



FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL

Alternative Residential Options Work Group

August 25, 2009 * 10:00 am – 4:00 pm

RENAISSANCE ORLANDO HOTEL AIRPORT

5445 Forbes Place. * Orlando, FL

MEETING NOTES

Attendance Chart

NAME	REPRESENTING	ATTENDED	COMMENTS
WORK GROUP MEMBERS			
Mary Beth Date	Governor's Office on Policy and Budget	No (listened via conference call)	Mary Beth Date replaced Tim Lawson
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 Stargell and Rachel Barnes	Her office	Yes	
Representative Bill Galvano		No	
Representative Sachs	Her Office	No	
Sheryl Soukup	Immokalee Non-Profit Housing	Yes	
Richard Chapman	Executive Director, ADAPT Florida	Yes	Self-advocacy organization
Kingsley Ross	Autism Society of Florida	Yes	(for Ven Sequenza on the phone)
Lila Klausman	Parent Planning Program	Yes	
Tito Balduci	Home Choice Supporters	Yes	
Damian Gregory	Self-Advocate and former Support Coordinator	Yes	
Leigh Meadows	Agency for Health Care Administration (AHCA)	No	
Suzanne Sewell	Florida Association of Rehabilitation Facilities	No	
Jack Kosik	Noah's Ark of Central Florida	Yes	
Betty Kay Clements	Family Care Council Florida	Yes	
Sylvia Smith	Advocacy Center	Yes	
Janice Phillips	Association of Support Coordinators Agencies	No	
Deborah Linton	ARC Florida	No	
Debra Dowds	FDDC	Yes	
Susan Goldstein		No	

NAME	REPRESENTING
PRESENTERS	
Susan Gold	Chair, Florida Developmental Disabilities Council
Susan Thiele	Earthserves Village
Jim Whitaker	ARC Jacksonville
Simone Tetreault	Statewide Coalition for Expanded Residential Options
Carl Penax	Loveland Center
Manyone Champavannarath	Self-Advocate

Windy McCarthy	LifeShare
Derrick Dufrense	Private Consultant
GUESTS	
Betsy Farmer	
Margaret McNutt	
John Maciarz	
Doreen Maciarz	
Eugenie Amalfitano	
Judy Owen	
FDDC STAFF	
Latarsha Williams	
Vanda Bowman	

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 went over the agenda and asked the participants to review the "Way of Work" that was created at the last workgroup meeting.

Guest Presentations on Residential Options

Six persons were requested to present in the morning. The presenters were selected based upon recommendations from the workgroup and were intended to provide the workgroup with additional information and perspectives regarding residential options. Four presenters focused on different approaches to Planned Residential Communities, one discussed her experience purchasing her own home, another discussed the need for an array of residential services from the perspective of the family, and, lastly, a short presentation was given on Lifeshare. A summary of the presentations is provided, below, in order of the presentations.

1. Jim Whitaker, Executive Director of the ARC Jacksonville

Jim Whitaker, the Executive Director of the ARC Jacksonville presented a proposal to use state property around the former Hodges Cluster to develop a planned community. At the beginning of his presentation he provided the participants with a handout entitled, "*Hodges Property Proposal and Concept Paper.*" The project is in the planning stage at this time and is based upon a preferences expressed by family members and persons with intellectual disabilities in the Jacksonville area. The planning group would like a place for persons with intellectual disabilities to socialize and recreate. They believe that a "community" must go beyond shelter, food and clothing and provide opportunities for friendship, and leisure. In this design, the planned residential community will be available only to persons with developmental disabilities. The plans include fifteen

single occupancy condominium units that will include staff support according to the individual needs. Additional apartments and group homes may be added. The intention to access employment, recreational and social pursuits in the broader Jacksonville community is also included in the concept. The area has seen an increase in commercial development which would provide job opportunities within close proximity to the homes. The ARC is working with the local YMCA to entice them to locate a facility on the grounds. Transportation to sites in the community will be provided by the ARC. The ARC intends to own the property, dwellings and provide services on-site. Mr. Whitaker stated that the program could be licensed as an Assisted Living Facility (ALF) but he would also like the opportunity to be licensed as a group home but the "1000" foot rule is an impediment. The ARC plans to use Home and Community Based Waiver dollars to fund the services. Funding for construction will have to come from other sources.

2. Susan Thiele presented information on Earthserve Village.

Earthserve Village is also in the planning stage. The intention is to create sustainable community for persons with disabilities. According to Ms. Thiele, the program will serve persons with many different types of disabilities. The identified property is a 30 acre track located on a 500 acre section of land owned by the state that is adjacent to Tacachale (a large institutional setting for persons with intellectual disabilities). A new road could be developed that would allow independent access to the Village. The program would share infrastructure with Tacachale. The program would serve persons with a range of functioning levels and would provide transportation for involvement in the broader community of Gainesville. Also, the planners hope to have a bus stop nearby to enable persons to independently access the broader community. The community is conceptualized as a "green" development (environmentally sensitive) and will be based on innovative service staffing models including volunteers, companions and perhaps Americorp workers. Alternative funding sources are contemplated as well as individual ownership of the homes if possible. The ideas for this project are still evolving as the planners seek innovative solutions.

3. Simone Tetreault with the Statewide Coalition for Expanded Residential Options presented information about the organization.

The Coalition is a new organization open to all interested parties who want to expand residential options for persons with disabilities. The organization would like to become an educational center for best practices. The Coalition members believe that currently persons with the most severe disabilities must live in the most restrictive environments. They have some serious issues with the current group home programs and she stated that because of the location of the homes, persons living in these environments tend to be isolated. She emphasized the planned residential communities could provide other options for group living that would not have the current shortcomings of the current group home situations.

4. Loveland Center presented by Carl Penax

Loveland Center is located in Venice Florida and situated like a college campus serving approximately 120 persons. The Center currently provides affordable housing and according to Mr. Penax, gives persons an opportunity to live where they chose. Currently, 50% of the persons living at the Center are over the age of 50. The Center is now considering expansion. They have obtained zoning approval for forty self-contained one to four bedroom apartments. They hope to be able to keep the rent at a low level and are working with the Florida Finance Corporation to fund the project. There is an adult day training facility nearby. The program provides transportation to the community as well.

5. Manyone Champavannarath, Self Advocate presented on Support Living

Ms. Cahmpavannarath provided an overview of the advantages of having her own home. She is a well educated self-advocate with physical disabilities who prefers to live alone in her own home with supports. She recently purchased a lovely home and believes that the option to live alone should be available to others. She enjoys living, working and socializing in inclusive environments.

6. Windy McCarty presented on Lifeshare Florida

The Lifeshare program in Florida provides mentoring, coaching and other community supports for adolescents and young adults primarily in the child welfare system. The services are intended to help the young person plan their future and access the supports necessary to “live their life”. Although adaptable to the needs of persons with developmental disabilities, that is not the current focus of the program

Lunch Activity

There was a working lunch that included an activity. Topic areas of residential options including group homes, supported living, life share and planned residential community were displayed on flipcharts. The participants were asked to place cards under each of the options indicating what they believed to be the good qualities of the option and what they want to know more about for each option. The purpose of the activity was to determine what items the participant believed were strong points of each option and what areas need further study and understanding. Below is a summary of the comments made during the activity. Please note that duplicative comments and those that were similar in meaning were collapsed into one comment.

Group Homes	
Good Qualities	Want To Know More About
Provides more individualized care.	Lack of services to address the “whole person” (e.g., a “shuttle” service between the house and day programs)
Staff are available when needed by residents.	Safety (broadly defined) a top concern
Makes it easier to provides services, such as transportation, care, etc.	Potential for abuse (not many eyes and ears)
Organizes a predictable schedule.	Services are too routine and based upon the needs of the group and not the individual.
Puts residents out in the community.	Depressing, institution-like environment
OK for some family members on the workgroup if group homes are operated as part of a Planned Residential Community (PRC)	No choice of providers such as staff and programs
Provides opportunity to develop friendships and to socialize with other individuals with developmental disabilities (while not having to do everything with the other residents).	Group homes are only a place to live. They do not provide a program of activities or a social support system. There is no guaranty of continued care or stability.
<p>Ideally, can operate while keeping each individual resident in mind:</p> <ul style="list-style-type: none"> • Each can work at different places of employment, or ADT, or whatever they choose. • They can join the clubs they want to join and be assured they will get there. • They can have friends in for lunch or a party. 	<p>Lack of individual decision-making, lack of freedom for residents to follow their own schedule instead of a routine mostly prescribed by the provider, and lack of food choice, with everyone eating the same meals; how to facilitate choice/control over:</p> <ul style="list-style-type: none"> • Who do I live with? • What do I do during the day? • When can I do what I want to do?
Promotes a stable staff with minimal turnover.	Use of “pool” staff who do not get to know the residents as individuals, their personal choices, emotional needs, and often their medical needs
	Low wages of staff resulting in high turnover rates
	Lack of appropriate training for staff about

Group Homes	
Good Qualities	Want To Know More About
	types of disabilities
	Funding cuts result in poorer services
	Questionable ability to survive in the current economic and political arena, resulting in a lack of quality ownership or management
	Confinement

Supported Living	
Good Qualities	Want To Know More About
Individual freedom, with less provider control over what happens in a resident's home	Social isolation (for instance, residing in an apartment house where the other residents do not include the person with developmental disabilities in social or neighborly interactions, thinking "Not in my backyard")
Driven by more consumer choices; person has a great deal of control	Inability to interact with neighbors because they don't understand the persons way of communicating.
Wonderful option to meet many needs at many locations	Need to find ways to address social isolation: <ul style="list-style-type: none"> • Combine with housing/neighborhood-based services designed to build relationships amongst neighbors • Intentionally creating "density"
Provides family-type of support and caring, while providing opportunities to be a part of the whole community.	Inability to access transportation or companion services (e.g., companions not available on Sundays)
Good for people who can communicate (e.g., use the telephone, express needs, exercise independence, etc.)	Currently, there often is not adequate support, or oversight as to abuse by providers or others.
The help the consumer needs when they need it- flexible ability to increase and decrease services as needed.	Not appropriate for persons with low intellectual functioning
Promotes a sense of accomplishment and the ability to live as others do, while still having needs met with supports.	If the person gets lost or find themselves in a difficult situation they may not be able to explain to strangers their situation or ask for help
Provides a stepping-stone to develop independent living skills and self-esteem (if a proper level of supports exists); person learns responsibility.	Poor supports: <ul style="list-style-type: none"> • Non-caring • Turnover • Fraud
Provides opportunities for a wide range of life experiences with a wide range of individuals.	Lack of adequate funding for needs that exist (startups, subsidies, etc.)

Life Share	
Good Qualities	Want To Know More About
Provides a more individualized approach.	Costs
Fills emotional need of belonging.	How easy is it to ramp up services?
Provides sense of family to those who may not have family, supporting people in a family environment.	Uncertain transition to life
Listens to the needs and desires of clients as they express them (as distinct from the needs and desires that their families or advocates may express) and attempts to tailor services to those needs and desires.	

Planned Residential Communities	
Good Qualities	Want To Know More About
Community understanding of diverse needs; flexibility in meeting daily needs of socialization, in movement into and out of the PRC, and in types of residences	The labeling that comes with concentration of persons with like conditions in the same area and the negative connotation that will likely occur with time; we don't want our loved ones to live in "the projects"; fear of "those people" who live in regular low-income housing; fear of crime as a given in affordable housing communities
Works throughout the person's lifespan	No uniform definition of the term PRC
Easy access to the community at large, with opportunities to work and recreate within and outside the planned community	Need for case-by-case, multi-factor determination if characteristics are "home and community-based"
Provision of a variety of amenities (pool, community center, ball field, etc.) and related activities; enriching activities	In 30 years, who decides who lives at a new PRC?
More opportunities for socialization, companionship, and community inclusion, with a variety of individuals in a neighborhood-type environment	Potential for institutional-type environment

Planned Residential Communities	
Good Qualities	Want To Know More About
Environment provides safety and security. My family member can take a walk by himself because his neighbors know him and can help if he gets lost. There is freedom from fear of molestation or danger from traffic.	How to ensure a person's safety (particularly when/if family members are not involved in the individual's life)
Social, educational, and recreational opportunities offered where people live, reduces barriers to participation (Note: Important to remember that relationships will be developed with others who participate. So, if only persons with developmental disabilities participate, relationships will be more limited to others with disabilities.)	Restricted to persons with developmental disabilities (even if families of the individuals and/or caregivers are included); segregation/isolation of persons with developmental disabilities from the non-disabled community
Built-in and developing natural supports (inter- and intra-dependence)	Possible removal of all risks, challenges, lessons, and experiences associated with broader, less protective community living (for some, too unnecessarily protective); opportunities for life experiences governed more by the community than the individual
Fun, friends, and family (extended); activities and peers nearby and accessible; a place to belong	Risk of missing out on the "web affect" that occurs as neighbors move and connect an individual with new people and opportunities in the larger community
Recognizes the need for persons with developmental disabilities to belong and have a sense of community.	Does not solve system-wide problems with provider-driven day activities, staffing problems, available funding etc.
Offers additional likelihood of meeting cognitively similar peers so that a true natural buddy system can develop. After-hours socializing, networking, and shared interest gatherings can evolve.	When social, educational, and recreational opportunities are provided in a housing community and you "bring in" others without disabilities to participate, you can have the reverse situation described at Loveland: when the structured activities are over, people who live there who don't have their own transportation are stuck there and may not have the freedom to visit their family and/or friends without disabilities.

Planned Residential Communities	
Good Qualities	Want To Know More About
I like the PRC because they have planned activities on weekends	Limits (although it does not eliminate) development of natural supports and relationships with people who are not either a) caregiver, b) family member or, c) volunteer.
Jobs are available based upon the persons preference and the person can get the supports necessary to accomplish the tasks and have a sense of achievement.	Services linked to housing provider; protection required so that individuals are not influenced to use a provider or accept things that otherwise might be unacceptable to avoid losing their housing (or vice versa)
At Loveland, there appears to be an attempt to meet the expressed needs of clients to spend more time with their friends from Loveland when they are not participating in a scheduled Loveland activity.	Parents and families cannot always separate what they want for their child and what that child would choose.
Comprehensive services, not a la carte only	Restricted deeds; lack of cross-disability/aging approach
Leveraging resources (human and financial), serving many people with a single administrative effort (e.g., single zoning approval, single certificate of occupancy, etc.)	Concern with the stability of financial and other resources to keep the PRC at optimum operational capability such as upkeep of the buildings and grounds, on-going services
Potential for better oversight; involves the eyes and ears of many people	Not enough watching eyes
Idealism	Too much Idealism- operational issues are not clearly defined.
Utilization of both paid and natural supports	
Affordable to people	
Easier transportation arrangements and probably lower costs	
Innovative providers	
People sharing common interests	
Getting serious about aging	

Planned Residential Communities	
Good Qualities	Want To Know More About
L'Arche communities, "where people with and without disabilities share their lives together" (larcheusa.org): in such a community, it is possible to create affordable housing opportunities in which extensive services are provided that promote development of relationships amongst neighbors and development of natural supports that extend beyond family members and volunteers.	
It is possible to screen all applicants of an affordable housing rental community to prevent criminal activity (which can also be enforced through leases and can be further prevented through neighborhood services).	
Provides a variety of options; makes more choices available to meet varying needs and likes.	

Another presentation occurred after lunch and is summarized below.

Presentation: Derrick Dufrense on National Residential Options

Mr. Dufrense was scheduled to discuss several different options that have been put in place throughout the nation that address some of the concerns raised by the workgroup and has the characteristics identified by the workgroup. The presentation was quite different than what the meeting planners expected. The following key points were made. Unfortunately the speaker did not provide any handouts.

- Persons with developmental disabilities currently outlive their parents.
- There is a great deal of variability in the functional abilities of persons with developmental disabilities.
- No other states have five Planned Residential Communities in the planning stage.
- He stated that in his opinion the option of Planned Residential Communities present dangers and because the ideas appear new to a group doesn't mean that it is a new idea.

- His personal experience leads him to believe that people with severe disabilities can be part of the community.
- Decisions have long term implications.
- He is concerned that available staff will become harder to obtain.
- He has concern that the new CMS rule will look at issues such as density, size, ownership etc.
- He talked about a “small community” which could be a group of persons interacting together in a small closed circle and the “big community” as the general community.
- He believes that self-determination should be a major factor.
- He cautioned that the public sector is moving toward funding services not buildings.
- The stress on the public sector to provide services is enormous. The public sector will not be able to address everyone’s needs.
- He stated that it is not regulations that keep people safe but other people.
- It is unhealthy to be isolated and lonely.
- He suggested that the workgroup become familiar with the positions taken by the ARC. And other national web-sites.
- He promised to send a bibliography regarding residential programs that have provided innovation ways to address high quality options that address the workgroups desired characteristics of residential options.

The workgroup participants were given copies of the “stories” sent to the Council over the last few weeks that described the residential issues that families and individuals are facing in Florida. The participants were asked to complete a homework assignment using the stories. Step one is to identify each of the supports that the individual will need to live successfully in the desired environment. The second step is to choose another residential option for the persons and to identify the supports the person needs to live in that environment. Responses are due one week before the next meeting on October 15th.

Public Comments summarized below:

1. Ven Sequenza- He expressed concern that the group may be caught up on the “fear factor”. He stated concern regarding whether any group should have the authority about what options should be available. He stated that there are many good group homes but he doesn’t believe that the residents really have much interaction or involvement in community living. He also believes that paid staff are going to continue to have to be involved. He thinks that the main concern is whether people should have an option for planned residential communities.
2. Susan Thiele- Ms. Thiele stated that she used her knowledge of best practices and data to convince schools and others to allow her son to be part of an inclusive setting. As she looks back on the situation she doesn’t think that integration was the best option for her son. Families and individuals with developmental disabilities need other options and innovative practices to solve the lack of residential options dilemma.
3. Betsy Farmer- She shared information on the “Promise” residential planned community which she is working on. Her vision is that people will be able to live and work in close proximity and will have access to a gym, food court, and accessible swimming pools. The idea reflects a residential program that is a combination of an ALF and college dorm. She would like to see one and two bedrooms that open to a shared suite.

The meeting adjourned on time. Participants were thanked for their time and commitment to the project. They were urged to complete the homework assignment.