



This joint study session will be held in person, with remote access. Members of the public may attend in person or watch the meeting live through this link. The recording will be posted later among archives at <https://www.co.champaign.il.us/mhddb/MeetingInfo.php>

***Champaign County Developmental Disabilities Board (CCDDDB) and
Champaign County Mental Health Board (CCMHB)
Joint Study Session Agenda***

August 16, 2023 5:45PM

*In-Person at the Shields-Carter Room of Brookens Administrative Building
With Public Access in Person or through Zoom ID 813 9367 5682*

- I. Call to order**
- II. Roll call**
- III. Approval of Agenda***
- IV. Citizen Input/Public Participation** *All are welcome to attend the Board’s meeting to observe and to offer thoughts during this time. The Chairs may limit public participation to 5 minutes per person and/or 20 minutes total.*
- V. Chairpersons’ Comments** – Ms. Vicki Niswander and Dr. Jon Paul Youakim
- VI. Study Session - “Preferences of Champaign County Residents with I/DD”**
To assist the boards in planning and prioritizing for the next funding cycle, advocates will lead the discussion.
*Participants from Community Choices’ Human Rights & Advocacy Group:
Eric Beasley, Jennifer Buoy, Jasmine Hague, and Tobie Wood
Representing Advocates at DSC (new group name TBD):
Darrin Chatman, Kentrell Graham, and Danielle Kolakowski
*Included in the packet to support this discussion and subsequent planning, is a memorandum collecting input from people with I/DD and on their behalf.**
- VII. Agency Input** - *The Chairs reserve the authority to limit individual agency representative participation to 5 minutes and/or total time to 20 minutes.*
- VIII. Board Announcements and Input**
- IX. Adjournment**

** Board action is requested.*

For accessible documents or assistance with any portion of this packet, please [contact us](mailto:leon@ccmhb.org) (leon@ccmhb.org).



BRIEFING MEMORANDUM

DATE: August 16, 2023
TO: Members, Champaign County Developmental Disabilities Board (CCDDDB) and Champaign County Mental Health Board (CCMHB)
FROM: Lynn Canfield, Executive Director, Kim Bowdry, Associate Director for I/DD
SUBJECT: Support and Service Preferences of Champaign County Residents with I/DD

Purpose:

This memorandum presents data and public input related to the preferences and unmet needs of Champaign County residents who have intellectual and developmental disabilities (I/DD). The information will help shape the 2024 objectives of the CCDDDB and CCMHB Three Year Plans and the PY2025 Allocation Priorities for each Board's fund and for their shared I/DD Special Initiatives Fund.

- Standardized data from the State of Illinois Department of Human Services - Division of Developmental Disabilities (IDHS-DDD).
- Additional preference assessment data reported optionally by Champaign County residents who are enrolled with the state's database.
- Review of relevant 2021 and 2022 survey results.
- Public input received by other organizations and shared with us.
- Review of PY23 (partial) and PY22 (full) data reported by funded I/DD programs.
- Questions shared with self-advocates for August 16, 2023 study session discussion.
- A self-advocate's recommended questions for future surveys.

Standardized Urgency of Needs Data, 2023:

Through its network of Independent Service Coordination (ISC) Units, the State of Illinois Department of Human Services Division of Developmental Disabilities (IDHS-DDD) collects data on the unmet service and support needs of residents who qualify for state

funded I/DD services. This Prioritization of Urgency of Needs for Services (PUNS) database was not initially a waiting list for services but serves as one now.

The July 10, 2023 PUNS report, sorted by County and Selection Data, indicates that a total of 62,172 Illinois residents have enrolled in PUNs. Of these, 1,060, or **1.7%**, are Champaign County residents. These totals include people waiting for services, those previously selected and currently receiving services, and those who have been closed or are deceased. Illinois' estimated 2023 population is 12.48 million, with 207,299, or **1.66%**, in Champaign County. There is not likely to be a higher incidence of qualifying I/DD here, suggesting that the ISC Units collect and report data in a consistent manner.

Attached are two pages from that July 10 PUNS report, with details on Champaign County residents' choices. Reports summarizing by County and Township, by County and Selection Detail, or by Zip Code can be requested from DHS.DDD.PUNS@illinois.gov. Some information is posted on the [Illinois Department of Human Services website](#).

In prior years, we have summarized local unmet needs by focusing on the most frequently identified PUNS categories. The pattern has held for many years and continues:

- Of 365 Supports Needed, the most frequently identified are **Personal Support**, Behavioral Supports, Speech Therapy, Other Individual Supports, Occupational Therapy, Assistive Technology, Physical Therapy, 24-hour Respite, Adaptations to Home or Vehicle, Intermittent Nursing Services in the Home (in rank order).
The total of 365 is an increase of 34 over last year.
- 355 people identified the need for **Transportation** Support.
This is an increase of 42 over last year.
- 269 people identified the need for **Vocational** or Other Structured Activities, preferring (in order) Support to work in the community, Support to engage in work/activities in a disability setting, Support to work at home, and Attendance at activity center for seniors.
The total of 269 is an increase of 23 over last year.
- 74 people are waiting for Out-of-home **Residential Services** with less than 24-hour supports, and 49 are seeking 24-hour residential.
These are increases of 4 and 5, respectively, over last year.

Higher numbers of enrolled individuals and supports sought may relate to increased prevalence of I/DD nationally, as reported by the Centers for Disease Control and Prevention National Center for Health Statistics. DD diagnoses among children increased to 8.56% in 2021, from 7.4% in 2019. From [Products - Data Briefs - Number 473 - July 2023 \(cdc.gov\)](#).

With low availability of CILAs and low interest in congregate care, many selected from PUNS are likely (as many have before) to choose Home Based Supports even if they had indicated a need for 24-hour residential options. For those requiring this level of support, especially if they have behavioral support needs, some may choose Intermediate Care Facilities (ICFsDD).

The State has issued letters of PUNS selection to 36 Champaign County residents aged 18 and older.

At the end of PY22, of those enrolled in PUNS and waiting for state-funded services, 140 were receiving CCDDDB-funded services, and 161 more were waiting and known to the ISC. Given that the PUNS list and DDB client lists are fluid and the potential for human error, the numbers may not always be an exact match. In PY22, CCDDDB funded services included: self-advocacy; family support network; linkage and referral; person centered planning; transition to adult services; preference assessment; service coordination; conflict free case management; physical and behavioral health care support; community living; connection to community; day programming; customized employment; community employment; intensive direct support; specific assistance (camp vouchers, equipment, etc.); transportation; and training and matching of personal support workers. CCMHB funded I/DD programs focus on very young children, who may not be included in the PUNS data. [Detailed descriptions of services offered by all currently funded programs](#) are available.

Preferences of Champaign County Residents, 2023:

The PUNS categories correspond to services offered through IDHS-DDD, and use of these categories assists their planning and budget processes. Standard across the state, they are helpful for comparison, but they do not address **preferences and attitudes residents have about services**.

To assist the prioritization of CCDDDB and CCMHB DD funding, the Champaign County Regional Planning Commission ISC Unit prepares an annual report, aggregating responses to additional questions asked of people who enroll in or update PUNS during the contract year. In PY2023, they implemented a survey they had redesigned with the Evaluation Capacity Building Team, compiling the responses of **268** participants. At their annual or initial PUNS reviews, all were offered this survey, and some declined to participate.

Demographic data of respondents can be compared with [general population data for Champaign County as of July 2022](#).

- 41% of respondents are female, compared with 50% of general population. (Two individuals selected the “gender non-conforming” option.)
- 68% of respondents are white, 22% Black/African American, 6% biracial or multi-racial, and 4% Asian/Asian American.
71% of general population are white, 15% Black/African American, 3% two or more races, and 11% Asian.
- 7% of respondents *and* general population are Hispanic or Latino/Latina/x. (Two individuals selected Middle Eastern/North African.)
- 34% of respondents are under 18, 33% 18-23, 12% 23-30, 6% 30-40, and 15% over 40.

In our County's general population, 19% are under 18.

- 85% of respondents have annual income below \$19k, 2% between 19 and \$30K. 15% of Champaign County's population are 'in poverty' while median household income is \$57k.

The respondent group's demographic characteristics are similar to those of the general population, other than gender and income, which are not surprising. I/DD diagnosis is more prevalent in males. People with I/DD have very low income, which has its own negative impacts, including increased need for supports. While it is unfortunate that 15% of respondents are over 40 and have no state funding, the large share of respondents under 23 may indicate thoughtful preparation for adult services.

Highlights from the PY2023 report are below. Given that respondents may not be the same individuals each year, we cannot fully account for apparent changes from PY2022.

- 45% were completed by the individual, 55% by a parent or guardian.
- 33% had been on the PUNS list longer than 5 years, 25% 3-5 years, 20% 1-3 years, and 22% less than 1 year.
- 81% were in the PUNS category "Seeking Services (Need services within one year)," and 19% "Planning for Services (Do not need services for at least one year)." *Urgency of need may have increased, as these were 76% and 24% in PY22.*
- 83% of respondents lived at home with family, 8% in their own home with occasional support, 7% in their own home with no support, and 3% in a supportive living facility.
- 67% prefer to live with family, 36% alone, 19% with roommates, 16% preferred various types of CILA, and less than 1% selected congregate care options. *PY22 results similar.*
- Ranked in order, preferred home locations were Champaign, Urbana, Mahomet, outside of Champaign County, within Champaign County, outside of Illinois, Savoy, Rantoul, St. Joseph, Tolono and Penfield (each selected by 4 people), Thomasboro, Sadorus, and Fisher (2 each), and Dewey, Seymour, and Sidney (1 each).
- 57% were interested in volunteering, 58% in competitive employment. *PY22 results were higher, at 72% and 67%.*
- 28% were currently working/volunteering in the community, *a drop from 41% in PY22.*
- Of the 250 people who indicated specific desired work/volunteer opportunities, the most frequently selected options were Other, followed by Retail and Working with Animals (selected 54 times each), Restaurant/Food Services (49), Education/Childcare (32), Outdoors and Public Services (25 each), the Arts (20), Recreation (16), Technology Services and Service Industry (14 each), Construction and Factory (10 each), Office (9), Writer (7), Trade Work (5), Agriculture (4), Health Services and Automotive (3 each).
- 64% were not active in a community group or organization. *Similar to 62% in PY22.*

- Respondents would like to participate in, from most to least frequently selected option, CU Special Recreation, groups and/or clubs, health and wellness, church, Special Olympics, YMCA, gardening, Best Buddies, continuing education, and other.
- From the most to the least frequently selected option, respondents enjoy eating out, recreation/sports, parks, zoos/aquariums, going to the movies, swimming, shopping, festivals, theatre/arts/museums, concerts, sporting events, and other.
- 5% of respondents would like to participate in leisure activities not available to them.
- People desired support in the areas of (ranked) financial, medical, independent/daily living, transportation, socialization, competitive employment services, behavioral therapy/counseling, community day services, respite, physical or occupational therapy, assistive technology, and other.
- Only 21 (or 8%) of all 268 respondents report being on waiting lists for these services. Of those 21 people, 13 or 62% indicated being on the waiting list for longer than a year.
- 57% of respondents were not receiving case management services. Of those receiving them, the provider was, from most frequent to least, DSC (77), CCRPC ISC (45), Community Choices (26), Rosecrance (3), and PACE (1).
- The assessment concludes by asking how comfortable the person is navigating the DD system and advocating for themselves, using a scale of 1 to 10.
- 5% selected 10/10, for 'very comfortable', fewer than 3% indicated 9/10, fewer than 8% chose 8/10, 6% chose 7/10, and 11% chose 6/10.
- The most frequent selection was in the middle at 5/10, or 'somewhat comfortable,' chosen by 27% of respondents.
- 11% chose 4/10, 14% 3/10, fewer than 9% chose 2/10, and 7% 1/10, 'not comfortable.'
- While most chose the middle 5/10 or near, as they had in PY22, more people indicated lower comfort levels than higher.

More people need state-funded services within one year and have waited longer than five. Most respondents live with family and prefer it. Though physical and recreational activities remain popular, people appear less interested and less engaged in community employment, volunteer opportunities, and community organizations than they were last year. If we make anything of that, it may mirror trends in the general population.

CCDDB/CCMHB funded programs may fill gaps for people waiting for state-funding and can be used more flexibly, developing plans based on people's interests, matching people with their preferred supports, and helping them build confidence in advocating for themselves.

Surveys of Champaign County Residents, 2021 and 2022:

In 2021, CCDDB and CCMHB staff completed a [community needs assessment report](#) which included survey results, focus group highlights, and other qualitative data from people who would be eligible for services funded by one or both Boards. Because these target

populations are small and not always interested in surveys, and to learn more from people who have I/DD, staff and an intern developed and conducted a revised survey during 2022.

Highlights of the Summer 2022 **I/DD self-advocates' satisfaction survey**:

- 62.5% of respondents felt good about current supports and services, 25% very good.
- Additional support for cleaning, exercise, MTD, and employment were desired.
- Attitudes toward staff were positive.
- Also of interest were opportunities for travel, sports events, concerts, zoos, museums, antique stores, and to join a bowling league.
- Asking for new supports was hard for 19% of respondents and very hard for 6%, and 25% did not always feel heard when asking for something new.

The interest in travel, sports, and other activities available in Champaign County echoes results of the CCRPC's current and prior years' preference assessments.

Public Input through Other Organizations, 2023:

For additional information about what people with I/DD might want or need, we reached out to The Autism Program at UIUC, CU Autism Network, CU Able, PACE, and the offices of State Senators Chapin Rose and Paul Faraci, who have demonstrated a commitment to this population and might share what they have learned from their constituents in their efforts.

Annie Bruno, LCSW and Consulting Specialist with The Autism Program responded:

“Thank you for seeking feedback from community members / agency staff on this question. Here are some thoughts that come to mind on where county funding could go -

- Education/training/support for gender diversity within the neurodivergent and disabled community
- Outreach & support for minority families and communities - in seeking a diagnosis, pursuing services, getting referrals, etc.
- Skilled, affordable, accessible counseling (talk therapy) for those with mental health & developmental disability.”

At the time of this writing, the others have not responded.

Utilization of Funded Programs in Program Year 2023:

Understanding how people have used the services available to them through CCDDDB and CCMHB funding offers clues on what is working and what could be improved.

Funded agencies submitted the Third Quarter reports and information featured on pages 27 -59 of the [CCDDB's May 17, 2023 meeting packet](#). Many reports include comments highlighting successes such as advocacy group growth (pages 32, 35) and individuals' successes (page 33, 37, 41, 43, 44). We hope this reflects a trend toward 'client choice' directing the formal supports. Similar detail is available in First and Second Quarter reports presented to the CCDDB in their [November 16, 2022 board meeting packet](#) and [February 22, 2023 board meeting packet](#) respectively.

Service claims are reported in broad categories, to understand when services are being delivered with the person present or without them, on their behalf, and to measure **community inclusion** ("off site") against time spent in agency offices or sites. Using data from the packets linked above, we find that, of the greater than 56,474 hours of service provided from July 1, 2022 through March 31, 2023:

- 60% of the total staff hours were spent **with the person**. Of those, 25,707.5 were **with the person off-site**, and 8,152 with the person at an agency location (due to two missing reports, the second value is undercounted by about 190).
- Of the other 40% of total staff hours, 3,792.25 were **on behalf of the person** off-site, and 18,822.25 at an agency.

PY23 and PY22 are comparable because most programs were continued, with small increases in capacity and no change in categories to be reported or methods of reporting. Although data for the Fourth Quarter and subsequent year-end analysis are not available, there appears to be a dramatic **increase in staff time spent with people in community settings** (any setting other than an agency site). The increase may be attributable to decreased COVID mitigation.

Utilization of Funded Programs in Program Year 2022:

Pages 88 -120 of the [CCDDB's September 21, 2022 Board Meeting Packet](#) contain similar reports and comments for Fourth Quarter PY22, along with claims data for the full year. From these, we find that, of 47,107.75 staff hours tracked for PY2022:

- 58% of total staff hours were spent **with the person**. Of those, 18,882 were **with the person off-site**, and 8,639 with the person at an agency location.
- Of the other 42% of total staff hours, 2,014.5 were **on behalf of the person** off-site, and 11,981.5 at an agency. (More staff time spent in agency offices may have made them more available to the people they served than if working off-site.)

Using service claims data reported during PY2022, Associate Director Bowdry analyzed utilization trends. The full report is available on pages 8-23 of the [CCDDB's March 22, 2023 meeting packet](#). Details highlight how people have used the available options.

- Service claims data were reported on **897 young children** (typically under the age of 3 but can include some up to 5) and **504 adults and older children**.
- 5 of the very young children used two programs, 2 children with slight overlap.
- There was no overlap of adults/older children in agencies with similar programs.
- Of adults and older children, **26% had state waiver funding**, while 74% had CCDDDB. Children in CCMHB DD programs did not have state waiver funding.
- Participants in CCDDDB funded programs also worked with the CCRPC ISC for consistency with the State’s planning requirements, to prepare for state awards.
- 352 people were served by **one agency only**, 150 by two, and 2 by three agencies.
- 307 people participated in **one program only**, 94 in two, 50 in three, 26 in four, 17 in five, 9 in six, and 1 in seven programs.
- Both **people served by three agencies** used: CCRPC Decision Support PCP, Community Choices, and DSC; one of them was closed from programs at Community Choices and DSC during the program year.

People who used more than one funded program were enrolled in CCRPC Decision Support PCP and DSC Service Coordination plus combinations of DSC programs. All had CCDDDB funding only, and 1 transitioned to state funding in the 4th quarter.

Questions Posed to Self-Advocates:

For discussion at the August 16, 2023 joint study session of the CCDDDB and CCMHB, board members developed questions for self-advocates to consider:

1. What do you recommend we spend the money on and how?
2. What would make your daily life easier or better?
3. Are there supports or services that you have now that you would like to keep?
4. When you are interested in finding a new opportunity or resource, what do you do?

Questions for Future Surveys:

Jennifer Buoy is a self-advocate with experience serving on advisory boards and committees. To build on her suggestion that a universal “client” survey be designed and implemented, Ms. Buoy met with us to offer specific input we should seek from participants in funded programs. This resulted in the following sets of questions, which she later reviewed and amended.

1. What services have you received in the last year?
Then ask questions that relate to the funded program. For employment (as an example):

2. Are the job coaches helpful when you're trying to find a job that is a good fit for you?
3. How long did it take you and your job coach to find a job that you liked and fit your capabilities, job requirements?
4. Are you paid by the hour or paid by the 'piece' (that is, the piece of work completed)?
5. How often do staff meet with you?
6. How often does the team meet for oversight of the service plan?
7. If you had a case closed with DRS or DHS, did you have support for the next steps, if you wanted that kind of support?
8. Are your supervisors and coworkers a good fit for you?
9. Did you work the amount of hours and at times that you wanted?
10. Did you meet your support staff outside of work hours?
11. Did you have any trouble taking time off when you needed to?
12. How do you plan for time off?
13. How many hours a week did you work?
14. Did income from work cause you to lose any benefits?
15. Are you happy with your current job and support services?

For housing, as another program-specific example:

2. Is your housing affordable, whether due to a voucher, subsidy, or other?
3. If it isn't affordable for you, what is specifically not affordable? Could include utilities, internet, phone, food costs, just to name a few.
4. Do you live with other people?
5. Do you have a choice in who else lives with you?
6. Are there efforts to improve security where you live? (cameras outside, e.g.)
7. Are there maintenance concerns where you live? (could include sidewalks, snow removal, safe conditions to and at the nearest bus stop)
8. If you were to have an emergency medical need, would you be able to get help?
9. Do you buy your own essentials, or are they provided?
10. Do you have a choice in what you eat and the ability to meet your dietary needs?
11. Do you have support for shopping, if you need and want that support?
12. Does your housing program purchase food for you, and if so, is it good quality?
13. Do you have enough food?
14. Do you have a choice in food?
15. Do you have opportunities to exercise and
16. to things you enjoy doing outside of work and home?

General:

- Transportation should also be available to Springfield to attend rallies and Speak Out events.
- Disability-friendly businesses should be added each year.



Division of Developmental Disabilities
Prioritization of Urgency of Needs for Services (PUNS)
Summary By County and Selection Detail

July 10, 2023

County: Champaign

Reason for PUNS or PUNS Update	1,060
New	64
Annual Update	269
Change of Category (Seeking Service or Planning for Services)	8
Change of Service Needs (more or less) - unchanged category (Seeking Service or Planning for Services)	16
Person is fully served or is not requesting any supports within the next five (5) years	322
Moved to another state, close PUNS	35
Person withdraws, close PUNS	37
Deceased	21
Individual Stayed in ICF/DD	1
Individual Moved to ICF/DD	2
Individual Determined Clinically Ineligible	12
Unable to locate	71
Submitted in error	1
Other, supports still needed	1
Other, close PUNS	200
CHANGE OF CATEGORY (Seeking Service or Planning for Services)	408
PLANNING FOR SERVICES	100
EXISTING SUPPORTS AND SERVICES	368
Respite Supports (24 Hour)	10
Respite Supports (<24 hour)	24
Behavioral Supports (includes behavioral intervention, therapy and counseling)	138
Physical Therapy	57
Occupational Therapy	106
Speech Therapy	145
Education	191
Assistive Technology	53
Homemaker/Chore Services	2
Adaptions to Home or Vehicle	6
Personal Support under a Home-Based Program, Which Could Be Funded By Developmental Disabilities, Division of Rehabilitation Services or Department on Aging (can include habilitation, personal care, respite, retirement supports, budgeting, etc.)	24
Medical Equipment/Supplies	49
Nursing Services in the Home, Provided Intermittently	8
Other Individual Supports	187
TRANSPORTATION	339
Transportation (include trip/mileage reimbursement)	105
Other Transportation Service	228
Senior Adult Day Services	1
Developmental Training	56
"Regular Work"/Sheltered Employment	52
Supported Employment	48
Vocational and Educational Programs Funded By the Division of Rehabilitation Services	67
Other Day Supports (e.g. volunteering, community experience)	32
RESIDENTIAL SUPPORTS	66
Community Integrated Living Arrangement (CILA)/Family	2
Community Integrated Living Arrangement (CILA)/Intermittent	4
Community Integrated Living Arrangement (CILA)/Host Family	1
Community Integrated Living Arrangement (CILA)/24 Hour	32
Intermediate Care Facilities for People with Developmental Disabilities (ICF/DD) 17 or More People	3
Skilled Nursing Facility/Pediatrics (SNF/PED)	5
Supported Living Arrangement	1



Division of Developmental Disabilities
Prioritization of Urgency of Needs for Services (PUNS)
Summary By County and Selection Detail

July 10, 2023

Shelter Care/Board Home	1
Nusing Home	1
Children's Residential Services	5
Child Care Institutions (Including Residential Schools)	5
Other Residential Support (including homeless shelters)	8
SUPPORTS NEEDED	365
Personal Support (includes habilitation, personal care and intermittent respite services)	319
Respite Supports (24 hours or greater)	32
Behavioral Supports (includes behavioral intervention, therapy and counseling)	143
Physical Therapy	63
Occupational Therapy	92
Speech Therapy	115
Assistive Technology	63
Adaptations to Home or Vehicle	24
Nursing Services in the Home, Provided Intermittently	10
Other Individual Supports	97
TRANSPORTATION NEEDED	355
Transportation (include trip/mileage reimbursement)	314
Other Transportation Service	335
VOCATIONAL OR OTHER STRUCTURED ACTIVITIES	269
Support to work at home (e.g., self employment or earning at home)	12
Support to work in the community	229
Support to engage in work/activities in a disability setting	149
Attendance at activity center for seniors	3
RESIDENTIAL SUPPORTS NEEDED	113
Out-of-home residential services with less than 24-hour supports	74
Out-of-home residential services with 24-hour supports	49
Total PUNS:	62,172