

PHILOSOPHY & VALUES COMMUNITY MEMBERSHIP

Overview/Definitions:

Within communities, people come to know, value and depend on each other. Community members develop a sense of identity and a feeling of belonging that comes from being actively involved. Each community has its own flavor; large or small, each has a different combination of attitudes, behaviors, options and customs. Communities are often made up of people of varying ethnic backgrounds, and perhaps languages. The full and open celebration of this diversity can greatly enrich the lives of all community members.

There are several levels of community involvement:

1. Presence: Simply being present, watching the interaction of others. The role played is spectator.
2. Participation: No meaningful interaction takes place. The role played is consumer of services.
3. Interaction: Beginning to develop friendly interactions with people we see on a regular basis, or with whom we share a particular interest. We are in the role of acquaintance.
4. Interdependence: People are counting on us. We count on others. When we are not present, we are missed. We are truly a member who belongs to this community. Our role is friend.

Most of us are able to *choose* the level of involvement we have with our communities, and that level may change over the course of our lives. People with disabilities often do not have any opportunity to advance beyond level one or two, regardless of what they might wish. Many people with disabilities have been, and still are, removed from the daily life of their communities. Those persons are cut off from the experience of “belonging”, which community membership can provide. Other community members are, in turn, denied the opportunity to know the person and the benefits and richness that person would have contributed to community life.

When people are segregated from the community, a message is sent to other community members that the segregated person is *different*, that he or she cannot function in the community, and that he or she requires some type of special treatment. In the extreme, this can foster the notion that these different people are *dangerous*. At a minimum, it reinforces the idea that people with disabilities are not like others.

Applicable Rules and Regulations: (<http://dmh.mo.gov/docs/dd/QualityoutMan.pdf>)

Quality Outcome # 1: People belong to their community.

Quality Outcome # 2: People have a variety of personal relationships.

Quality Outcome # 3: People have valued roles in their family and in their community.

Quality Outcome # 4: People are connected with their past.

Quality Outcome # 5: People’s communication is understood and receives a response.

Quality Outcome # 8: People express their own personal identity.

Guiding Principles:

The goals are for people to:

- Have days that are as diverse and enriching as others in the community.
- Be supported in efforts to actively participate in community life.
- Be familiar with their communities.
- Use generic community resources as others do, not depending on “special” services.

Support Coordinator Roles/Responsibility:

1. Helping people express their identity:

Other people in the community who meet people with disabilities see not only the person, but also how *we* feel about and respond to them. If we are interested in what the person has to say, others may model this interaction or believe the person has value. Support coordinators (formally known as service coordinator) can prepare people to be community members by helping them enhance their self-image and learn how to express their personal identity.

This is extremely difficult for many people we support, because they have had fewer life experiences, and have lived segregated lives with a smaller social circle. In order to express our personal style, opinions and preferences, we have to have a variety of experiences from which to form a self-image. As human beings we develop a sense of “me” and “mine,” and at times go to great lengths to protect it.

Many people with disabilities have never been asked for their opinions. Quite to the contrary, they have been told what they need and what they should want, and how they should behave. Often, people we support look to us, and worry about displeasing staff, so they adopt our views. They don’t even know what their own opinions are. We need to help people begin to feel comfortable expressing how they feel. We may even have to help them label their feelings or opinions.

We may have to help them explore different choices in dress, hairstyle, and places to go, etc., in order to assist them in learning more about what they like and dislike.

A support coordinator’s responsibility is to follow these best practices:

- Have positive expectations. When in the community, use any available avenue to express these positive beliefs to others.
- Look for ways to let the person know he or she is valued.
- Look for ways to support others in finding things to value about the person.
- Listen to and respond with interest.
- See the person’s positive attributes. Regularly share those observations, even when the person’s behavior may be less than likeable.

- Encourage the person to develop and express personal opinions and preferences.
- Respect the person's right to hold and express his or her own views, even when those views do not agree with your own.
- Help the person express what he or she likes and doesn't like, and support the person to incorporate some of the things he or she likes into daily activities.
- Work to increase the person's exposure to a variety of opinions, including his or her own.
- Know the individual well enough to know to what degree he or she has developed their own personal style. Help people to express their own style. Assist in ensuring that the person has access to those things which will support him in expressing his own style. If the person doesn't yet have a defined sense of personal style, assure that the person's life includes exposure to a wide variety of people, activities, events and ideas.

2. Helping with relationships and connection to the past:

Part of our image of ourselves is developed through a sense of "belonging" to our family, our friendship network, our communities, school or work, and our faith community. Each of these types of relationships offers a different level of support and involvement, and helps shape our identities. People with disabilities, particularly those who live in segregated settings, often do not have these relationships. It is not uncommon in these situations to find that the person has no relationships at all, except with staff that is paid to be with them. Try to imagine the social isolation and diminished sense of self-worth which accompanies this.

Another way in which we form our self-image is through knowledge of our own personal history. This can include knowing our family history and heritage. Sometimes people with disabilities, particularly those who may have lived in settings away from their families for many years, have lost touch with their families. Sometimes, a way to support an individual can be to help him or her re-establish contact with relatives. It may be helpful to assist the person to collect some family or hometown photographs to put in an album or to listen to him or her speak about his or her memories.

Real relationships add warmth and meaning to our lives. Relationships teach responsibility and enhance self-esteem. We need to help people find ways to develop friendships in their community. Frequently, the single thing people need most is others who truly care about them as individuals, and to have others they can truly care about in return. People need to be supported in developing and sustaining current friendships, reestablishing relationships with people in their past, and sometimes in developing and sustaining responsible, consenting, intimate relationships.

Real friendships are formed by regularly seeing someone and getting to know them over time. This requires long term commitment with recurrent attempts to establish contact with others. Many times, people with disabilities only have community contact during organized group events, which have the flavor of "field trips" or "outings". These usually are one-time trips,

making the possibility of forming and sustaining an outside friendship virtually impossible. Support coordinators need to identify the opportunities for repeated contact in the community.

Sometimes we develop friendships with people who share the same interests and competencies. Support coordinators need to assist others to see the person's abilities rather than the disability. Support coordinators can assist people to get involved in the things they are interested in and good at. If a person likes plants, maybe he or she could do paid or volunteer work at a local nursery. If the person likes little kids, maybe he or she could assist with story hour at the library.

Intimacy is a part of life, which is often denied to persons with disabilities. This has two aspects which support coordinators need to understand. In fact, persons with disabilities may have very limited understanding of their rights to their own personal space. People need to have opportunities to learn about loving and caring in warm supportive environments where they feel free to talk about what they are feeling and experiencing, but they need to understand the importance of the responsibilities that go along with such a relationship.

The support coordinator needs to know whom the person likes and with whom he or she wants to maintain a relationship. They need to know how to contact people with whom the person has a relationship and support the person in calling, writing, or visiting. They need to know enough about the person to be able to provide support in continuing the relationship.

People with disabilities do not always know the socially acceptable way to greet others, express happiness at seeing them, or interact in general. When people deviate from the norms of society, it can leave others with a negative impression, which does not do justice to the sentiment in the heart of the person. Others in the community may be very uncomfortable around or even afraid of the person.

If the goal is to develop and maintain relationships with others, the person will need to learn to use these skills. Support coordinators should support the person in understanding the unwritten rules of social interaction (for example, we may hug our family or very close friends, but shake hands with those we don't know well). Support coordinators need to help the person in learning what to expect with others, and model appropriate interactions.

A support coordinator's responsibility is to follow these best practices:

- Support the person in getting information about family and friends and help him or her connect with the past.
- Listen to the individual talk about his or her personal history in order to better understand the person, and if new staff begins working with the person, make sure the personal history is passed on in a manner that is respectful of the person and his or her family.

- Know whom the person's friends and families are and talk to them about ways to nurture the relationship (keeping important information such as addresses, phone numbers, birthdays and anniversaries).
- Support them in reconnecting with family members or friends from the past, in keeping snapshots and other memorabilia or to keep favorite possessions that once belonged to someone who is important to them.
- Helping people learn about the responsibilities that go along with relationships.
- Support people in meeting new people and adding to their circle of support.

3. Providing Support with Communication and Other Needs

For friendships to occur, people need to be able to communicate. We build relationships with others through communication. People with disabilities have had limited opportunities at communication within the community. In fact, most of the people who listen to them are paid to do so. Some people do not use words to communicate or they may have limited verbal skills. The person's communications need to be recognized, responded to, and supported. Without support, these people are cut off from the rest of the world. They need:

- Opportunities to communicate in a variety of settings with a variety of people.
- Supports and/or services to enhance functional communication.
- Alternative or augmentative communication systems which are functional, if needed, and available for use at all times in all environments.

Support coordinators need to know the types of people and situations the person would enjoy and support the person to access those situations on a regular basis. Support coordinators can facilitate communication between the person and others, but should be careful not to speak FOR them.

For those who need supports, these supports should be considered as crucial to the success of inclusion. Support coordinators need to respond to these needs with a sense of urgency. They should work proactively to determine what method of communication or types of augmentative system works best for the person. It should meet the person's own unique functional needs in the places he or she will use it and in the manner in which he or she will use it. A person should never be without a means of communication that works for him or her in that setting. We need to be sure that those who will be interacting with the person on a regular basis (friends, family, and staff) learn the person's means of communication. We need to offer opportunities for them to learn, both formally and informally, the means of communication a person uses.

Our homes reflect our personalities, with all kinds of personal items such as art, memorabilia, books, pictures, hobbies, etc. These give us something to talk about.

In homes of people with disabilities, most of these things are confined to the bedroom areas and the living rooms take on the sterile flavor of a motel lobby or a waiting room. It limits the number of things to start conversation about. We need to support people in incorporating things into their main living areas, which reflect their personal style, experiences or interests. When more than one person lives there, we need to support the individuals to negotiate what each person can bring into the main living area, which tells us more about that person.

When we talk with others, we sometimes talk about things we have done or are planning to do in the future. People we support often don't have a diverse set of experiences to discuss. Instead their experiences are often limited to home, workshop or day program and occasional "outings", which most people in the community do not share. It makes it difficult to communicate on an equal plane with folks who have such limited experiences. We need to help people have a variety of experiences, so that they will have things to share of interest to others.

People may need other supports to be successful in interacting with others in the community. Those giving support need to consider the community's potential acceptance. While too much support may create the impression that the person is more disabled than they are, too little support can leave the person floundering and unable to enjoy the full benefits of being in the community.

Supports should be as natural and unobtrusive as possible to facilitate the person's involvement, rather than becoming a barrier. Specialized supports should be given in a place and a manner typical for all other community members of the same age. Transportation provided should be typical for other members in the community. The more readily usable the support or adaptation, the greater the likelihood that the community will accept and perhaps even help provide the support.

4. Helping with Valued Roles

We need to support people to develop valued roles, so that real friendship and community membership can occur.

We also need to be aware that when people with disabilities participate in activities, which people who are much younger typically engage in, they may be perceived as being more child like. If they participate in recreational activities with senior citizens, they might be stigmatized as frail and weak. People need to be given the opportunity to participate in the cultural and ethnic life of the community, such as ethnic celebrations, art fairs, craft festivals, concerts and community theater, as do many typical adults. Helping people know how to interact with others in the community can make them more accepted. We need to find ways to teach social skills within the community setting, so that people are not set apart from others in the community. Modeling appropriate social interactions can be helpful.

A valued role in the community is being a contributor. Contributing to the world in which we live makes life fuller and gives it meaning. It gives the person a way to be useful and productive. Each of us that choose to contribute have our own way of doing so, ranging from making donations to assuming roles in churches, synagogues, temples and other community organizations. We choose the level of involvement from being very active to working behind the scenes. The benefits are learning new skills, forming friendships, feeling like we belong, and experiencing more meaning in our lives. It can enhance our status to be a “giver”. People with disabilities are frequently perceived as being “takers”.

Support coordinators can work with community members to identify ways the person can contribute and in learning to appreciate the contributions made by the person. If the person chooses to get involved, support coordinators should support them in demonstrating their competency to assume this role.

Volunteering is a way of contributing to a cause that is bigger than us. It allows us to follow our interests and express our personalities. We can practice competencies, learn new skills and meet new people. Volunteering is a valued role in our society. It is often a way for people to build skills and experience in order to get a paid job – it can work this way for people with disabilities as well. Support coordinators need to support people in becoming involved in those causes they choose to support at the level and intensity they desire. They can also support the community members in incorporating the person in valued ways.

A support coordinator’s responsibility is to follow these best practices:

- Look for opportunities in the community that match the person’s interest or gifts and make connections to others with those same interests.
- Provide the proper amount of support necessary (not too much or too little) to include the person in a way which is typical of others of the same age.
- Look for ways that people can contribute to their community (helping out a neighbor, serving on a committee) that are valued by others in the community.
- Assist the person in finding and identifying things he or she is good at and support the person in developing and using those skills.
- Know the community well and support the person in finding opportunities to exercise his skills.
- Make sure that the person knows when others appreciate his or her competence in a certain area.

Additional Considerations:

QUESTIONS TO ASK RELATED TO ASSESSING COMMUNITY MEMBERSHIP

1. To what extent is the person participating in age-appropriate, integrated community activities?
2. To what extent is the person interacting with other community members during this activity?
3. To what extent does the person have relationships with others in addition to people with whom they live or who are paid to support them?
4. To what extent does the person have relationships with members of his/her family?
5. To what extent is the person learning skills that will facilitate acceptance in the community (especially how to interact and get along with others?)
6. To what extent are the person's interests and competencies emphasized in the activities she/he does?
7. To what extent does the person have opportunities to contribute to others (via valued roles in relationships, volunteer work, etc.)?
8. If the person needs supports or services for communication, to what extent is this provided? (is a functional alternative or device available at all times in all settings, do staff respond to the person's communication, do staff help facilitate the person's communication with others?)
9. If the person displays unacceptable behaviors, to what extent is the communicative intent of those behaviors addressed?
10. Is the person assured access to community activities even though he/she may be displaying unacceptable behaviors? (or is access to the community used as a reward for "good" behavior?)
11. If a individual service plan exists, are the person's goals, interests and preferences considered within its content?

Mandatory Reading:

Missouri Quality Outcomes <http://dmh.mo.gov/docs/dd/QualityoutMan.pdf>