



FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL

Alternative Residential Options Work Group

October 15, 2009 * 10:00 am – 4:00 pm

ALOFT TALLAHASSEE DOWNTOWN

200 North Monroe Street * Tallahassee, FL

MEETING NOTES OCTOBER 15, 2009

Attendance Chart

NAME	REPRESENTING	ATTENDED	COMMENTS
WORK GROUP MEMBERS			
Bob Brown- Barrios	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)	No	
Senator Altman	Brittany O'Connor for Senator Altman	Yes	
Representative Stargel	Rachel Barnes for Representative Stargell	Yes	Representative Stargel on the phone
Representative Bill Galvano		No	
Sheryl Soukup	Immokalee Non-Profit Housing	Yes	
Richard Chapman	Executive Director, ADAPT Florida	Yes	Self-advocacy organization
Ven Sequenza	Autism Society of Florida	Yes	Kingsley Ross also in attendance
Lila Klausman	Parent Planning Program	Yes	
Tito Balduci	Home Choice Supporters	Yes	
Damian Gregory	Self-Advocate and former Support Coordinator	No	
Pam Kyllenon	Agency for Health Care Administration (AHCA)	No	
Susan Sewell	Florida Association of Rehabilitation Facilities	Yes	Courtney Swiley for Susan Sewell
Jack Kosik	Noah's Ark of Central Florida	Yes	
Betty Kay Clements	Family Care Council Florida	Yes	
Sylvia Smith	Advocacy Center	Yes	
Janice Phillips	Florida Association of Support Coordinators	Yes	
Debra Linton	ARC Florida	No	
Debra Dowds	FDDC	Yes	
NAME			
PRESENTERS			
Susan Gold- Welcome	Chair, Florida Developmental Disabilities Council		
Richard Neal	Camphill		
Kevin Johnson (by phone)	Bishop Grady		
Dianne Yaconetti (by phone)	Lambs Farm		

Jim Freyvogel Steve Beauchaine Betty Beauchaine	McDonald's Center Supported Living Live-in Model
Molly McKinistry	Agency for Health Care Administration
Deb Blizzard Vicki McCrary	Agency for Persons with Disabilities
NAME	
GUESTS	
Eugenie Amalfitano	
Chris Dugan	
Simone Tetreault	
Susan Thiele	
Susan Creek	
Richard Simson	
Jim Whitaker	
Lin Kosik	
Logan Taylor	
Doreen Stewart	
Casey Stewart	
FDDC STAFF	
Latarsha Williams	
Vanda Bowman	
Margaret Hooper	

Welcome and Introductions

The meeting was called to order at 8:40 a.m. with a welcome given by the Council's Chairperson, Susan Gold. Everyone present introduced themselves.

Overview of the Day and Agenda

Celeste Putnam, the facilitator, opened the meeting with a discussion of the purpose of the meeting. She asked all the participants to try to view issues from as many perspectives as possible. Using stick men illustrations, she showed the comparison of an elated winner and downcast loser and asked everyone to try to create a win-win scenario.

Guest Presentations on Residential Options

Four presenters discussed examples of residential options. Two of the presenters were from out of state and two live and work in Florida. An overview of each presentation is provided below.

Camp Hill, by Richard Neal

Mr. Neal is a senior administrator with Camphill Villages, which is an organization that operates several intentional communities for persons with developmental disabilities. Due to last minute changes, he flew with little notice to Tallahassee to make a personal presentation but did not have time to prepare PowerPoints.

Mr. Neal explained that Camphill was founded in Scotland by persons fleeing Nazi Germany. The program adopted a mission to serve persons with special needs through the creation of communities designed to promote ongoing relationships and provide for life's necessities through shared responsibilities. Currently, there are 104 communities worldwide, with about 4 in Canada and 9 in the United States.

Mr. Neal lives and works in the village in upper New York State. This village started as a result of the Willow Brook Institution scandal of 1961. Families needed other options for the care of their loved ones. Camphill focuses on three basic essentials:

1. the absolute belief that a healthy human spirit resides in all human beings,
2. that everyone has the responsibility to develop, learn, and grow personally, and
3. that we all need to continuously strive to create a sense of community.

The Camphill Village in New York is located on 680 acres, with 22 households living on that parcel of land. People (without developmental disabilities) come from all parts of the world to live for two or three years. Additionally, several young adults from Americorp come to live at the village. Everyone does what they can do and no one receives a salary. Instead, their basic living needs are provided by the community. This setting is very rural. The persons living at the village are very interested in organic and biodynamic farming and work with these concepts in a non-commercially based manner. Because they are so rural, they must transport persons to the broader community. The broader community also comes to them, especially to use their large hall which is open to the broader community for use.

Currently, 103 persons with developmental disabilities live with 60 long-term co-workers and 40 short-term co-workers. The long-term co-workers are persons who have chosen to make Camphill Village their lifelong work and home. Individual action and opportunities for social interaction are the focus of the day-to-day activities. Those involved with farming interact at the village with other farmers and also with the farmers in the community. Mr. Neal stated that choices for daily action must be broad enough to provide opportunities for all the workers at the village. Traditional therapies are available. Two additional homes have been added to allow aging villagers with special needs to remain in the village. Everyone is expected to make a contribution. The program in New York receives 45% of its funding from state and federal sources, 20% from foundations, and 35% from fund-raising. New York State has created a new licensure category for Camphill Villages.

Mr. Neal briefly discussed other sites. The California program is located in the suburbs of Santa Cruz and is in close proximity to other residential areas. Camphill Hudson is located in a small town in upper New York State and consists of two homes with four people living in a home. Persons in this program receive Medicaid home and community-based services. Additional information can be found at www.camphill.org.

Bishop Grady Villas, by Kevin Johnson

Bishop Grady Villas is a residential program for persons with developmental disabilities. The program is licensed as an Assisted Living Facility (ALF) through one license. There are six Villas with 8 individual rooms and private bathrooms. There is a fully equipped kitchen for personal meal preparation as well as a dining hall. Persons living in the Villa may receive Medicaid Waiver services, including residential habilitation. At this time, 44 persons live at the Villa. The company is part of the Ticket to Work employment network and works hard to help persons with developmental disabilities find paid employment in the community. About 50% of the people living at the Villa are working in the community. The Villas are within walking distance to shops, restaurants, gyms, and churches. The PowerPoint on Bishop Grady Villas is posted on the FDCC website.

Lambs Farm by Dianne Yaconetti

Ms. Yaconettie is the President and CEO of Lambs Farm. She presented by phone. The mission of their program is to empower people with disabilities to live personally fulfilling lives. Currently, Lambs Farm serves 250 persons with developmental disabilities, with 172 living on campus and 28 living in the broader community. There are nine homes that serve 12 persons which are all individually licensed as a group home and are located on the main campus. There is also an apartment building with 18 individual units and 1 unit for two persons. Activities are based upon individual choices of a variety of options and may take place on campus or in the community. There is regularly scheduled transportation to the broader community and back through the program's transportation system known as Rainbow Run. All programs are staffed by paid staff who work on a shift schedule.

Lambs Farm also operates a Community Integrated Living Facility in nearby suburbs and one Intermediate Care Facility that serves 16 persons in 8 double occupancy bedrooms.

For further information please see www.lambsfarm.org.

MacDonald Training Center by Jim Freyvogel, Steve Beauchaine, and Betty Beauchaine

Jim Freyvogel, CEO of MacDonald Training Center presented information on their live-in residential program. Steve Beauchaine now lives in his own apartment and he and his mother spoke about his other residential experiences and his great pleasure with having his own apartment. Their PowerPoint includes several pictures of Mr. Beauchaine in his home.

Mr. Freyvogel stated that MacDonald Training Center decided to close all their group homes and use only supported living settings. To accomplish this, they designed Live-In Support (LIS) settings in which the person providing care and supervision lives with

persons with developmental disabilities in a leased home. Currently, there are 38 persons with developmental disabilities living in these settings. The most common configuration is three persons with developmental disabilities living with one live-in companion. Four persons live in settings with two in a home with one live in companion and in one home there is a one-to-one living arrangement. The live-in companion receives a salary, and the company leases their share of the home so they have no direct living expenses. The staff are provided with relief on weekends and for vacation.

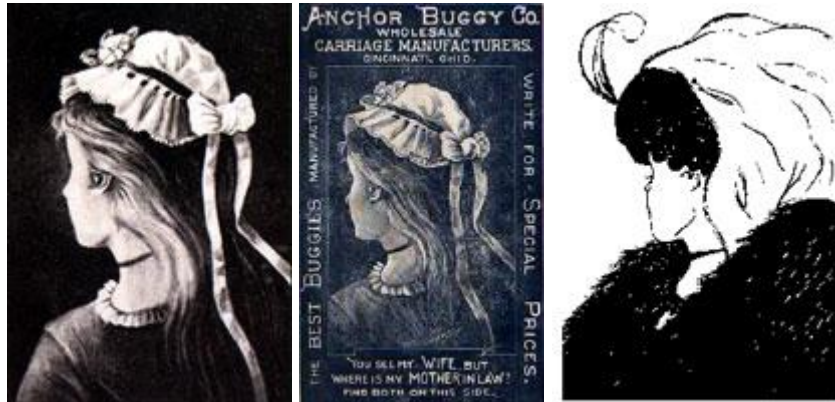
These settings have many of the features of life-sharing programs. There is a lot of socializing between and among the homes and individuals. Significant interaction occurs with the friends and family of the live-in companions, and ongoing contact with neighbors has evolved. The persons with developmental disabilities and the live-in companions often plan social events with persons in the other homes. As the program has evolved, many persons with developmental disabilities have asked to move to certain sections of town to be closer to friends. The only limitation to moving is that the persons must honor their one-year lease.

MacDonald Training Center sold all their residential properties and chose to lease instead. This significantly reduces upkeep costs and allows persons with developmental disabilities to move if they choose when their lease expires. Also, when providing supported living services, the agency does not have to be concerned with local government zoning and licensing issues. Currently, the homes are scattered throughout the county, but, if persons choose, they may live next door to each other without dealing with local zoning and the 1,000 foot rule.

The agency also provides supported living services to persons without live in-companions. These individuals receive an array of services that are “wrapped around” to provide the full array of services. Another 20 persons receive, other than work-related services, only supported living coaching. Consistency of services and continuity may be easier to achieve when one program is providing and coordinating services.

Lunch Activity

There was a working lunch that included an activity. The group was asked to look at the Young Girl and Old Woman illusion shown below and asked to find the young girl and the old woman. There was a brief discussion about shifting perspectives and about how each individual views things differently. The activity was used to prepare the group for the discussion that followed.



Discussion

The facilitator stated that the group was going to examine their different views of planned residential communities. The facilitator first asked the group to raise their hands if they were fairly comfortable with the idea of a Planned Residential Community (PRC). She told this group that they were the A group. She then asked the rest of the participants if they were still learning more about planned residential communities and had remaining questions. They said they did. This group was labeled the number One group. Both As and Number Ones were considered winners.

Attachment A, entitled “Planned Residential Community - Desired Qualities”, was used as a discussion document. It presents five descriptions, numbered 1 through 5. References to numbers in the body of the write-up, below, refer to the numbered items in that paper. The facilitator used Attachment A to generate dialogue regarding differences of opinion about the desired characteristics of a PRC. The chart below reflects the comments made during the exercise. As is apparent from this chart, after the teams “got going”, it was not necessary to track the Desired Qualities by number. Therefore, only numbers 1 and 2 from Attachment A are referenced in the write-up.

Comments	
Team A	Team Number 1
<p>Desired Quality 1</p> <ul style="list-style-type: none"> • Team A basically agreed with the first statement in Attachment A. • It is important for persons with intellectual disabilities to have their own space • Freedom of mobility, within the planned community and into the broader community, is essential. 	<p>Desired Quality 1</p> <ul style="list-style-type: none"> • There should be no imposed limits on how persons with intellectual disabilities live their lives. • There should be continual comings and goings of persons with intellectual disabilities from the PRC into the broader community and of persons without intellectual disabilities into the PRC from the broader community. This free

Comments	
Team A	Team Number 1
	<p>exchange with the broader community should not consist only of paid staff.</p> <ul style="list-style-type: none"> • Concern about the term “campus” as implying something large and separate. • The words in number 1 of the Desired Qualities paper are not clear and should be specifically defined.

Comments	
Team A	Team Number 1
<p>Desired Quality 2</p> <ul style="list-style-type: none"> • A PRC should be set in and part of the broader community. Its “boundaries” should be invisible. • PRC is a concept and not a place. • If a PRC is everything, then it is nothing. We want something special for our family members with intellectual disabilities. • A PRC must be a place that facilitates access to the broader community. There should be an easy, seamless flow just as from any neighborhood to the broader community. • Access to services should not be dependent on where someone lives. Persons with developmental disabilities should be able to get Waiver services without regard to their living setting. • Money should follow the person. • Why is the discussion focused on persons with intellectual disabilities when persons with other disabilities face the same issues and challenges? A PRC should be open to everyone. • There are PRCs for other populations, and they are not questioned or subject to rules like the 1,000 foot rule. Examples are retirement communities and communities for veterans (the members of these communities receive federal funds through the VA). Why is there a need to regulate communities where people with developmental disabilities live? 	<p>Desired Quality 2</p> <ul style="list-style-type: none"> • A PRC should be open to all persons with disabilities. • The PRC does not currently exist as a residential option. The question is whether we should have this option available. Should we let the market decide if this option is desirable? This is a value/belief-driven discussion, and the decision should be a public policy question. • There should be continual and easy access to the broader community. • Interactions of the PRC with the broader community should be individually-driven and not group-based. • The person’s preferences for activities should drive their interactions with the broader community. • Why would the 1,000 foot rule be eliminated just for PRCs and not for all situations? If there is no 1,000 foot rule for persons with developmental disabilities, then there should be no such rule for persons with other disabilities or special circumstances.

Panel on Residential Regulations

Because of the room setup, it really was not possible to have a panel discussion; therefore, each agency representative made a short presentation and answered questions.

The first presentation was by Molly McKinstry from the Agency for Health Care Administration. She spoke on the regulations for ALFs. Her PowerPoint is available on the FDDC Website. Below is a brief summary of her comments.

There are 1,836 licensed ALFs in Florida, with about 58% of these having the capacity to serve ten or fewer persons. Ms. McKinstry clarified that any program that meets the definition of an ALF must be licensed unless they fall under a list of exemptions in the regulations. Facilities licensed by the Agency for Persons with Disabilities do not have to be licensed as ALFs, since they are already licensed as residential providers. [The following clarification is added for benefit of the reader]. This means that “any private home, boarding home, home for the aged, or other residential facility, whether operated for profit or not, which undertakes through its ownership or management to provide housing, meals, and one or more personal services for a period exceeding 24 hours to one or more adults who are not relatives of the owner or administrator” (Chapter 429, Florida Statutes). Ms. McKinstry also emphasized that there are very heavy fines for operating an unlicensed program.

Ms. McKinstry also shared a form entitled, “Community Residential Home Affidavit of Compliance with Chapter 419, Florida Statutes for Assisted Living Facilities”. The purpose of the form is to ensure that the zoning regulations for the 1,000 foot rule (as well as other regulations) are followed prior to licensing. The form states that six or fewer beds can receive a variance from local zoning authorities to allow them to have homes closer than 1,000 feet. Also, the form states that facilities with 7-14 beds can receive such a variance if they wish to locate a facility within 1,200 feet from another community residential home or within 500 feet of an area zoned single-family. The issue appears to be that of local government control of land use.

Vicki McCrary presented for Tom Rice on licensure requirements. Vicki went over the requirements outlined in 65 G-2 of the F.A.C., which provides the necessary information regarding licensure of family foster homes and group homes. Deb Blizzard discussed supported living and confirmed that there are many options for putting services together for this population. She briefly discussed how persons can be approved for the quarter hour in-home services in addition to the in-home companion if they have extensive needs. She also stated that there is no longer a density requirement for supported living, which means that several people with developmental disabilities can choose to live in the same apartment building without the application of a “density” factor.

Public Comment

The following persons provided public comment.

- Eugenie Klausmen
- Susan Thiele
- Doreen Stewart
- Simone Tetreault
- Richard Stinson

Unfortunately, the person responsible for recording the public comments thought that the session was being electronically recorded and did not capture the comments. Each individual will be asked to send a brief summary of their comments.

Homework Assignment

At the end of the day, the facilitator asked that the workgroup members wrestle with the question, “What is your vision of a Planned Residential Community?” Members were asked to define the concept and tell the group how they thought the concept should be implemented, including in their response what a PRC is, where it should be located, how it should be operated, how it could be funded, and how it would be sustained. The homework should be submitted to the facilitator at celesteputnam@earthlink.net.

Attachment A

Planned Residential Community

Desired Qualities

Planned Residential Community
Desired Qualities

- 1. A place where persons with intellectual disabilities can live together, have friends, have their own space, have the ability to move freely around the campus, feel completely accepted and valued, and be safe.**
- 2. A place with easy access to the broader community, with regular on-going transportation (either independently or assisted); and opportunities to work, socialize, attend religious functions, participate in recreational activities on a regular basis as the individual desires, and interact and create friendships with people that do and do not have disabilities.**
- 3. A place where family and friends are always welcome to visit and be with their loved ones.**
- 4. A place where a person can establish their own “natural rhythm” with natural supports and personally chosen friendships, and where after-hours socializing, networking, and shared interests can evolve.**
- 5. A place that combines affordable housing (with varying levels of support depending upon individual needs) with services that promote development of relationships among neighbors and the development of natural supports that extend beyond family, staff, and volunteers.**