



THE UNIVERSITY OF
MAINE

Center for Community Inclusion
and Disability Studies

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Community Advisory Committee Meeting Minutes

University of Maine • Orono
Wells Conference Center
June 29, 2016

Members attending: Gail Fanjoy, Janice LaChance, Maryann Preble, Avery Olmstead, Kathy Adams, Jon McGovern, Paul Picard, Staci Converse (for Kim Moody) and Toni Wall. **CCIDS staff:** Alan Cobo-Lewis, Sue Russell, Alan Kurtz and Sandra Horne.

Members attending via video call: Nancy Cronin

Members unable to attend: Traci Flagg-Tynes, Clare Collins and Cindy Brown.

Minutes: Ann Zielinski

Welcome and Review of the Day: Janice LaChance

Director's Update: Alan Cobo-Lewis

The Center has completed the internal move in Corbett Hall; consolidation of office space.

The Center has been actively pursuing research opportunities and publicizing the current research.

- Three students presented posters at the University Research Symposium at the Cross Insurance Center this spring, which was well attended and was good exposure for the Center.
- The LEND grant in conjunction with UNH has been submitted, but we haven't heard the results yet. It is expected that it will be approved, since UNH has held the grant for about 20 years and has always had a very high rating. We are actively recruiting students for the new cohort.
- Two grants were submitted to NIH
 - Liz DePoy and Stephen Gilson related to the mobility devices i.e. "Afari"

- Alan Kurtz for transition training.
- Three grants were submitted to UMaine, but were not chosen for funding this time. Two of them received good reviews and we were encouraged to resubmit with changes for the next round.
 - Liz and the Center on Aging’s grant for the mobility cane “MOJO”; and
 - Alan C’s proposal for an online dementia screening tool.

Old Business

Membership updates: there will be new candidates for membership, but the committee % has not finished its review yet. %

Paul Picard wished to discuss the location of the meetings, but Janice tabled that % discussion. It was noted that the meeting location might need to be adjusted based on % the new membership. %

Janice announced that she will be retiring but would be willing to stay on the CAC as a % community member. %

Volunteers were requested to serve on the By-Laws update committee. %

Research Summary: Alan C. %

Alan explained the University’s Signature Areas and Emerging Areas of Research, and % how our work meshes. (see Power Point.) %

Early Childhood: State asked for revisions to the Quality for ME and we are suggesting % disability updates. %

Alan showed and explained the Quality for ME Validation (Child Care Professional % Development Network) and the Environmental Rating Scale. The website for childcare % quality was viewed. %

It was noted that DHHS did not change the standards as much as we suggested. %

Educare: An on going initiative of high quality pre-school/day care in cooperation with % George Mitchell Elementary School. Children are being followed as they enter public kindergarten and data collected. This is testing what high quality care looks like and the % results. Maine has been participating for 2 years now, but nation wide there are 10 % years of data. %

In general kids who participated in Educare do better than their peers. About 10 to 15% of children in Educare have disabilities. Nearly all children in Educare gain one standard deviation point. Gains in the Peabody Assessment are quite large. %

Computerized Assessment

Developed by Alan Cobo-Lewis, the computerized CDI adaptive test is built on the paper model. It is useful for tracking child development. Results are comparable to the paper test but the time to take it is greatly shortened. Test is not published yet.

Aging Initiative

Working with the DDC in the planning stages. Similar to the child development adaptive test. The hope is to help diagnostics about developing dementia. There is concern about over shadowing diagnostics the test should help pinpoint new symptoms.

Goals and Objectives

At the previous meeting it was decided that going over the Goal and Objectives in detail was time consuming so copies were distributed ahead of today's meeting. Gail raised the question about some goals that have no progress. Sue explained that not everything was included on this summary; some goals have had progress in previous years.

Gail suggested that the Center play a greater role in advising policy makers. For instance, DHHS says they are "ahead of the game" on the Olmstead Waiver, but they are, in fact, in trouble.

The question was raised as to what the committee could do to help inform the policy makers.

Gail suggested reaching out to other UCEDDs to see how they are handling things.

Alan Cobo-Lewis asked a small group, Gail, Staci, and Jon to assist.

Staci said that the policy makers need to hear from families, self-advocates and providers.

Janice stated that the state doesn't do a good job of pointing out what works. There is no strong family voice.

Blank Goals – 2.3 it was strongly suggested that the Center participate in the Margaret Chase Smith academy for new legislators

Goal 3.1 Research goal will be changed to reflect the research that is on going.

3.3 Housing – Adult community living

3.4 Playgrounds – Sue planned to address this in the afternoon session. Toni – the Maine Municipal Association needs to start training about making play areas more accessible.

Goal 4.1 Providing testimonies in legislative hearings. Alan said it was on the agenda for the next Staff meeting.

Meeting was adjourned for lunch.

Alan brought up a potential collaboration and asked the CAC for advice.

The Center was contact through the Division of Life Long Learning about proposed project for community housing, to be called “Jonna’s Place.” The project would be a communal home with a shop next door.

The CAC’s reaction was very negative. This was essentially a “sheltered workshop” and attached home. It was not community living. The CAC advised strongly that the Center not be involved in this endeavor.

Alan brought up the DHHS proposed Section 21 changes. Supporting Individual Success (SIS). The department wanted to tape the interviews and the publisher would not allow.

The department wants to go forward with Person-Centered Planning with a similar tool.

A very lively discussion ensued regarding the SIS and how degrading and humiliating it is for the person being evaluated. The support people have to describe the client on their very worst day in front of the client or services would be denied. It is a disturbing experience at best.

Wrap-Up, Meeting Feedback

Discussion of the location for the next meeting was tabled until the membership committee completed their work.

Evaluation forms were passed out.