Minutes – CAC Staff Joint meeting Wednesday October 18,2017

Attending: CAC Mambers, Kathy Adams, Rachel Dyer, Gail Fanjoy, Moriah Geer, Brian Harnish, Dave Lawrence, Jon McGovern, Staci Converse, Kile Pelletier, Maryann Preble, Kate Quinn Finlay, Carrie Woodcock

CCIDS Staff: Alan Cobo-Lewis, Susan Russell, Bonnie Robinson, Angie Schickle, Jackie Wilson, Jennifer Maeverde, Alan Kurtz, Linda Labas, Marnie Bragdon-Morneault, Janet May, Ann Zielinski

Unable to Attend: Mark Kavanaugh, Tracie Flagg-Tynes, Liz Depoy, Stephen Gilson

Maryann Preble opened the meeting by welcoming everyone. The results of the election were announced: Kathy Adams and Maryann Preble were re-appointed to a new term, and new members, Brian Harnish and Moriah Geer joined. Maryann Preble and Kile Pellatier were elected Co-Chairs.

Bonnie Robinson presented the results of the survey conducted at the SUFU regional conference. (see Appendix A). A discussion followed. Several people asked for copies of the survey and results.

Gail Fanjoy and Janet May led a discussion on Community Engagement.

Gail opened the discussion by noting that transportation, spirituality, housing, employment were all disability issues, but they were also community issues. Issues that a community needs to address. The discussion was wide ranging and lively. Points mentioned included:

* What is CCIDS’s role around these issues?
* Maine Health Access Foundation Groups including the Rise Piscataquis are working to help
* Doctors in some areas are now asking patients about food insecurities and connecting them with help
* Community Action programs – Aging in Place, Thriving in Place
* Building capacity at local level – AARP and others
* Rachel Dyer mentioned the Advocacy Day in Augusta. While it was helpful for self-advocates to see and meet the legislators, it is a busy day. The suggestion was made to hold something similar with local groups
* SUFU of Lincoln - asking about groups and what’s happening. They hoped for the National Monument and saw that as connected to more jobs.
* The discussion shifted to day programs and the pro and cons. One program is working the land trusts to evaluate the trails for accessibility. While some self-advocates enjoyed this, others did not. Kile stated the one of the problems with day programs is that there is no freedom. The daily schedule is dictated by the provider or sometimes by a majority vote. No dissention or alternatives are encouraged.
* Gail said that building caring communities would help mitigate the system of paid providers. Communities meet your needs better, people who give and take. With labels throughout the system, you are at that systems mercy. Having people you know and people who know you, the community is better off. Some paid support will be always needed but minimizing it is the goal.
* Kate mentioned models for group transportation, trusted people who will give rides to meetings.
* Gail agreed that while there are those people out there the problem is how to connect.

Alan Cobo-Lewis wrapped up the discussion with a summary of the themes about which the Center could be involved.

* General lack of self-direction
* Spending time in day programs but not being employed or under employed
* Trapped by the system – lack of jobs means lack of money which means lack of choices
* Day programs are the system. There is a disincentive for them help client find employment. Their reimbursement structure is by how many clients they serve. More clients working = less clients in the program = less revenue.
* The Center can do something about education to give day programs incentive to help people find employment. Work to change the reimbursement structure.
* Stacie confirmed that Maine has an “Alpha Waiver” so self-advocates can hire their own staff. It would be interesting to see the out comes from this model from other states.
* Janet mentioned that most parents see the day programs as an extension of school thinking it is a safe place.
* Carrie Woodcock weighed in that we have to start earlier to teach parents and children to speak up for themselves.

In preparation for the group discussions, Alan Cobo-Lewis reviewed the Core Functions

***Four Core Functions*** that Every UCEDD Must Engage In  
From DD Act at [42 US Code 15063(a)(2)](https://www.law.cornell.edu/uscode/text/42/15063)  
(Each UCEDD must engage in all four core functions.)

* Interdisciplinary pre-service preparation and continuing education of students
* Community services, including training, technical assistance, and/or demonstration and model activities
* Research
* Dissemination of information

Potential ***Areas of Emphasis*** UCEDDs Must Select from

From DD Act at [42 US Code 15002(2)](https://www.law.cornell.edu/uscode/text/42/15002)  
(Higher-scoring applications tend to emphasize fewer areas.)

* Quality assurance
* Education and early intervention
* Child care
* Health
* Employment
* Housing
* Transportation
* Recreation
* Other services available or offered to individuals in a community, including formal and informal community support, that affect their quality of life

Projected measurable goals for ***one or more area(s) of emphasis*** for ***each core function***From DD Act at [42 US Code 15064(3)](https://www.law.cornell.edu/uscode/text/42/15064)

* Based on data-driven strategic planning
* Developed in collaboration with CAC
* Consistent with, and to the extent feasible, complement and further
* Goals in Maine DD Council State Plan
* Goals of Disability Rights Maine
* Will be reviewed and revised annually, as necessary, to address emerging trends and needs
* Will be implemented in a manner consistent with objectives of DD Act

Feedback on Prioritizing Areas of Emphasis from CAC’s 7/7/2017 Meeting

* Based on priorities and CCIDS capacity, we’ll emphasize the following areas:
* Education and early intervention
* Health
* Child care (including social emotional development and trauma-informed care)
* Employment, especially in transition to adulthood and including family expectations
* On the cusp, because it’s important, but unclear to what extent CCIDS has capacity:
* Transportation. (CCIDS director will meet with other UMaine faculty with expertise in this area to see to what extent their research agenda over next 5 years may support this potential areas of emphasis for individuals with developmental disabilities.

The meeting split into four groups for two rounds of feedback and comments.

Break for lunch reconvening at 1:00

At 1:00 Dr. Kody Varahramyan, Vice President for Research and Dean of the Graduate School joined the meeting via Zoom video. Short introductions and getting to know Dr. Varahramyan, followed by the third round of group feedback and comments, now including a fifth group.

Summaries of the group notes are in Appendix B.

At 1:50 the everyone reconvened, Dr. Varahramyan signed off and Alan Cobo-Lewis did a short summary of the next steps.

* Review of the group notes by CCIDS staff, and how CCIDS can address some of these issues.
* A follow up meeting with the CAC and staff will be arranged in mid-winter. Most likely via video conferencing to eliminate travel.

Evaluations and other paperwork were passed out.

Maryann adjourned the meeting.

# Appendix A

Structured Conversations with   
Speaking Up for Us to Inform   
CCIDS’ 2018-2023 Strategic Plan  
  
A Summary Report

Prepared by

Sandra Horne, M.A., M.A.

Bonnie Robinson, M.Ed.

Surveys conducted during the 2017 SUFU Annual Statewide Conference

The SUFU Annual Statewide Conference was held at Sugarloaf in September. An announcement was made that CCIDS would like to ask attendees some questions to gather information for our strategic plan and if anyone would like to volunteer to answer them to let us know.

By the Numbers…

**Interviews**

21 over two days

**Types of Questions**

31 close-ended

10 open-ended

**Conversation Length**

15 to 30 minutes

This was a very small sample size from a group of Self-Advocates attending their state-wide conference.

Over the course of the two-day conference there were:

1. 21 individuals volunteer to do our survey
2. There were a total of 31 close-ended (multiple choice or checkboxes) questions and 10 open-ended ones.
3. Each survey took between 15 and 30 minutes to complete

Key Results

The sample was diverse in:

* gender,
* geographic distribution, and
* age

Gender Identity:

* Female - 10 (47.6%
* Male – 11 (52.4%)
* Age Range: 22 to 59 years

Participants by County

* Androscoggin (2) 9.5%
* Aroostook (4) 19.1%
* Cumberland (1) 4.8%
* Oxford (2) 9.5%
* Penobscot (8) 38.1%
* Washington (2) 9.5%
* York (2) 9.5%

Guardianship

* Of the 21 people 8 reported they were their own guardians
* 1 person had a guardian for some things
* And 12 reported they had a guardian for everything

Satisfaction with Medical Care

* Hard time finding a doctor?
* Yes (3) 14.3%
* No (18) 85.7%
* Travel time to doctor’s office?
* Under 30 minutes (19) 90.5%
* 30 minutes to 1 hour (2) 9.5%
* Do you think the doctor listens and understands you and your needs?
* Yes (21) 100%

Question #20: What do you do during the day?   
(Check all that apply)

* Half of the respondents reported having a job where they worked part-time
* 6 people were looking for a job.
* Many of those working part-time also attended a day program.
* Some also volunteered at various locations and
* half reported that they were involved in activities within their communities.
* One respondent was a student attending college.

There are Some Concerns

Some notable responses to our last question:

What else would you like to tell us about your health, employment, housing or annual planning meeting?

* Housing
* “I would like to move back to my hometown. I don't know why the housing people won't let me live where I want.”
* “I am not allowed to have a pet unless it's a service animal.”
* Annual Planning Meeting
* “I can't read or write. I need someone to help me understand more about what's in the plan.”
* “My parents meet with the case manager before the meeting. I would like to have a say in the plan.”
* What else would you like to tell us?
* “I am a college student… People with disabilities need to learn about their options for finishing high school or going to college.”
* “I would like to change some things because I don't agree with everything. I want to be my own guardian but want someone to help me. I would like the Supported Decision-Making thing. I would like a job, but haven't been able to find one that meets my needs.”

# Appendix B Summary of Group notes

# Child Care

* Build on community connection – current structure Umaine and higher ed
* CCIDS liaison and connectivity – prevention, EI, CC-various forms
* Connection to families and how we support them
* CC provides knowledge of community supports – perhaps more on FCC
* FCC – new rules – preventing expulsion policies
* Trauma mental health
* Mental wellness – relate ECM HC
* Natural support
* MPF – parent groups/education supports
* Community connection – PTAs
* Child Care is a natural support
* CC is not seen as this natural support and isn’t actually seen as a system
* FFN – Family friend and neighbor – legal unlicensed, where most of our kids go
* Study of where our children are/how many in child care
* What happens to children when they are out of school (OST)
* Belonging – staring in CC does it make a difference being part of their community – longitudal study across lifespan
* Asking adults and others were they in CC
* Research – data – parents/ families access to child care for their children with disabilities – are they able to access? So can they work because they can access? Where? What kind of care? Other items
* Child care as a caring community – is there a way to identify how involvement at an early age leads to better quality of life later on?
* EC expulsion data… recent Maine data (MCA and MCGC) can we go deeper and look at those who are identified and have disabilities or does this already identify – Gilliam study did not (his looked at gender and race)
* EC behavior products to disseminate – CCIDS behavior framework – monograph update and rollout to others
* Partnerships with DDC and / or DRM – developing policies, understanding 504 application to early childhood etc
* Forums or some way to connect ec folks with SUFU – listening sessions – long range planning – if we want our children to have a quality of life- community building from the start infancy leading to adulthood and elders ….. lessons from our community citizens (SUFU)
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# Education and Early Intervention

* Parent education
* -System navigation
* -Advocacy
* -What a good “program” IEP/IFSP looks like. Understanding their role in the “program”
* Parent role in allowing child-adult to become “self-determined” “school supporting”
* Educate parents on systems for transitions
* IEP roles/responsibilities – students roles – self determination – starting in elementary
* Building high expectations of kids with disabilities
* General education on benefits of inclusion for typical/atypical children
* Info on inclusion modeling for all of school day
* -For teachers
* -For parents
* -For community members
* Current CDS transition
* -Currently overstretched, change chaos
* -New “system” needs to be EI not 3rd grade coming down to EI
* Community supports –knowing your resources
* Early identification (Child find)
* Family-centeredness
* -Relationships with families and schools (school roles)
* -How can schools partner, not add to the plates of families
* Preparing the school “community”
* -Teachers, administrators, families, peers for child with disabilities
* Start early for transition planning
* Building prevention, addressing bullying
* EI – lack of community capacity/preparedness due to eliminated infrastructure
* Variation/inconsistency in quality
* Regionalization and special purpose schools
* Regionalization
* -Some families want this
* Exclusion
* -Putting people in “system” very early – CDS
* -Sorting
* -Lack of self-determination
* Coordination of Education and EI with community services
* Restraint and seclusion
* Universal design for learning
* Supporting students who lack effective family supports
* -Research
* Parents need to know who can be child’s advocate
* Resilience

# Employment

* Existing system can be used to find comp. emp
* Challenges with VR – increase
* Communication, career exploration
* Variability with quality of VR depending on where you live
* Employment First Law – Implementation ongoing?
* State variability -
* Employment supports – culture different kinds of jobs – geography
* People may have number of hours they can work capped due to physical needs (VR not flexible to help find better match for person)
* Being mobile to find a job
* Transportation as an employment challenge
* Shift-time challenges to get support
* Telework as an option
* VR – Transition counsel as assigned to specific high schools
* More people prepared to be employment supports (JC/ES)
* Expectations of individuals/families that people can and should work
* Misinformation about earning money and benefits – loss (Maine Medical Center program)
* Use of asst. tech as jobs to compliment employee supports
* Project SEARCH – like programs
* Options for rural areas
* Self-employment
* Importance paid work in H.S.
* Emp. Expectations need to begin at birth – (chores, responsibilities, contribute to family)
* Conversations with these children – what do you want to be – (no limits on dreams)
* Employment first law
* Service when approaching service systems – implementation currently weak
* Wait list – still lets people choose leisure life
* Shift what system will pay for
* Some people don’t want to work because they go to day program for “fun” activities – important to talk to those attending that they are missing out on paid employment.
* Comfortable not working – why work when getting money (SSI, other) – work can be stressful
* Work when in H.S. would create more possibilities for working in the future as an adult
* SSI income – Stay at poverty level
* Lose SSI money can still keep Medicaid
* Educations of parents to help them understand importance of trying out work, earn money, manage money and educate on how SS income works
* People do start at entry level jobs and move on much of the time (Gail ice cream serves)
* Transition plans – may mislead – need to look at scope of V&C experiences
* College education as pathway to employment
* Changing expectations – work, college, and future job as options
* EFM Initiative
* In Maine PCP process employment is supposed to be discussed – would you like a job? Would you like to earn money doing something you like to do/good at?
* Mike, what does your job mean to you? My job means to me – can pay rent, go out to eat, movies – do whatever people without disabilities do
* Work societal expectations
* Consequences of how seem when someone does not work
* People working – have a look back- Gail same as Mike example

# Health

* Get info on what’s out/available there – (service tapestry) including waiver info
* Shifting more toward resiliency less on trauma
* -Trauma can be polarizing
* -Money goes to label (sick)
* Mental health, have to be really bad off before help – give up rights
* Availability of help MH and DD dual diagnosis
* Use of anti-psychotic pwdd
* Meds to control behavior – restraint – intersection bh, MH
* Criminal justice safety issues loophole MH and pwd
* Environmental –health – vulnerability intersect at university
* Education of pro – shared decision making in one’s health care
* Medical model doesn’t allow for “own voice”
* Education system’s navigation so you can move with it
* Diagnosis younger – always trying to catch up
* Support families
* Transition from pediatric to adult health care is nightmare/education
* Healthcare system doesn’t understand issue
* What is connection to health care and communities
* Lack of connection with individual and health care providers
* What about sitting on each other’s committees?
* Health care system not aware of accommodations to access system
* What is the best one to communicate with patient
* ACES study – not well known in DD communities
* Use of technology/devices to track communicate about health
* LEND
* Collab/partnership El/Educ, CC, health between UCE DD, NH-ME, LEND, ME LEND
* Home-health monitoring system?
* Medical home - ?
* Informing/educating dis about IDD/DD (non-verbal)
* Example: Sprained ankle – wasn’t able to communicate – someone noticed swollen – if not able to communicate what is wrong doesn’t get addressed
* Behavior can be an indication of something isn’t right
* Research or share findings link between behavior and GI problems, etc.
* MS SPED therapist – when move manual to power – home not accessible –Maine Care - deny
* Medical necessity –to communicate with dr/spec. – com devices for younger children
* Medical home – doesn’t seem to working well – would like to know where/when it works well – how do we get there
* Dementia – research hands on educ and serv provision
* Bridging aging and disabilities
* Aging caregivers – trying to take care of themselves and loves ones
* Trainings – area agencies and Center on Aging
* Telehealth – systems moving toward paying for telehealth, educate and research
* Implicit bias – drs but also dentists, eye doctors, other sending messages – and picking up on messages
* Family, caregiver –validated, listened to, condescending attitude
* ACA – research, educating, informing

# Transportation

* Transport to dr unavail
* Transport for job unavail – employment barrier
* Capacity – more Chucks
* Reduced rate –subsidy or sliding scale
* Open state van pools to public
* Uber
* Utilize pine tree
* Allies: senior citizens with same/similar challenges
* Facilitate ride sharing
* Transition plans defining transportation skills in IEP
* Long commutes on public transit
* Income too high
* Cost of hand controls – driving
* Non-emerg “med” transport – no support by broker for some uses who need support to ride – unreliable.