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*SUPPORTIVE LIVING:
A SINGLE SOLUTION? No.
A VALUE? YES*

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by

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SUPPORTIVE LIVING: A SINGLE SOLUTION? (NO)-A VALUE? (YES)

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Every five years or so throughout the past two decades, progressive professionals in the field of disabilities have discovered a new answer, a new model or new "magic" to providing residential services for people with disabilities. The most recent concept to emerge within this trend is known as "Supportive living." Contrary to popular opinion, however, supportive living has not come to us as a single solution or a model approach with a single set of procedures to be applied to all people with disabilities whom we assist with residential supports. Rather, to embrace the concept of supportive living is to acknowledge that we must give up the notion of a perfect model, a single answer, or magical solutions to the challenges posed in providing residential supports.

In order to understand and embrace the principles of what supportive living is, it is important for us to review what it is not. The article will begin with an introduction to what supportive living is not by examining components of traditional residential services which have served to further segregate and isolate people with disabilities from our communities. Following this section, a discussion of what supportive living is not will continue by examining how the rejection of traditional residential services has been handled by some programs. The article will conclude with a brief look at what supportive living is by examining principles which can guide us towards a way of assisting people with disabilities to receive the residential supports they need in homes they choose and control.

Traditional Residential Services: What Supportive Living is Not

Traditional residential services created places where people with disabilities went to get the services and treatment they needed. In this section are presented the following components of traditional residential services in order to address what supportive living is not: program and professional paradigm, readiness and movement, community-based services, determining ability through assessment, and criteria which determine expectation.

Program and professional paradigm. Although many of the places where people live are called houses or homes, both people who work and live in these places describe them as programs. They are typically referred to by an agency name (UCP group home), street name (Alder Street group home), provider name (Warehimes group home), famous person's name (Kennedy group home), or a corporation name (New Life Center, Inc.). By giving programs professional sounding names, it follows that these programs then need professionals to work in them. These professionals must be well trained experts who know how to provide programming and deal with the problems that will arise within the programs.

Readiness and Movement. Once people are accepted into programs they are thought of as needing to progress through some sort of continuum. The professionals involved then put together a treatment plan and training schedule, resulting in what is called an Individual Habilitation or Service Plan. This plan is said to be designed to help people attain the skills necessary to move to the next setting in the continuum, or a less restrictive setting. If things do not go well for people in programs, sometimes they are moved to another (more restrictive) program where professional services are better designed to meet their needs.

Community-based services. Inherent in the name "community based services" is the assumption that such services are based or located within the community. However, despite the common belief that people's presence in a community makes them an actual part of that community, in actuality, this is hardly the case. Not only are people living in places referred to as "home-like" and "family-like" rather than in homes or families, but also traditional community-based services do little toward assisting people to assume roles, responsibilities, and activities that make them a part of their community.

Assessment driven. Programs tend to evaluate people's abilities through the use of assessments to determine and legitimize their programming. Typically the assessments used are composed of a series of questions which determine the things people cannot do. All this information is then compiled and a final set of scores determines into which program a person fits.

Criteria which drive expectation. Each program has its own set of entrance criteria. In order to be eligible to get into a certain program, people need to have or not have some predetermined characteristics. For example, the entrance criteria might state that the program accepts only people who need 24 hour supervision, know how to cook, can take care of their personal hygiene, have a physical disability, have autism, do not need more than 3 hours of attendant care, or are visually impaired.

Recent Program Changes: What Supportive Living Is Not

Having seen the apparent inconsistencies and dehumanizing characteristics of operating residential services using the traditional residential service components described above, some programs have made significant changes in an attempt to be more responsive to what they believed people with disabilities needed. In this section we will address how some programs changed their name, reduced their size, manipulated language, responded to market needs and availability, continued agency ownership, and bought into a new manual or model in order to further illustrate what supportive living is not.

Changed name. In an attempt to be more progressive and to go along with current trends in the field, programs searched for new titles which would better describe what they said they were trying to accomplish. Titles or names such as The Independent Living Program, Personal Care Alternatives, Individual Service Options, Community Options, and Enhanced Family Living began to emerge. Upon closer examination of some of these "new" programs, not much had changed from the old way of viewing and programming people, except the name.

Reduced size. Policies around the country on state, local and agency levels began to emerge which stated that all new programs or group homes would be no larger than fifteen beds, eight beds, six beds, four persons, three persons, or two persons. There is a vision of a big "meat grinder" which larger programs are put into; of course what comes out the other end looks different and is smaller but has the same qualities. Again as we looked more closely size is the only thing that changed in some programs.

Manipulated language. A new set of terminology has begun to emerge that describes programs as promoting choices, community participation, relationships, person centered services, and individualized programming. Unfortunately, even though some programs have these words written in their mission statements, the reality is that few people have choice, participate in community, have friends, have services built around their needs, and have a program which is not shared with others. Even though the language has become more positive, it also has served to confuse what is really occurring for people.

Market needs and availability. Programs responding to the need to downsize and close institutions, serve a large number of people, assure support for people with more intensive needs, and acquire accessible places coupled with the availability of funds to develop congregate housing resulted in the creation of complexes and group living settings which serve people with a specific disability. Some of these programs continue to operate under the premise that these settings are the most appropriate and cost effective for the individuals living there. These programs argue that they were created to respond to the market needs of the system and continue to be the most appropriate and cost effective available.

Continued agency ownership. Agencies have begun to state that they give people an opportunity to have a home of their own. Even though some programs talk of the home as belonging to the person who has the disability, the setting is still referred to by a name other than the person's, the person does not hold the mortgage, the person does not sign the lease, things in the home are still agency owned, and most importantly, the person does not describe the home as his or her own.

New models and manuals. Once an approach seemed to work for one, two, three, or four people, agencies began believing once again that they had found the answer or the most correct model for providing residential services. Program models such as adult foster care and congregate apartment living with communal supports had become the new "magic". Again we fell into the trap of believing that one model would fit everyone. Agencies ran out and bought the latest manual and began setting up programs that still had many of the same qualities as the old ones.

Principles of Supportive Living

Now that we have discussed what supportive living is not, it is time to discuss the excitement many people around the country and in New Hampshire are beginning to experience about the concept of supportive living as envisioned by its conceptualizers. Basically, there are nine major principles of supportive living that will be discussed. They

are: (1) individualization; (2) everybody is ready; (3) future planning; (4) use of connections; (5) flexible supports; (6) combining natural supports, learning, and technology; (7) focusing on what people can do; (8) using language natural to the setting; and (9) ownership and control resides with the person.

1) **Individualization.** Webster's dictionary defines "individual" as a particular being or thing as distinguished from a class, species or collection, as a single human being as contrasted with a social group or institution, as a single organism as distinguished from a group, and as an indivisible entity. Therefore, if we say supportive living is "individual," it must be something that is for one person without exception. This does not mean that everyone has to live alone. What it does mean is that if people want to live with someone else, they choose with whom they live. The magic number becomes one. When people get to be adults in our society they choose to live with others who they are romantically involved with, are close friends, or are relatives. Usually living with a close friend lasts longer than living with a relative. Unfortunately, in our country we have only a fifty per cent chance of continuing to live with the first person who we are romantically involved with. It makes sense that people with disabilities also prefer to have these same choices instead of being congregated or segregated based on their disability. Some people with disabilities need intensive assistance to carry out their everyday tasks. In these situations, people may choose to live with someone who can assist them or may have their assistance provided on a regular schedule or on an on call-basis.

2) **Everybody is ready.** There are no criteria to receive the support being described. Since what occurs is individually designed, there are no prerequisites. We must give up trying to make people ready by simulating how it is to live in a home and begin supporting people to have that home. If people cannot do something, then we can find someone to do it for them rather than requiring them to learn to do it before they will be ready. There is nothing magical about any program, or building. What can be magical is what the program, building, and the people who "hang out" there offer. Our challenge in supportive living is to create this "magic" in the person's home.

3) **Future planning.** It is crucial to those people who are assisting others to find a home and to access needed supports to get to know these individuals, the people in their lives who care about them, their desires and preferences, and what an ideal living situation would look like for each of these people. Once this information is gathered, the people who care about the person get together regularly to develop a plan for getting as close as possible to the ideal living situation.

4) **Use of connections.** Our traditional residential services relied predominantly on system solutions to concerns and problems. By relying only on system solutions a whole wealth of potential resources is ignored. One of the components of supportive living is eliciting the assistance of all who want to and can help. Therefore, people who care about the individual along with the individual should continually ask, "Who do we know who can help?", "Who do we know who will help us think about it?", and "Who will ask for their assistance?"

5) **Flexible supports.** Support is based on the individual's schedule and needs, not on a program's. Individuals receive support where, when, how, and with whom it is needed. Any support given must be flexible enough to be adjusted based on the individual's changing needs, preferences, and desires.

6) **Combining natural supports, learning, and technology.** Whenever possible,

supports which are natural to the place, time, delivery, and person are sought. The designing of individual supports takes into consideration opportunities for individuals to learn to provide their own support, for it to be more natural, and to use technology which may give the person more control.

7) **Focusing on what people can do.** Traditional residential programs focused predominantly on what people could not do and tried to offer a treatment plan designed to teach people how to do what they could not do. Supportive living focuses on what people can do, provides support for things people cannot do, and provides opportunities for them to learn how to do the things they want to do.

8) **Using language that is natural to the setting.** Supportive living includes language that is natural and promotes inclusion. Thus, places people live are described as Joe's home, or Mary's home; people clean their home and do their laundry rather than learn programs; people live with roommates, not with staff or providers; friends come over to visit, not volunteers; and people are referred to as neighbors, friends and citizens, rather than clients, consumers, and residents. As we begin to give up talking about "them", "those people", and "they", our language becomes more inclusive and guides our actions.

9) **Ownership and control.** Lastly and most importantly, the home is the person's and that person controls the support that is received. Home ownership does not mean that most individuals with disabilities who do not have many financial resources will hold the mortgage to a home. It does mean, however, that they sign the lease, things in the home belong to them, and the place is their home. In addition, roommates sub-let from the person, support people are hired by the person, and support people respond to the need for assistance when, where, and how it is needed.

In summary, supportive living is not a model, the answer, or some new magic. It is, however, a way of viewing people and assisting them in ways that enable these individuals to receive the support they need and to live in a home they want. When asked about what model they were using in North Dakota for 598 people who receive funding under a category called supportive living, Russ Pitsley said, "We have 598 models."

In order for us to promote this shift towards supportive living, we must remember where we came from, recognize some of our recent responses, and make that paradigm shift everyone is talking about. This will require us to do things much differently than we did in the past. We cannot add another "rung" on the continuum. We will need to focus our efforts on assisting people to receive the supports they need to live beside us in places they can call their homes.