



**Consumer Advisory Committee (CAC)
LSUHSC-Human Development Center (HDC)
University Center for Excellence in Developmental Disabilities (UCEDD)**

**MEETING MINUTES
Friday, October 20th, 2017**

10:00 am – 2:30 pm
Human Development Center, Room 452
411 S Prieur St, New Orleans, LA 70112

Meeting Called By: Philip Wilson, PhD

Facilitator/Note Taker: Lauren Griffiths

Attendees:

Anthony, Chris (Guest/LRS)	Luna, Melinda (HDC)
Blanco, Maria (HDC)	Morel, Sigmund (LRS)
D'Aquila, Shannon (Parent)	Rowe, Jeff (Advocacy Center)
Fontenot, Maria Lynette (Self Advocate)	Stazio, Laura (HDC)
Griffiths, Lauren (HDC)	White, Patsy (Parent)
Jacob, Mary (Families Helping Families)	Wilson, Philip (HDC)
Killam, Susan (HDC)	

Agenda Item: Updates from HDC's Four Initiative Areas

Early Childhood Initiative: Maria Blanco, MEd

- Goal is to make sure families are self-sufficient and children are ready to learn
- Focus on building capacity and inspiring change, especially building the capacity of systems to serve all kids with and without disabilities
- Program works with at risk kids, families in poverty, especially very young children
- [Early Head Start childcare centers](#) partnership to serve all kids, even those with disabilities; Working at state level to fill gaps
- [Early Learning Center](#) serves children with and without disabilities; Provide opportunities for LSU students to observe how to effectively include children with disabilities in childcare setting
- [LA Leadership Education in Neurodevelopmental and Related Disabilities \(LEND\)](#) program trains graduate students, community leaders, and self-advocates to be leaders in maternal and child health (MCH) fields
 - o In addition to completing didactic coursework, trainees will complete a variety of clinical and field experiences; a research-based project; a policy advocacy project; family mentoring experience; and fulfill required rotations
- Four health-related projects
 - o Collaboration with the LSU School of Public Health and Schweitzer Fellow Lisa Staples who runs Little Bitty Learning – project promotes physical health in families with young children through weekly afternoon cooking classes

- Health Care Institute – a subaward from the University of California at Los Angeles that addresses mental and oral health and nutrition; seeks to teach at risk families living in poverty how to achieve wellness for their young children
- Adverse Childhood Events (ACEs) initiative – looks at impact of diversity/toxic stress on physical/mental health; investigates/attempts to build resilience
- Developmental screening surveillance pilot – collaboration between Louisiana Title V and the HDC and other partners to promote universal screening for all children through preschool; increase early identification and improve access to services
- Upcoming: To be named HDC “early childhood inclusion institute” to offer training/technical assistance/job-embedded training for teachers, administrators, early interventionists/related service providers, parents and others on how to include all children
 - Other trainings being developed and/or offered include but are not limited to:
 - Job-embedded coaching to improve practice
 - Basic trainings for childcare centers, especially preschools

School Age Initiative: Melinda Luna, MEd ([see presentation slides here](#))

- Louisiana Autism Spectrum and Related Disabilities (LASARD) Project
 - 5 facilitators across the state
 - 3 goals
 - Build statewide capacity by developing pool of highly effective educators
 - Develop model exemplars that demonstrate evidence based practice
 - Facilitate partners teams for sustainability
 - Summer – LASARD met with all partners for two day planning session; also has monthly meetings to stay updated on progress
 - Three workshops/year – fall/ winter/spring
 - 9/8 – 97 LASARD partner team members attended workshops
 - Team workshop in January on behavioral intervention plans
 - 12 free workshops per year – 5 offered to date
 - Upcoming: high school workshop
 - 11/2 – “Breaking Barriers and Building Connections: Social Skills for Life”; to [register \(free\)](#)
- Teams Intervening Early to Reach All Students (TIERS)
 - Goals
 - Provide professional development
 - Technical assistance
 - Coaching
 - Joint project with Families Helping Families Northshore recently completed – student and family centered IEP meeting training
- Louisiana School Psychology Internship Consortium (LAS*PIC)
 - 27th year of training doctoral level students in school psychology programs
 - Joint venture between HDC and local educational agencies (LEAs)
 - Dedicated to provided interns with vital experiences to help them become successful
 - Developed online module with in depth information on [training program accessible online](#)
 - Currently has 10 interns; 6 partner LEAs this year
 - To date: 600 hours of direct service to students

Transition, Secondary Education, Employment & Careers: Sue Killam, MEd

- Paycheck: Pilot with Louisiana Rehabilitation Services (LRS)
 - o Includes paid apprenticeships for young adults with disabilities with the goal of launching youth into employment and career paths
 - o Includes a semester at Delgado Community College, job shadowing/paid apprenticeship at University Medical Center (UMC)
 - o LRS reimburses UMC for wages (\$8/hr), up to 240 hours training at community jobsite
 - o All current students will exit program in December; 2nd year of program starts in January
 - o Launch party 12/8 at 5pm for the celebration of the completion of their program
 - o Plan to work largely with Jefferson Parish schools next year; interest from New Orleans charters, especially Inspire Nola
- Benefits Planning program
 - o Three benefits planners at HDC serving all of Louisiana except for the New Orleans, Baton Rouge, and the Northshore
 - o Teaches Social Security beneficiaries about the availability of work incentives and the impact of employment on the benefits that they receive; provides information and referrals to other employment support related agencies and organizations
 - o to use social networks to get job
 - o Program manager: Ray Leger (email: dleger@lsuhsc.edu)
 - o 2nd year of 5 year grant from Social Security Administration
- Laura Stazio provides Supported Employment core trainings (40 hours) and Continuing Education trainings for Employment Support Specialists
 - o Trainings are back on track → monthly trainings to build capacity, build expertise; gearing up for national certification exam (CESP) at the DD Council Employment Conference on November 8th at 1:00pm in Baton Rouge
- Supported Employment Mentoring Project funded by the Louisiana DD Council began October 2017: Will identify providers on Northshore and in Alexandria area to partner with to do more community based employment services
- Jefferson Parish Transition Capacity Building Pilot: Contract from Jefferson Parish schools to build capacity of special education staff and regular educators to support transition of youth with disabilities from high school to employment and careers
 - o Live webinars will be archived to make them available online
 - o Dr. Wilson: Training minimally effective for change, but through Paycheck, students are in real world settings that has encouraged Jefferson Parish to invest in their students
- Potential project with Louisiana Workforce Commission: Ms. Killam has been in discussions with Shannon Joseph, Director of the Louisiana Workforce Commission, regarding programs for people without disabilities who need employment

CAC member discussion of parent trainings

- Ms. D'Aquila: Why not include parents included in trainings geared toward other target audiences (e.g. teachers)?
- Dr. Wilson: Always an option; may have to do with funding structures or family member may not have time to attend long trainings
- Ms. Killam: Trainings are often same table of contents, just with different levels of depth; some are targeted to specific populations; we do a tremendous amount of trainings with Families Helping Families; we see need to train/provide resources to parents and do try to accommodate that

- Dr. Wilson: HDC can try to market to parents/family members, and may be able to offer at affordable cost
- Ms. D'Aquila: Believes it would be beneficial to parents to sit in on trainings offered that would affect their children
- Ms. Fontenot/Ms. Jacob: Agree
- Ms. D'Aquila: Additional benefit is that professionals hear same thing parents are hearing; decreases misunderstandings
- Ms. Killam: One of biggest employment barriers in research right now is that a lot of vocational providers don't believe everyone can go to work; been told for years their way is best; need to see employment success stories
- Ms. White: Has 20 year old; have gone to trainings with him and he often has different expectations than her; looks forward to having own special training just for parents though does want to understand what expectations are for him, but also for her as a parent; of biggest deterrents to employment is fear families have, training helps get parents on board through exchange of information among parents themselves
- Ms. Killam: Biggest myth: if you go to work, lose your benefits; employers don't want to hire disability; parents and providers hold to these myths out of fear
- Ms. White: Let families know there is a safety net and don't fear failure/isn't all or nothing; won't have to start back at square one
- Ms. Killam: Savvy employers can get wage reimbursement for hiring people with disability and often seek them out if they understand how the system works

HDC Interdisciplinary Clinics: Philip Wilson, PhD

- Dr. Banajee will no longer coordinate clinic activities as her workload is too great at the moment; reorganization of this initiative area is underway
- Main reason HDC has clinics is that the LEND grant focuses on interdisciplinary practice and early identification of disabilities, especially ASD; HDC tries to create clinics that will serve as training ground for LEND trainees
- Dr. Banajee will continue to provide Augmentative and Alternative Communication (AAC) evaluations and clinic at Morris Jeff School and Collegiate Academy as part of her roles and responsibilities as an HDC faculty members
 - o Dr. Banajee's clinical efforts serve approximately 15 clients and provide 2 evaluations per week
 - o Continue transform the current uni-disciplinary approach of the Assistive Technology (AT) and AAC clinics to interdisciplinary: In the process of credentialing physical therapist, BCBA and dietician
- In process of establishing a feeding/swallowing clinic
 - o Vision: Interdisciplinary team that will include
 - Registered dietitian (in negotiations now)
 - Julie Riley, director of LASARD, a nationally and state certified behavioral analyst (credentialing in process)
 - Brittney Wright, speech language pathologist
- Upcoming in Spring of 2019: Fit Families obesity prevention for families in poverty
- Nutrition is for Everyone: Lauren Griffiths, MPH
 - o Project to improve nutrition behaviors among people with disabilities using the Act Early Ambassador model

- Currently seeking Deputy Ambassador to represent program as part of the Complete Street Initiative; small stipend offered

Agenda Item: Nominate/Elect CAC Officers (Lauren Griffiths)

- Call for nomination of new members; please submit suggestions to Lauren Griffiths (email: lgri10@lsuhsc.edu)
- Ms. Patsy White will serve as interim chair until next meeting

Agenda Item: CAC Governance and Bylaws (Lauren Griffiths)

- 2 major charges of the CAC
 - Review what has been accomplished and give feedback, make recommendations, assess success, give input on goals/objectives of HDC
 - Offer input on development of next 5-year grant
- CAC to be included in planning, development, implementation, dissemination of the work that the HDC does

Agenda Item: CAC Governance and Bylaws (Lauren Griffiths)

- Review and amend CAC bylaws to suit the needs of the CAC (see updated bylaws)

Agenda Item: Discussion of HDC Five-Year Plan Revisions (Philip Wilson)

- Updates from National Information Reporting System (NIRS) (NIRS presentation link to be)
- Recruiting CAC members to present on a topic of their choice at upcoming Lunch and Learn events
- Ms. D'Aquila: Website not easy to navigate; not logical where things are
- Dr. Wilson: Suggests ad hoc committee to address website issues
- Ms. D'Aquila: Consider having special pages for specific audiences (e.g., parents, teachers, self-advocates, etc.)

Agenda Item: CAC Vision and Direction (Philip Wilson)

- Potential organizing theme for next year's core grant: *Resiliency*
 - Regardless of disability status, poverty, behavioral health issues, *resiliency* helps people live a full life
- HDC employees sometimes fail to understand they work for one large organization, not just the project that funds them; HDC to establish an overarching theme for the next five-year UCEDD Core grant to unite staff
- In the new proposal, Dr. Wilson suggests the creation of 2-3 questions to be included in each project's evaluation on the impact on the resilience of the individuals served

Discussion of tracking HDC's impact on resiliency

- Dr. Wilson to CAC members: Share ideas on how to build/track resiliency
- Ms. D'Aquila: Stop losing track of the people you've helped; Can HDC find people previously served and ask them if HDC made a change/difference in life today?
- Dr. Wilson: Great idea for transforming how we track our impact
- Ms. White: Still stays in contact with LEND/Sparkle families; sends out "where are you now" surveys; still remembers first LASARD meeting where she was told best practices for children on and off the spectrum; was life changing to see now 10 years later that I still think of LASARD experience



- Ms. D'Aquila: Asks how to turn data points back into people
- Ms. White: Brought LASARD strategies to my home, used with children, and now being used with grandchildren; 2 generations
- Ms. Jacob: Sometimes average parent that's not that involved; waiting too long to get back in touch with them means they may not remember all the details; need to follow up more regularly, e.g. twice per year
- Ms. D'Aquila: Biggest issue with HDC is that it is not a one-stop shop, too compartmentalized; HDC sometimes does not use its own resources efficiently (e.g., like Ochsner that has one-stop shops all over the city); ties back into website that is difficult to navigate
- Ms. White: One of HDC core values is interdisciplinary practice; but sometimes there's a disconnectedness
- Dr. Wilson: Some administrative barriers make such interconnectedness difficult; but still needs to be addressed
- Ms. Blanco: CAC could have impact if it starts making noise; important that people who make decisions that impact other people's lives/work hear from folks affected; when a parent comes up to complain about something, Dean starts to listen because image of university is impacted
- Dr. Wilson: Encourages CAC to establish a positive relationship between CAC and Dean

**NEXT MEETING: Tentatively scheduled for December 15, 2017
(Poll to be sent to CAC members)**