.46%
From Mental Health Board	$	7,288.07	$	-	-
Other Misc Revenue	$	25,315.23	$	300.00	>100%
TOTAL	**$**	**3,724,702.91**	**$**	**3,712,610.00**	**100.33%**

Expenditure		**FY 17 Final**		**Budget**	**% of Budget**
Contributions & Grants	$	3,262,938.45	$	3,311,957.00	98.52%
Professional Fees	$	324,511.00	$	350,653.00	92.54%
Transfer to CILA Fund	$	50,000.00	$	50,000.00	100.00%
TOTAL	**$**	**3,637,449.45**	**$**	**3,712,610.00**	**97.98%**

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disABILITY Resource Expo: Reaching Out For Answers
Board Report
March, 2018

11th disABILITY Resource Expo – Coming Saturday, April 7, 2018: Next Steering Committee-March 20

Exhibitors: Exhibitor interest has been overwhelming this year, with a total of 105 exhibitors registered. Registration was closed approximately a week prior to our deadline due to reaching maximum exhibitor capacity. In fact, there are currently six additional organizations on a wait list, with little hope of being able to accommodate any additional exhibitors. Mapping an event of this size is very challenging, so Jim is working to ensure adequate space and location for each exhibitor. Approximately 25 percent of the exhibitors are for-profit.

This year's scavenger hunt, featuring local star athletes is coming together nicely, with assistance from our friends at DRES. This game is the impetus for receiving feedback (evaluations) from our visitors, which aides in planning for future Expos.

Marketing/Sponsorship: Sponsorship response this year is also at an all-time high. Cash donations received to date are $10,320. Additional in-kind support has an estimated value of $12,334. Additional funds are continuing to come in by way of booth fees and other sponsorships.

The annual Expo Resource Book is in process of development. These books contain contact information for all of our exhibitors, and are used throughout the coming year.

Promotion of the Expo is well underway. Large moving ads are circulating the community by way of C-U MTD (15 buses), and vehicle window clings. Radio advertising is scheduled to begin 2-3 weeks prior to the Expo, and several radio and TV interviews will occur the week of the event. Press releases will be sent out at various intervals to encourage media coverage of the event.

Our newsletter blurb has been appearing in a number of agencies newsletters. Thank you to those agencies who have helped get the word out in this way. We will begin doing email blitz's in the coming week.

Posters and brochures are beginning to be distributed throughout the county, and 15,000 school flyers will be appearing in backpacks prior to Spring Break. Quality Med Transport will be setting out our 200 yard signs on March 24.

Our Social media presence has increased, thanks to Allison Boot. We encourage everyone to Like and Share our Facebook and Twitter Expo Event Page to help us get the word out.

We have secured EMT services as a sponsorship for the event through PRO Ambulance, who will be on site for the day.

Entertainment/Accessibility: Entertainment will be occurring on two different stages at the Expo. Diane Ducey and Josh Laskowski from S.J. Broadcasting will be our wonderful MC's again this year. Debra Myers Sounds of Music Studio in collaboration with Penguin Project will perform, as will instrumentalist, Kevin Elliott, and classical pianist/composer, Charles Joseph Smith. We will also have prize drawings and an AMTRYKE presentation.

Sign language interpreters and a Spanish interpreter, personal assistants, equipment needs, and other accessibility accommodations have been secured for the Expo. The Resource Book will be available in alternative formats through downloading program information onto flash drives and onto smart phones. We will be offering this service to visitors on the spot at the Accessibility Booth.

Children's Activity Room: We have received our annual donation from Flaghouse, a mail order company that has partnered with us for many years. They have, once again, sent well over $1,000 worth of adaptable games and toys for the Children's Activity Room. Along with Flaghouse, First Federal Savings Bank is a co-sponsor of this area of the Expo through their cash sponsorship.

Volunteers: Shandra Summerfield and Becca Obuchowski are identifying and registering the large number of volunteers we use each year to help us cover various tasks. Several U. of I. student groups tend to volunteer each year as service projects. Parkland College's Occupational Therapy Program will again be providing student volunteers to help in the Children's Activity Room.

Website: The Expos new, fully accessible website is up and running. It spotlights an expanded search feature for the Expo Resource Book, as well as featuring greater ADA accessibility for our viewers. Jim and Pat Mayer, and Chris Hamb with Chrispmedia have done an exemplary job with the new website! Several of our new exhibitors have come as a result of seeing us on the web. There are approximately 140 different organizations listed. It is hoped that many participating local organizations will consider adding a link on their websites, directing people to the Expo website/directory.

Respectfully submitted
Barb Bressner & Jim Mayer
Consultants