

GET ON BOARD AND MAKE A DIFFERENCE!



*Effective Practices for Including
People with Developmental
Disabilities and New Members on
Boards and Committees*

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Acknowledgements

In 1997, the Vermont legislature decided that boards and standing committees of agencies providing developmental services should include 51% representation of people with developmental disabilities and their families. This law reflected historical efforts by provider agencies to include parents of people with developmental disabilities on their boards and standing committees. In 2003, the Division of Developmental Disabilities further stipulated that the Standing Committees of Developmental Service Provider Agencies must consist of 25% people with developmental disabilities.

In 2003, Green Mountain Self-Advocates and ARC of Vermont compiled this book in response to the ongoing challenge of supporting people with developmental disabilities to be active decision-makers on agency boards and standing committees. We have included effective practices published by Advocates in Action from Rhode Island, Center on Human Policy at Syracuse University, Oregon Office of Developmental Disabilities, and People First of Illinois.

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INTRODUCTION

"I was recruited to be on the board of directors of my agency by the director. In the beginning it was interesting for me and the other consumers to know what was going on in the agency. The president of the board and the rest of us make suggestions about what the director should be working on.

We get minutes of how the money is spent but it is confusing to me. Now the director is meeting with us individually to break it down and explain what all the numbers mean.

We talk about what is going on like for instance renovating the office, if someone is going to be hired and using the initials of consumers instead of their names. But you know it really doesn't take much to figure out who they are talking about.

I think it is good to be on a board because consumers have the right to know what is going on. We are also involved in making motions and the other members are very open to anyone opposing. They are also open to consumers bringing up issues of concern about the agency.

My advice is you need good communication skills in general especially good listening. Try to understand where self-advocates are coming from. If a self-advocate can't find the right words encourage them to ask another self-advocate. Don't step in unless we ask. Know that it is harder to do less. Be willing to change how you do things, how you provide support. Be flexible and comfortable enough to be wrong and take and encourage criticism."

Veteran Self-Advocate Board Member

Throughout Vermont, Developmental Service Provider agencies promote active participation of individuals with developmental disabilities and family members on their boards and standing committees. People with developmental disabilities and family members make up over half of the board's and standing committee's membership.

Green Mountain Self-Advocates (GMSA) and ARC of Vermont through the Real Choices Project, compiled these *Effective Practices for*

Including People with Developmental Disabilities and New Members on Boards and Standing Committees. It is our goal to assist local boards and committees as they continue to develop their groups to reflect the philosophy of inclusion and to model active participation in decision-making by all members to the greater community. Inclusion is more than just being present it involves active participation.

INCLUSION

Inclusion is a belief in every person's inherent right to participate fully in society. Inclusion implies acceptance of differences. It means welcoming a person who otherwise would be excluded. Translating this philosophy into reality is a process that requires collaboration, teamwork, flexibility, a willingness to take risks, and support from a whole array of individuals and supports.

King County Board for Developmental Disabilities

Historically, long before legislation on board composition was passed, agencies have included parents of people with developmental disabilities on their boards and standing committees. Doing so reflects good practice and complies with Vermont law, but is it inclusion?

Vermont is and should be proud of the exemplary services provided for people with developmental disabilities. Yet the reality is, in the year 2003, we are only beginning to see more than one or two people with developmental disabilities serving on boards and committees. Yes, parents of people who receive developmental services can, and do, provide needed information, but they speak from a parent's point of view. Guidelines from People First of Illinois state, "The only person who can speak from the perspective of a person with a disability, is a person with a disability."

GETTING STARTED

1. Read these effective practices.
2. Develop a plan for introducing all or some of these effective practices to existing boards and committees. Consider this as a vehicle for reflecting on how a group includes people with developmental disabilities and family members and evaluating if changes are necessary.
3. We suggest that all members of a board or committee review the first four sections of this manual. They describe how all participants can encourage and support people with developmental disabilities and new members to be effective decision-makers. The sections are titled:
 - A. **What We All Can Do to Include People with Different Learning Styles**
 - B. **Tips for Being a Support Person**
 - C. **Suggestions for Other Board Members**
 - D. **Suggestions for the Chairperson**
4. Some boards and committees may opt to use mentors. **All about Mentoring** describes a process for establishing a mentoring program. A mentor is typically a veteran board member whose role is to assist a new member to understand their role as a board member. *The mentor role is different than that of an individual support person.*
5. Provide an opportunity for existing board and committee members to complete the **Accommodation Checklist** at the end of this guide. The checklist can be completed with the person and the chairperson,

another board member or a support person. Be sure to share a copy of the checklist and any recommendations with the chairperson.

6. For new members who have a disability, give the person the option of meeting before or after their first board meeting. Some self-advocates report that a better plan is to sit together at the board meeting and then meet afterward to complete the **Accommodation Checklist** based on the meeting experience. Discuss whether they want to have a fellow board member be their mentor and/or to have an individual support person.
7. This manual contains a glossary, entitled **Words to Know**, of abbreviations, acronyms, and definitions of the most commonly used phrases and jargon by boards and standing committees. Many times in meetings abbreviations are used and it is easy to get lost when terms are used such as Independent Support Agreement (ISA) and Division of Developmental Services (DDS) etc.
8. Robert's Rules of Order is a set of rules and procedures that many boards and committees use to conduct business. **An adapted version of Robert's Rules of Order written by Green Mountain Self-Advocates** included here will help explain these rules.
9. You are now ready to begin!

WHAT WE ALL CAN DO TO INCLUDE PEOPLE WITH DIFFERENT LEARNING STYLES

How to refer to a person with a developmental disability:

- 💡 People prefer to be called by their name, and referred to just as a “person.” People with disabilities have made it clear that they do not want people to use the term “mental retardation.”
- 💡 If the person’s disability must be referenced, use “People First” language, such as referring to him or her as a “person with a disability,” (not a “disabled person”).

Respect:

- 💡 Treat adults as adults; be sensitive to their needs.
- 💡 Encourage people to make their own decisions, to speak for themselves, to disagree, to do things on their own, and in their own ways.
- 💡 Become familiar with people's needs/accommodations.
- 💡 Because people like to please others, it is important to be mindful of your body language, tone of voice, and other gestures that may influence a person's decision.

- 🧠 Avoid using stereotypes in your thinking. Some people with developmental disabilities are patient and caring whereas others are short-tempered and impatient. Some are truthful and some are not. Most, like the rest of us, are truthful most of the time but not always.
-

Communication:

- 🧠 Make eye contact.
- 🧠 Speak slowly and clearly.
- 🧠 Keep distractions to a minimum.
- 🧠 Use straightforward language, words that everyone understands.
- 🧠 Ask one question at a time.
- 🧠 To encourage discussion ask open-ended, rather than “yes/no”, type questions. “Forced-choice” questions may also be helpful (e.g., “Do you think we should buy new chairs or a new computer?”).
- 🧠 Take time. Be patient for a response. Give a person a chance to explain things or ask questions even if it takes time.
- 🧠 Do not try to guess what the person is saying, or cut him or her off, rather wait until she or he has finished a sentence or story, even if you think you know the end or can say it faster.
- 🧠 Avoid abstract concepts (references to time, dates, sequences or reasons). Use visual or concrete examples. Try to connect an issue

to a personal experience (e.g., To decide what kind of training to offer say, "Would you rather have your case manager go to a training about supporting self-advocacy or writing ISA's?") Avoid the use of numerical or quantitative concepts.

- 🗣️ Check to make sure that people understand what has been said. This can be done by asking the person to explain what has been said in his or her own words.
- 🗣️ In general do not assume a person cannot read, but also do not assume they can. Ask the person what accommodations they need. Read aloud, clearly, anything that is written that the person needs to understand.
- 🗣️ Written material needs to be in easy-to-understand language. Use graphics, large print, (minimum 14 point font size) and double space. A brief summary can help. Highlight critical information. Think about other creative ways to format information.
- 🗣️ Always mail written material that will be presented or discussed in the meeting ahead of time. Be sure the person has enough time to review the material with her or his mentor or support person. Ten days before the meeting is a good practice.
- 🗣️ Feel free to ask a question. Open the lines of communication from the beginning. Also consider alternative and creative ways of communication besides printed materials, for example, regular phone calls, personal visits, tapes, or e-mail.

- 💡 Do not assume a person who has limited or no speech cannot understand what is being said. People can usually understand more than they can express. (The use of visuals helps).
- 💡 Provide short, frequent breaks. A seven-minute break each hour works better than 15 minutes after two hours.
- 💡 Avoid speaking for others – encourage people to speak on their own behalf, but if you must interpret/paraphrase, be careful not to change the intent.

TIPS FOR BEING A SUPPORT PERSON

The Commitment:

- Have an idea of the time you can commit to a person and be honest with them about this from the start.
- Be willing to go over the agenda and written materials beforehand, if the person wants this.
- Come a few minutes early to a meeting to check-in with the person you are supporting.
- Check in with the person ahead of time to find out how they want to be supported during the meeting. Some people will ask for help. Some people like to pass notes. Others prefer that their support person periodically ask them if they need assistance.
- Be on time for meetings and bring the materials you will need.
- Be prepared for changes in the person you are supporting and that they might change their mind about ideas.
- If you are going to be late for a meeting or cannot make it, make sure you tell the person you are supporting in advance so she or he can make arrangements for another support person. (Do not make

arrangements for another support person without talking to the person you are supporting first.)

- Consider how you will support the person to make a decision you do not agree with. Help her or him understand what decisions means. For example: it's okay to share alternative ideas or options, but it is not okay to strongly influence or convince the person to say or do something different.
-

Respect:

- Because people like to please others, it is important to be mindful of your body language, tone of voice, and other gestures that may influence a person's decision.
- Respect confidentiality:
 1. Remember as a support person you might be given information that is confidential and you should keep to yourself.
 2. Ask the person you are supporting before sharing any information about them.
 3. If you work for an agency you might be given information about a co-worker that is confidential.
- Be aware that the person you are supporting might like to hang out with others during the break times.
- Try and have your support of the person be “invisible” to others.

Teamwork:

- If you are uncomfortable doing something as a support person, discuss it with the person you are supporting (only personal care attendants should be providing personal care).
 - Be open and willing to learn from each other.
 - Use your mistakes as learning experiences.
 - It's okay to be quiet and not say a whole lot when supporting a person but be mindful of the person's body language and periodically ask if they need help understanding something.
-

Outside of the Meeting:

- Meet with the person a couple of times, as needed, before their first board meeting to complete an accommodation list together.
 - Take time now and then to see how things are going in general.
-

On a Final Note:

- Get training if the person uses alternative communication devices and methods. Do what is needed to help make sure the device is in the person's possession, is in working order with necessary extension cords or extra batteries and the table is at the right height.

- Keep in mind what the person said they do *not* want help with. Don't over support.
- Ask the person if it is okay for you to give a personal opinion on something that is being discussed.
- Give notice as early as possible if you can no longer be a support person.

SUGGESTIONS FOR OTHER BOARD MEMBERS

The goal is to have a diverse group on your board or committee. Here are some suggestions to ensure that all are effective participants:

- * Follow the same procedures used to recruit and select other group members. Base your selection on an individual's qualifications, diverse experiences, and commitment.
- * Invite people to a couple of meetings and, if requested, encourage them to bring a friend, advocate, or support person.
- * Identify a board/committee member who can welcome and help orient the prospective member for initial meeting(s). This includes calling the person with meeting reminders and following up about how the meeting went.
- * All board members are encouraged to use social and break times to get to know new board members better.
- * Regular introductions at the beginning of each meeting help everybody learn people's names and roles. For some people it takes time to learn all the names of the other members and their roles in the group. Providing nametags and/or place cards is encouraged.

- * Be specific and honest when talking to group members. What role(s) will they take in this group? What will be their responsibilities? What are your general expectations for group members?

- * During the meeting, point out issues of confidentiality that should not be discussed outside the meeting.

SUGGESTIONS FOR THE CHAIRPERSON

- ❖ Send out agenda and information well in advance of each meeting. This allows time for preparation. Make materials available in alternative forms, such as tapes, LARGE PRINT, or on disk. Consider using colored paper, numbers, pictures, or highlighting main points to organize the materials. Highlight what decisions are going to be made in the meeting.
- ❖ If written material is being presented in the meeting that was not sent out before the meeting, read it aloud.
- ❖ If necessary, help new group members learn how meetings are run, such as when to vote, when to discuss issues or ask questions, how to get on the agenda, etc. If your group uses Robert's Rules of Order, explain them. Consider reviewing the attached adapted version of Robert's Rules of Order.
- ❖ Check-ins during and after the meeting are suggested to see if the self-advocate needs assistance.
- ❖ Take a short break before voting to check in and make sure everyone understands what the vote is about.
- ❖ Find out what individuals need before they join your group. Go over the accommodation checklist together with the self-advocate. Designate a contact person to orient the person to the board or

committee, its purpose, expectations, and facilitate choosing of a mentor.

- ❖ Prompt each group member to actively participate in discussions. Be sure everyone has an opportunity to speak, including the new members and people who are generally quiet.
- ❖ If there is something you want to discuss with a self-advocate, concerning board/committee matters, don't hesitate to ask the person directly.
- ❖ Working with a diverse group of people is the greatest asset your group or organization can have.
- ❖ One common barrier to including people with different learning styles is maintaining an appropriate pace during the meeting. Consider asking the group if the pace is too fast or too slow prior to beginning the next agenda item.
- ❖ Have fun working together.

These checklists were adapted from: Gobel, S., and Flynn, J. (1994). Not Another Board Meeting! Guide to Building Inclusive Decision-Making Groups (Manual). *Order Information:* Oregon Developmental Disabilities, 540 24th Place, NE, Salem, Oregon, 97301-4517, (503) 945-9941.

ALL ABOUT MENTORING

**"A mentor is someone who sees more in you
than you would ever see in yourself."**

-Lee Brussard 1999

So, What is mentoring?

A mentor is an advisor. Someone who has experience, wisdom, and a desire to share it with others.

The purpose of mentoring

Becoming a board member can be a confusing process for most people. Mentoring helps new members of the board have access to the knowledge, skills, and supports they need to be effective participants in all board activities.

How does the board benefit from a mentorship program?

- The board benefits by having well-informed members who have the skills and supports they need to be effective participants.

Who can be a mentor?

- Any experienced member of the board can volunteer to be a mentor.
- The new board member picks his or her own mentor whenever possible. A board member may assist with this if needed.

What is the role of a board mentor?

- Mentors assist new board members by listening, advising and supporting them.
- Mentors make sure that new members' issues come to the attention of the board chair or others as appropriate.
- Mentors help the member get and understand information that is needed so the member can make informed decisions.
- Mentors help the new members learn about the board and its activities.
- Mentors help the new members develop new skills, become active and informed participants and have enriching experiences as board members.

Why would you want to be a mentor?

- Mentoring is a relationship that benefits both people through the exchange of information and experience. Sometimes a friendship develops.
- The mentor receives satisfaction from helping someone develop knowledge and skills.

What is the commitment of a mentor?

- Mentors support the new member through their first full year or until they are comfortable.

- Mentors and new members will share what's working and what's not with the board chair.

Can you have a support person and a mentor?

- Some board members may have a support person or personal care attendant employed to provide assistance.
- A support person is familiar with how to provide accommodations specifically for the board member they work for.
- The mentor provides expertise on the role of being a board member to the person and their support people.

What is the new member's role?

- New members meet with the mentor for the first year or until they are comfortable.
- New members put together an accommodation plan with their mentor that includes opportunities for learning and the supports needed to be successful.
- New members discuss issues and ideas with their mentor and consider the mentor's advice.
- Over time, new members discuss their progress in learning the issues identified in their plan.

How does mentorship work?

- The board chair or a committee recruits mentors from current board members and suggests matches. Matches are based in part on the

geographic location of the mentor and the new member and personal preferences.

- When the match is made between a mentor and a new member, the mentor makes the first contact to welcome the new member.
- The mentor sets up a meeting with the new member and together they use the accommodation checklist to help them identify supports that may be needed.
- Mentors make sure the new members can get to their first board meeting and the new member orientation. Mentors attend the meeting and orientation with the new members, if possible.
- Soon after the first board meeting, the mentor and the new member review an accommodation plan and meeting schedule.
- Regularly scheduled face-to-face meetings are recommended for the first year.
- Phone calls can be an alternative when schedules and distance are a barrier.

What should the mentor and the new member cover?

- Introduce the new member to the inner workings of the board; how the Board functions; who are the current members; the current priorities; role of staff; role of officers; role of members and the culture of the organization.
- Help the new members increase their meeting skills. Help the new member learn how to prepare for meetings and discussions, how to

identify opportunities to express their opinions and make suggestions, and how to deal with conflict.

- Discover the new member's needs and arrange supports. The needs of each new member are unique. It's the job of the mentor to discover those needs and provide or arrange for appropriate supports.

How do mentors support new members during meetings?

- Mentors typically sit with them during meetings and check in occasionally to see how they are doing.
- Mentors encourage them to participate and make suggestions.
- Mentors and new members exchange feedback after meetings.
- Mentors might make suggestions to the chair that could help new members participate.
- Encourage new members to raise their hand and ask questions if they don't understand.

How will progress be monitored and encouraged?

- The chairperson will check in occasionally with the mentor and new member to see how the relationship is working out and if there is anything that the board can do to increase participation of the new board member.
- The new members can talk to the chairperson if they wish to make changes in the mentor or discuss other concerns.

- At the end of the first year, the new members will be asked to evaluate what went well, what could be improved, and what is still needed.

These guidelines were adapted from: Office of Developmental Disability Services. (2003). Mentoring New Board Members. Order Information: Office of Developmental Disability Services, 2575 Bittern St. NE., Salem OR 97309 Phone: (503) 945-9774 Fax: (503) 373-7274 and TTY: (503) 945-9836.

ACCOMMODATIONS CHECKLIST

Hint: Our experience has taught us that sometimes using a checklist like this one can encourage people to ask for more support than they need. So if you are not sure if you need support, first give it a try yourself before asking your mentor or support person for assistance.

THINGS I AM REALLY GOOD AT AND LIKE TO DO

I am good at:

I like to:

MY PROFESSIONAL NEEDS

Understanding how the group works: Examples: How are meetings run and what are the bylaws of the group? How do people communicate with each other? Does the group use Robert's Rules of Order?

No help needed.

I specifically want support with:

As the person who supports me, you will:

Remembering People: Examples: Remembering the names of board members and their roles on the board, arranging for people to wear nametags, knowing important contact people, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Understanding what is most important for me to do in the group:

Examples: Which project will I do first, what will I talk about during meetings, which projects or subcommittees will I be a part of, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Going over materials for the meeting: Examples: Minutes, agendas, reading materials, etc. Pointing out what materials are just for information and which ones I need to act on. When do we do this?

No help needed.

I specifically want support with:

As the person who supports me, you will:

Getting a time to talk in the meeting: Examples: Getting on the agenda, being an equal member who gets listened to, making motions, etc. Do I need signals to speak up?

No help needed.

I specifically want support with:

As the person who supports me, you will:

Giving me information or checking in during the meeting: Examples: If I need help I will ask for it. Ask me periodically how I am doing. Pass me a note.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Asking Questions: Examples: Writing down questions that I have before meetings, remembering to ask the questions during meetings. Do I need help getting other people's attention?

No help needed.

I specifically want support with:

As the person who supports me, you will:

Saying exactly what I want to say: Examples: Talking about my ideas before meetings, helping me to prepare speeches, helping me to make sure I get my points across, etc. Did I get my points across?

No help needed.

I specifically want support with:

As the person who supports me, you will:

Staying on the topic: Examples: If I wander off the topic, give me a signal, highlight main points I want to talk about, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Reminding me of things: Examples: Meeting times, making a calendar, making phone calls, writing letters, getting information, getting work done, bringing materials to meetings, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Putting materials in other formats: Examples: LARGE PRINT, tape, computer disk, Braille, translation into my native language, putting materials in easy-to-understand language, printing materials on colored paper, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Reading materials: Examples: Taking them out where I can get to them, turning pages, underlining main points, writing a simple summary of each reading, reading the materials to me, explaining charts and tables to me, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Explaining hard-to-understand language: Examples: What do certain words mean or initials stand for? What is the group talking about right now?

No help needed.

I specifically want support with:

As the person who supports me, you will:

Taking Notes: Examples: Writing down things that interest me or that are important, explaining your notes to me, etc. Should I give you a signal if I want you to write something down?

No help needed.

I specifically want support with:

As the person who supports me, you will:

Sign language: Examples: Signing for me during meetings, arranging seats in front of the room so I can see the speaker as well as the person who is signing, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Advocating for me when I need it: Examples: Making sure the board supports me as they promised, standing up for me if I feel I am being discriminated against, reminding people to treat me with respect, etc. Knowing who I should go to if I feel my needs are not being met. When needed, remind people to speak slower, one at a time, and slow the pace of the meeting down.

No help needed.

I specifically want support with:

As the person who supports me, you will:

MY PERSONAL NEEDS

*Working together as a team involves people supporting each other.
However, only personal care attendants should be providing personal care.*

My mobility: Examples: Walking, helping with stairs and elevators, transferring in and out of my wheelchair, opening doors, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Orientation: Examples: Dates and times? Directions to the meeting?
Where is the meeting room? Where can I find the bathroom? Where is an accessible bathroom?

No help needed.

I specifically want support with:

As the person who supports me, you will:

Food and drinks: Examples: Carrying food or drinks, cutting up food, assisting with eating and drinking, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Special diet: Examples: No-salt, low-fat, vegetarian, diabetes, following my diet, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Dress Code: Examples: Knowing what to wear to meetings?

No help needed.

I specifically want support with:

As the person who supports me, you will:

My Transportation Needs

Arranging public transportation: Examples: Finding bus schedules, knowing where I need to go, scheduling door-to-door transportation, calling cab, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Paying for transportation: Examples: Arranging to pay for transportation, keeping track of travel receipts, filing out an expense form etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Arranging private transportation: Examples: Arranging to be picked up, knowing the person who will meet me, knowing the meeting place and time, getting directions to where I need to go, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

Other transportation issues: Examples: Going places when it is dark, getting home from late meetings, getting to out-of-town meetings, plane rides, hotel accommodations, etc.

No help needed.

I specifically want support with:

As the person who supports me, you will:

This accommodation checklist was adapted from: Gobel, S., and Flynn, J. (1994). Not Another Board Meeting! Guide to Building Inclusive Decision-Making Groups (Manual). *Order Information:* Oregon Developmental Disabilities, 540 24th Place, NE, Salem, Oregon, 97301-4517, (503) 945-9941.

WORDS TO KNOW

Accommodations: How a place or an activity is changed to make sure that a person with a disability can participate fully. For example, a ramp on a building so a person who uses a wheelchair can enter, or a support person who reads written materials for a person who cannot read.

Agencies or Developmental Services Agencies: The service agencies that get funding from the State of Vermont to support people with developmental disabilities to live as independently as possible.

Applicant List: A list of people applying for services who are eligible based on their disability, but whose needs do not meet funding priorities. This is different from the Waiting List, which is a list of people kept by the agency who are eligible for services and for funding, but who are denied services because the agency did not have enough funds available.

Authorized Funding Limit or AFL: The amount of money set by the designated agency or specialized service agency that a person can use to pay for her or his supports. The AFL is based on the person's needs assessment and is reviewed every year.

Bylaws: A set of rules that are created by a board that tells the board members what their role is and how their organization and their meetings will be run.

Community Alternative Specialist or CAS: Someone who works for the Division of Developmental Service whose job is to help agencies improve their services. Each agency has a CAS assigned to them to be their contact person. Once a year, a team of CASs goes to each agency, visit people who get services and look at their services to see if the agency is doing a good job supporting them.

Case Manager or Services Coordinator: The individual who helps a person coordinate her or his services. This often involves checking in with the person, setting up meetings and appointments, doing paperwork, supervising and supporting the person's workers, and seeing that supports meet the person's needs.

Cash Flow: When there is enough money coming into an organization or agency to cover the bills and expenses that need to be paid. For example, enough money has been received to pay the staff and the electric bills.

Chairperson or President: The board or committee person chosen to lead the group and to run the meetings. When two people share the duties of being the chairperson, they are called the co-chairs.

Confidentiality: When something is not to be told to anyone outside of the group. Something that is confidential is considered private.

Designated Agency or DA: The agency responsible for making sure that needed developmental services are available in a specific area of the state.

People go to the DA to apply for services. The DA provides direct supports to people as well as makes referrals to other agencies.

Developmental Home or Shared Living Provider: People who share their home with someone who has a developmental disability and provide supports to that person. They are also called a home provider and are paid out of a person's Medicaid waiver.

Division or Division of Developmental Services or DDS: The State Division that oversees services and financial matters for the developmental service system throughout the state of Vermont. Their main office is in Waterbury.

Director of Developmental Services: The person who manages and directs an agency. They run the agency, hire staff, report to the Division of Developmental Services, and report information to the Board of Directors and the Standing Committee. The Board of Directors and Standing Committee are responsible to give advice in the hiring and evaluation of the Director.

Executive Session: Most board or committee meetings are open to anyone interested in coming to listen. However, if confidential issues need to be talked about then an Executive Session will be called during a meeting. These special meetings may be closed to the public and sometimes only certain Board members may be present. An example is when an issue needs to be discussed concerning an agency employee.

Equity Fund: Local funding committees can apply to this fund if they do not have enough money to meet the needs of a person in their area. This money usually comes from people who no longer need it because they have died, moved away, or left services.

Expenditures: The money that is spent to run an agency, organization or a group, such as a board or committee. Expenditures can be items such as staff salaries, phone bills or insurance.

Family Member: An individual who is related to a person with a disability by blood, marriage, civil union, or adoption. For example, a family member may be someone's birth or adoptive mother or father, sister or brother, husband or wife, grandparent, aunt, uncle or cousin. Other people may be considered a family member depending on the situation.

Flexible Family Funding or FFF: These funds are available to families and individuals when the person lives at home with her or his family. The money can be used in many different ways, such as for respite or buying things the person or family needs.

Funding Committee: A group of people at the designated agency who decide if a person can receive funding for their services and how much. When a person first applies for supports, the Service Coordinator takes the person's needs assessment and other information to their local funding committee. This committee then makes a decision as to whether the person is eligible for funding and if there are funds available.

Funding Priorities: A list of situations set by the State System of Care Plan that a person must meet in order for the state to pay for supports. For example, when a person is at risk of being homeless or abused. If a person's needs meet a funding priority and there are funds available, she or he will be given funding for services. If there are no funds available, she or he will be put on a waiting list. If the person does not meet the funding priorities, but is eligible for services, she or he will be placed on an applicant list.

Guardian: An individual appointed by the court to supervise and protect the interests of another person who is found to not be able to make decisions on her or his own. A guardian may be a family member or friend. If there is no one who is able to be the private guardian, a public guardian is assigned. A public guardian is called a Guardianship Services Specialist and works for the Division of Developmental Services.

Intake: What a DA does when a person first applies for services. During the intake process, individuals are evaluated to see if they are eligible for services, learn about their rights, what their choices are, and participate in a needs assessment to see if they are eligible for funding.

Individual Support Agreement or ISA: An agreement between the person, the person's guardian (if there is one), and the agency that tells about the person's services and supports. Every person who receives Medicaid services must have an ISA. The ISA tells about how the person wishes to be supported, what will be different in the person's life because of

services, and what the person and the agency's responsibilities are. A person getting Flexible Family Funding does not need to have an ISA.

Individual Support Broker or ISB: An individual hired by a person or family member to help manage developmental services. The responsibilities of the ISB may include helping the person develop and follow a budget, take care of employer responsibilities, find back-up staff coverage and anything else that needs to be done to support the person.

Medicaid: A state administered program that is a type of insurance for people who have a low income and/or have a disability. Benefits include things like medical and hospital care, medical equipment and supplies, and community based supports and services.

Mentor: A mentor is someone with experience who helps another person who is learning a new skill. For example, an experienced board member can mentor a new board member to help learn about the agency and the responsibilities of being a board member.

Needs Assessment: An assessment done by the agency when a person first applies for developmental services to see if she or he is eligible to receive funding. The person and members of her or his circle of support take part in the assessment. Each year, before the ISA is updated, the person's needs are reviewed to see if there are any changes in support needs. If there are, the amount of the money the person can use to pay for services may increase or decrease.

New Caseload Funds: The funds put into the state budget by the legislature for people who are new to services or have received only very small amounts of funding. The funds are divided among designated agencies throughout the state and are given to people, as needed, by the local funding committees.

Per Diem: This word means “per day”. It means being reimbursed a set dollar amount for the time period of one day. For example, a person getting paid \$50/day to help present at a conference is getting paid a “per diem”.

Psychological evaluation: An evaluation performed by a licensed psychologist or psychiatrist that evaluates a person’s current developmental status and needs. It is part of the intake process that helps the DA make a decision about whether a person is eligible for services.

Quorum: The smallest number of people who are on a board or committee who must be present at a meeting to take a vote. The board or committee decides the number of people in a quorum. For example, if there are 11 people on a committee and the bylaws say that six have to be present to take a vote, if there are six committee members present, there is a quorum and the group may vote.

Qualified Developmental Disability Professional or QDDP: A person who must meet state and federal requirement to oversee and approve specific developmental services. If a person meets these requirements they can perform other important services. For example, a QDDP must review and sign a person’s ISA each year.

Receivables: Money that is owed to the agency that makes up part of their budget. It may refer to monies that have not yet arrived at the agency, but that are expected soon.

Reimbursement: Money that is given to a person or organization to pay back expenses or something that had been allowed and paid for in advance. For example, a board member may be reimbursed by the board for the cost of gas to go to a meeting. Many boards and committees have policies that say what expenses they will cover for their board or committee members.

Respite Care: Short term or temporary care of a person with a developmental disability to provide relief for the caregiver.

Self-Advocate: A person with an intellectual disability who speaks up - alone or with others - for their rights, equality, and freedoms in our communities and around the world.

Self-Advocate Group: A civic organization run for and by people with intellectual disabilities. The purpose of self-advocate groups is to provide leadership experience, community involvement opportunities and to support the inclusion of people with intellectual disabilities in the community.

Secretary: A member of a board or committee who is responsible for taking notes at the meetings and making copies for other members. These notes are called the minutes of the meeting. The secretary may also be

responsible for keeping copies of the minutes and other important documents.

Self-Directed Services: All people who receive developmental services have the right to provide input into the services they receive. The amount an individual chooses to be involved in directing her or his services is up to the individual and varies from person to person. For example, a person may choose to be very involved with deciding where she or he is going to work as well as interviewing the workers who will be providing job support.

Self/family-Management: When an individual or a family member chooses to manage all of her or his services. This means that the person or family member has the responsibility of hiring workers and overseeing the funding and other parts of her or his supports. The person or family member may choose to hire an Independent Support Broker to help manage their affairs.

Shared-Management: When an individual or family member chooses to manage some, but not all, of her or his developmental services. For example, the agency may provide service coordination and home supports, but the person may choose to hire and oversee work supports separately.

Specialized Service Agency or SSA: An agency similar to a DA that provides supports to people with developmental disabilities. The SSA does not do intake but does take referrals from other agencies.

Supported employment: A program that supports a person with developmental disabilities to work in the community.

System of Care Plan: A statewide plan developed by the Division of Developmental Services every three years and updated every year. It describes what supports will be provided, who may be eligible for funding, how funds will be spent, and what programs need to be developed. To create this plan, the Division gathers information from people with disabilities, advocacy groups, family members, State and Local Standing Committees, caregivers and agencies. Each Designated Agency also develops a system of Care plan.

Treasurer: A member of the board or committee that puts together and reviews a report that shows the budget of the organization. Sometimes the Chief Financial Officer prepares this report. The person is responsible for sharing this information with other board or committee members.

Waiver or Home and Community Based Waiver: Funding that allows community services to be provided to people eligible for Medicaid who otherwise would be at risk of being in an institution.

Waiting List: A list of people kept by the agency who are eligible for services and for funding, but who are denied services because the agency did not have enough funds available. This is different from the Applicant List, which is a list of people applying for services who are eligible based on their disability, but whose needs do not meet the System of Care Plan funding priorities.

These definitions were adapted from:

Department of Developmental and Mental Health Services. (June, 2003). Administrative Rules on Agency Designation (Manual). Order Information: Division of Developmental Services. 103 S. Main St., Weeks Building, Waterbury, VT 05671, (802) 241-2614 or in Vermont only (888) 468-4860.

Department of Developmental and Mental Health Services. (January, 2000). You Can Get There from Here, Finding Your Way Through the Service System (Manual). Order Information: Division of Developmental Services. 103 S. Main St., Weeks Building, Waterbury, VT 05671, (802) 241-2614 or in Vermont only (888) 468-4860.

Gobel, S., and Flynn, J. (1994). Not Another Board Meeting! Guide to Building Inclusive Decision-Making Groups (Manual). Order Information: Oregon Developmental Disabilities, 540 24th Place, NE, Salem, Oregon, 97301-4517, (503) 945-9941.