Helping People Move: An Introduction

Principles, Practice and Process

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Introduction

We have been involved in helping people leave congregate settings for over 20 years. During that time we have seen that the community clearly offers more potential than congregate care but achieving that potential is not automatic. Unless the process is thoughtful and intentional, people will move to community settings but not necessarily to better lives. What follows is an overview of our learning and recommendations about how to insure that everyone leaves to a better life.

The best efforts begin with commitment to a set of principles:

1. Each person can tell us what constitutes a good life and each person must move to a better life.
2. The person, using the description of what is required to have a better life, must be the primary "driver" of the process
3. The efforts must happen inside established budgets and timelines.
4. Where the services needed to best support the person do not exist they must be developed before the person moves.
5. The learning about a better life continues after the person moves and acting on it must be required and supported

Following these principles requires a set of skills that can be easily taught and a discipline that is difficult to maintain. It begins with being able to reliably describe what a "better life" looks like and the circumstances and supports that will create that better life. But is also includes:

1. An analysis of the current process for movement that looks at both efficiency and efficacy.
2. An honest comparison of current community capacity with the community capacity needed.
3. The development of budgets and timelines that are affordable and take into account the time needed to develop new capacity.
4. A respectful process that:
    - Develops a person centered description[1] with each person who is going to move that includes how that person wants to live and needs to be supported
    - Uses the person centered description as a key document throughout the process.
    - Helps families feel listened to and assured that both issues of health and safety and those things that make the person happy are addressed.
    - Builds trust and partnership among all of the key stakeholders
    - Acknowledges the commitment, relationship and knowledge of those who work in the facility
    - Accounts for the challenges that can be anticipated and provides a process to address them

[1] Contact the authors for examples of person centered descriptions with a picture of a life

- Sees the actual move as the beginning of learning, not the end, and supports providers in acting on that new learning

Principles - Begin with commitment

The best efforts begin with commitment; commitment to a set of principles that will guide the process and the decisions made in its implementation. The commitment goes beyond simple endorsement – the implications of each must be understood and followed.

> **Each person can tell us what constitutes a better life and each person must move to a better life**

Understanding what constitutes a better life begins with learning what is "important to" the person (happy, satisfied, and comforted) as well as what is "important for" the person (healthy, safe, and valued member of the community) and then describing what a reasonable balance between them would look like. We learn by listening to the person and to those around the person. The mythology that this only applies to people who are articulate self-advocates persists. But we have known how to listen to those who communicate only with their behavior for many years. The nature and severity of the disability changes the techniques we use to learn, but they do not stop us from being able to learn. For many people with complex medical needs we have found that they have people providing their services that deeply care about them, know what is important to them, and just need help in describing it. For people who are moving, the description has to include describing the environment and circumstances where a good balance between important to and important for is likely to be present (referred to as a "picture of a life"). All of this learning is recorded in a "person centered description" that must help the person become the driver of the process.

> **The person, using the description of what is required to have a better life, must be the primary "driver" of the process**

The people who use the service should be in charge of what they get and how it is delivered. This is easy to say but challenging in implementation. It requires that we balance rights and responsibilities. There are boundaries of choice for everyone, some imposed by society and some that arise from our circumstances. The challenge here is that in creating the description of how the person wants to live and needs to be supported we are also creating a set of boundaries on choice. They are boundaries that can and should change as learning occurs but they are boundaries none the less. The description must be created with the person and use the knowledge that those who care about the person have. The description has to tell the reader how to listen to the person and how to respond.

Once it is completed it gives the person (and/or family) the power that comes from being able to compare what is offered with what is expected. But for the person, using the description, to be the "driver" of the process also requires that the description has power within the process. A good description not only creates the opportunity to have control over the large question of where to move but also the opportunity to have day to day control in how to be supported. But, a good description is useless unless there are structures and processes that support its use.

Where the services needed to best support the person do not exist they must be developed before the person moves

A key piece of the planning process is to account for community capacity. This begins with looking at the characteristics of the people who are expected to move and best practice in support for people with those characteristics. Then those who are planning need to ask:

1. To what degree can they use existing "vacancies" – i.e. will the criteria for how the person wants to live be met within that vacancy?
2. Can they expand existing capacity – are there service providers who are doing well with people who have similar descriptions of how they want to live and are those providers willing to expand their services? (Note that the best providers are often small agencies who are concerned that too much expansion could diminish quality.)
3. If new capacity is needed from existing providers – is there qualified interest from existing providers to develop new services/supports?
4. Are new providers needed – to best meet the criteria in the description do service providers need to be recruited from other areas or do you need to develop new local service providers?

This is the time to engage current service providers and begin to build the partnerships needed for success. This is also an opportunity to promote and support system change. One of the drivers for both capacity development and system change is for those who are moving to have control over their resources and be able to "shop" for services. A critical piece of this effort is developing the support needed for those who are moving to be able to effectively use the person centered description in finding and developing the services that will result in their having the life described

The efforts must happen inside established budgets and timelines

A person centered process can and should happen within an established budget and its associated timetable. However, the decision to use a person centered process to help people move must occur before the budget and timelines are created. The timelines and the budget must reflect the time and cost required to:

- Develop the person centered descriptions
- Build partnerships with families and likely providers of services.
- "Shop" for services
- Develop absent capacity
- Support ongoing learning and acting on that learning

The cost of these activities will not increase the overall cost of helping people move. However, this assumes that those doing the planning know how to develop a picture of a life where the response to challenging issues is more sophisticated than simply requiring more staff. It also assumes that those managing the process understand that good services are not always expensive services. It assumes that those who negotiate can use the person centered description to see what is required and what is not. If these conditions are met, the cost of the additional activities listed is more than offset by the savings that result from not having moves that fail or people who are in chronic crisis.

When this process is used to "downsize" or close congregate facilities, those who develop the timelines and budgets for people need to keep in mind that what begins as a "target" number of people to move within a fiscal year becomes an absolute number of people that must move. System planners need to keep in mind that if the numbers of people who have moved is below the target there will be intense pressure toward the end of the fiscal year to compromise what makes sense for the person in order to meet the target. The numbers of people scheduled to move must be realistic (not optimistic). Careful monitoring must be built in to track the activities so that "slippage" at the beginning of the year does not result in compromise at the end of the year.

The learning about a better life continues after the person moves and acting on it must be required and supported

An enormous amount of energy goes into helping people move to settings that make sense. Once the person moves the efforts at learning and making changes based on what has been learned must continue. But these efforts will not continue unless there are structures in place to support them in continuing. The budget needs to account for the needed support. Those who are providing the services need training in using the person centered thinking tools needed to implement plans. Once people move those who provide support need support in how to best use the person centered descriptions; how to easily and effectively record new learning; and how to respond to the learning by changing the services.

Process

Developing a new process should begin with a careful look at the existing process. We recommend that an analysis of be done using "process mapping with swim lanes". Typically a well done mapping will show where current inefficiencies are. Once that is done the current process should be revised to both increase efficiency and to conform to the principles noted. What follows is a "model" process where the use of the person centered description is highlighted:

- Develop local person centered descriptions as examples
- Train all players/stakeholders in how to use them
- Meet the time frame/movement schedule in developing person centered descriptions, while building local capacity by offering training in how to develop the person centered descriptions.
- Referral/shopping
    - There are several ways to start the process, two of them are sending the person centered description to potential providers and have the person and their representatives "shop" by evaluating the proposals or have a group of providers come together and the person and/or their representative goes from provider to provider with their description and asks the providers how they would respond to what is listed.
    - With either approach, the only document that potential providers initially receive is the person centered description. They should have already received training in how to use it and can ask specific questions about areas where they want more information.

- Proposal
    - Once the provider has determined that they are interested in supporting the person they:
        - Meet the person (and family)
        - Review relevant records
        - Develop a formal proposal to serve that person
- Negotiation
    - The initial evaluation of the proposal is to compare what is proposed with the "picture of a life"[2], and if it is responsive to what is listed, then
    - Compare the proposed cost with what is budgeted, and if it is within a negotiable range
    - Engage the person and their family to see if it is acceptable to them, and what if anything should change
    - Based on all of the above, negotiate the specifics of what will be in place for the person and the cost
- Acceptance
    - Assuming there is agreement between the person/family, the provider, and the relevant state officials the final proposal should layout:
        - When the person will move
        - What will be in place before the move
        - What are the circumstances in which the person will live (to include location, nature of the home and supports, day time plans, any special arrangements to assure safety, etc.)
- Plan for the move
    - What kind of transition makes sense for the person
    - What can be learned during the transition and how can it be incorporated into that learning
    - What is the hiring and training process for the staff who will work with the person
- Immediately after the move
    - Focus on learning about the person while the provider is also focusing on the administrative challenges (e.g. staff coverage, training, etc.)
- After the move
    - Use of the person centered descriptions where people live and spend their days
        - Selecting and training staff
        - Ongoing learning
        - Acting on the learning
    - Formal monitoring
    - Enlisting and supporting family members as quality assurance partners

This synopsis is intended to give the reader a brief overview. Contact the authors for more detail.

[2] The "picture of a life" is based on work done by Peter Kinsella in the UK (unpublished).

Other Considerations

There are some other issues to consider where the planning is for a set number of people to move. First there are inherent competing pressures. The development of person centered descriptions and a person centered process creates a pressure for people to move to the lives described. On the other hand, the budget has timelines that creates pressure to meet the established goals of having a projected number of people move by a fixed set of dates. Where it seems likely that there will be a failure in meeting the goals that relate to numbers there is intense pressure to compromise on moving to a better life. Coping with this pressure begins with accounting for all of the factors noted earlier when timelines and budgets are developed. Establishing partnerships by having provider and advocacy representation in the initial planning stages helps in: looking at capacity; developing timelines; and understanding the importance of meeting time commitments. However, even with realistic timelines, those engaged in implementation need to be vigilant about avoiding slippage at the beginning of the project. Missing deadlines in the beginning of the effort will result in a time crunch at the end of the effort. The effect of being short on time at the end results in intense pressure to look for solutions that ignore what works for the person in favor of what will get people out within the time frames dictated by the budget.

Another set of issues to address are those that come with planning for closure. First, closure happens in stages, parts of the facility close before others. As this happens, the people who know the person best are reassigned and then leave. While the information they have is easily gathered while they are still working with the person, it is progressively harder as the staff move on to other buildings and then other places. As the facility becomes smaller and smaller it becomes more and more likely people will move more than once and be supported by people who may not know them well or how best to support them. Those people who are most effected by these circumstances need to move before it is an issue.

Conclusion

The best system managers see this as an opportunity; an opportunity to move a system change agenda forward. It will be successful to the degree that all of the necessary pieces are in place. Only requiring that good person centered descriptions be developed will have little impact on the outcomes. There has to be a person centered process that supports the goal of person directed services. System managers need to keep in mind that the decisions made in the beginning regarding the process, budget, and timelines will largely determine the outcomes at the end.

This brief overview is intended to give the reader a framework for thinking about helping people move. It is rooted in a core principle – people should only move to a better life. A better life is best obtained in community settings but simply looking at disability labels while moving people will not automatically improve quality of life. Developing descriptions of how people want to life and need to be supported is the beginning but making sure that those descriptions are used is just as important. Moving should happen no faster than responsive community capacity can be developed but it must also happen within the timelines and budgets that were developed while looking at community capacity and costs. All of this will happen well only if it occurs inside a set of respectful partnerships.

We have tried to make this overview complete, but it is at best a complete skeleton of the process. Many of the details that put flesh on the process have been left out. The authors have developed examples of person centered descriptions and a manual on how to use them. For samples of these and other details the reader is invited to contact the authors at:

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