



FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL

Alternative Residential Options Work Group

July 24, 2009 * 10:00 am – 4:00 pm

FLORIDA DEPARTMENT OF LAW ENFORCEMENT (FDLE)

2331 PHILLIPS RD. * TALLAHASSEE, FL

MEETING NOTES

Attendance Chart

NAME	REPRESENTING	ATTENDED	COMMENTS
WORK GROUP MEMBERS			
Tim Lawson	Governor's Office on Policy and Budget	Yes	
Bryan Vaughn	Governor's Council on Disabilities	Yes	
Jim DeBeaugrine	Director, Agency for Persons with Disabilities (APD)	Yes	
Senator Altman		No	
Representative Stargell		No	Attempted to call in
Representative Bill Galvano		No	
Sheryl Soukup	Immokalee Non-Profit Housing	Yes	Affordable farm worker housing developer
Richard Chapman	Executive Director, ADAPT Florida	Yes	Self-advocacy organization
Kingsley Ross	Autism Society of Florida	Yes	for Ven Sequenza
Eugenie Amalfitano	Parent Planning Program	Yes	for Lila Klausman
Tito Balduci	Home Choice Supporters	Yes	
Damian Gregory	Self-Advocate and former Support Coordinator	Yes	
Pam Kyllenon	Agency of Health Care Administration (AHCA)	Yes	for Leigh Meadows
Suzanne Sewell	Florida Association of Rehabilitation Facilities	Yes	Ellyon Turnquest in AM Suzanne Sewell in PM
Jack Kosik	Noah's Ark of Central Florida	Yes	
Patti Houghland	Family Care Council Florida	Yes	for Betty Kay
Sylvia Smith	Advocacy Center	Yes	Sylvia Smith in AM Dana Farmer in PM
Janice Phillips	Florida Association of Support Coordinators	Yes	
Deborah Linton	ARC Florida	No	
Debra Dowds	FDDC	Yes	
Susan Goldstein	Friends of Floridians w/Developmental Disabilities	No	
NAME			
REPRESENTING			
PRESENTERS			
Susan Gold	Chair, Florida Developmental Disabilities Council		
Terry McGarrity	APD		
Tom Rice	APD		
INDIVIDUALS, GUARDIANS, & HOUSING ORGANIZATION PARTICIPANTS & OTHERS			
Amanda Balduci			
Mary Ellen Balduci			

NAME	REPRESENTING
Judy Owen	Parent & Member of Florida Developmental Disabilities Council
Doreen Stewart	PCA for Casey Stewart
Casey Stewart	Florida Developmental Disabilities Council (FDDC) & Self-Advocate
Simone Tetreault	Parent & Statewide Coalition of Residential Options
Denise Arnold	APD
FDDC STAFF	
Margaret Hooper	
Latarsha Williams	
Vanda Bowman	
Bonnie Newsome	

Welcome and Introductions

The meeting started at 10:15 am with Dr. Susan Gold, FDDC Chairperson, providing introductory remarks. Dr. Gold stated that the purpose of the four meetings is to explore how to best meet the residential needs of individuals with developmental disabilities in Florida. She emphasized that the group is organized to gain an understanding of the positive components of our current residential options, as well as to describe associated concerns and issues. The ultimate goal is to develop consensus on legislation that will provide for residential options that best address the needs and key issues. She then described the intent of the four meetings, stating that, in this first meeting, the participants will identify the issues associated with residential options and gain an understanding of what is currently available. The work group meetings are structured to build a mutual understanding of the issues and create a setting for planning and collaboration. She went on to describe the next three meetings, stating that the second meeting will focus on learning about living arrangement across the nation; the third will discuss the relevant laws, regulations and procedural requirements that impact the implementation of certain options; and the fourth meeting will discuss specifics relative to the desired residential options and reach consensus on appropriate legislation.

Dr. Gold also explained how the phone call-in system would work, and invited individuals on the phone to notify the staff if they desired to speak during public comments (unfortunately, the phone system did not function as intended: the speakers were unable to pick up the conversation; although the FDDC staff tried numerous options to correct the problem, the phone system remained inadequate). Dr. Gold closed her remarks with her favorite quote from Margaret Mead, "Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has."

Hopes and Norms

During this session, participants were asked to meet the person sitting next to them and have a brief conversation regarding what they hoped to achieve during this first meeting and how they would like to conduct themselves as a group. The participants were then asked to introduce themselves, share something about why they were involved, and state what each person hoped to accomplish. The group was fairly consistent in their hopes, stating that they wanted to fully explore the issues and hoped that some agreements could be made about residential options. A discussion followed regarding meeting norms, with the following identified:

- Disagree without being disagreeable

- Be respectful with one another
- Listen with an open mind
- Stay away from hot button issues
- Don't use labels that have multiple meanings, such as "institutions or inclusion"
- Recognize that there are many opinions
- Listen for what you agree with first
- Seek to understand before seeking to be understood
- Don't use acronyms

Presentation on Current Residential Options in Florida

Terry McGarrity and Tom Rice from the APD made the presentation (their PowerPoint is posted on the FDDC website). The group asked numerous questions. Terry McGarrity invited any work group members or other to send their questions to FDDC, promising to prepare responses. The group appeared uneven in their understanding of how the APD system works. There was some discussion on how the Tiers and Prior Authorizations impacted access to residential services and supported living.

During the presentation, several issues were raised:

- Need a better understanding of how the whole system works
- Need more information on the support plan and services and supports approval process
- Impact of the Tiers on access to residential options and supported living
- What information is available about people on the waiting list, especially regarding residential services
- How is change in status documented
- How is room and board paid for persons covered on the Waiver
- What type of housing stipends are available through APD and how are they administered
- Need to know more about the use of the assisted living facilities for persons with developmental disabilities.

Lunch

Because the meeting was running behind, the time for lunch was reduced.

Small Group Work—Qualities of Desired Residential Options

The participants were divided into groups of three. They were each asked to review two scenarios describing persons receiving services in Florida in group homes, supported living, or living at home. After discussing the person's strengths and needs, they identified the characteristics of a residential program that would meet these needs. They also identified issues that they thought "could go wrong". From this information, they developed a list of key requirements for residential options. The groups were asked to select a spokesperson and present their findings, which are summarized below.

Yellow Group:

Must have the most independent setting possible, including:

- options to self-manage daily needs and tasks,
- access to transportation options,
- opportunities for socialization,
- choices of whom to live with,
- access to mental health services, and
- access to state of the art technology.

Blue Group:

Must have:

- available assistance in developing natural supports,
- use of paid supports to help access generic services and develop natural supports,
- a safe environment,
- fully informed ability to make choices; and
- continual re-assessment, to ensure that needs are still being met because needs change over time.

Green Group:

Must have:

- socialization opportunities and connections with family,
- a safe environment that is free from harm,
- ways to avoid isolation,
- a sense of purpose, and
- continuity, reliability, and competence of staff providing daily supports.

Whole Group Discussion

After the three presentations, the participants developed a list of characteristics of residential options that they would like to have available in Florida, which are summarized below. Note that the necessary characteristics applied to the overall system as well as to residential options.

- Supports to gain independence and leave the system if desired
- Housing which is affordable for persons with disabilities whose income is primarily SSI or SSDI
- Access to health care that is appropriate to individual needs
- Informed choice regarding all services and supports
- Least restrictive setting
- Reliable, consistent, and competent supports, including natural and paid supports
- Access to long term natural supports, preferably outside of the formal system
- Flexible services that recognize changing needs
- Social supports that promote regular and ongoing choice of friends and family, not necessarily with other people with developmental disabilities if that is the person's preference
- Accessible transportation that helps connect with the broader community, friends, and family (note that natural supports were discussed; however, the point was made that natural support for transportation for persons with physical disabilities is very difficult)

- Formalized methods to help people develop and sustain natural supports using their personal social capital
- Environments that provide for safety from abuse, victimization, and exposure to violence or psychological trauma
- Environments that protect against isolation from others
- Environments that provide access to all necessary services, including medical and behavioral/mental health
- Ensure daily personal contributions, purpose, and meaningful participation in the community
- Ensure that support staff and others know the individual with developmental disabilities and can help them express their individual wants and desires for all aspects of their lives

The group next listed the type of information that they would like to receive from the expert presentations in the next meeting. These are listed below:

- Strategies for providing subsidies to ensure that housing costs are less than 30% of the individual's monthly income
- Evidence-based practices regarding residential options (what does the data say?)
- Successful programs on roommate matching or live-in situations
- How services have been packaged to provide for living environments for people with all levels of functioning
- An analysis of the Florida data that shows what percentage of persons at specific functioning levels are served in which type of settings
- Provide the group members with the "2008 Priced Out Study"

Public Comment

Due to the problems with the phones, public comment was available only to those attending the meeting as guests. Simone Tetreault spoke and asked if future meetings could be recorded and posted on the website. She also asked if the term "consensus" had been defined. The answer was deferred to the group for future consideration.

Discussion Concerning the Next Meeting

Prior to adjournment, the group discussed possible expert presenters for the next meeting. Jack Kosik suggested that Diane Yaconetti from Lambs Farm be invited to present. Tito Balducci requested that a representative from the Camphill Communities also present. Richard Chapman made two suggestions and will send Debra Dowds the contact information. Jack Kosik requested that the group schedule one of their meetings in Orlando and tour the Bishop Grady Villas in St. Cloud. No decisions were made regarding the expert presenters or the location of the next meeting, but Debra Dowds stated that she would consider the requests.

Adjournment

The meeting was adjourned at approximately 3:10 pm.