Individual

Listen/learn → Act on what is learned → See what is not working →

Organization

What is not working → Analysis → Act on what is learned →

Listen, Learn, Act

Selected Writings by Michael W. Smull
on Essential Lifestyle Planning,
Self-Determination, and
Organizational Change

January, 2000

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Preface

Essential lifestyle planning is a guided process for learning how someone wants to live and for developing a plan to help make it happen. It's also:

- a snapshot of how someone wants to live today, serving as a blueprint for how to support someone tomorrow;

- a way of organizing and communicating what is important to an individual in "user friendly", plain language;

- a flexible process that can be used in combination with other person centered planning techniques; and,

- a way of making sure that the person is heard, regardless of the severity of his or her disability.

Essential lifestyle plans are developed through a process of listening, learning and acting.   In the pages that follow, you will find a collection of articles on how to do that in a responsible way. A way that supports people in living the good quality life they deserve.

Person Centered Planning: Should We Do It With Everyone?

by Michael W. Smull

Over the past five years person centered planning has undergone a transformation. It has gone from something mysterious that only a few dedicated and skilled people did to something where nearly everyone says "I have been doing person centered planning for years". Person centered planning and person centered services have become trendy. It has become a litmus test for being politically correct. Any activity where people are asked what they like or want is seen as person centered. Further, states, regions, and counties are beginning to require (or to consider requiring) person centered planning for everyone receiving services or entering services.

From my travels (and from the materials that get sent to me) I have learned that many of the alleged person centered plans and person centered services are not person centered at all. Plans are being written where what is important to those who provide services is written as if it were important to the person receiving services, that abuse the "voice" of the person (e.g. "I must be restrained"). People whose only real dream is to get out of the institution they live in have plans that say that it is their dream to live by themselves in a house in suburbia. People are asked questions where they do not have the life experiences necessary to give an informed answer. Questions are asked that have the answer built in. Equally troubling are the honest plans that are not implemented. Over and over again I hear of people who tell us things such as desperately wanting a new roommates who never get one. Much of what is being done represents no real change in practice. It is business as usual masquerading as being person centered.

Person centered planning is a means not an end

A person centered plan is a means and not an end. The life that the person wants is the outcome, not the plan that describes it. Person centered planning is a process of learning how a person wants to live and then describing what needs to be done to help the person move toward that life. It is a description of where the person wants their life to go and what needs to be done (and what needs to be maintained) to get there. Good plans are rooted in what is important to the person while taking into account all of the other factors that impact on the person's life - the effects of the disability, the views of those who care about (and know) the person, and the opportunities as well as the limitations presented by the need for public funding.

A person centered plan reflects a process:

That is respectful of the person with the disability, the family, and those who support the individual;

Where the time and effort necessary is spent to be sure that the "voice" of the person with the

disability is heard, regardless of the severity and nature of the disability; and

Where there is a focus on learning what is important to the person in how he or she wants to live, what is important to those who love the person, and any issues of health and safety (from the perspective of the person).

The resulting plan is a written description of what is important to the person, how any issues of health or safety must be addressed, and what needs to happen to support the person in their desired life. The plan cannot be separated from the process. A compromised process produces a compromised plan.

Beyond these common elements there is considerable variation. Some of the better known formal processes include: personal futures planning; PATH; essential lifestyle planning; individual service design; 24 hour planning; and whole life planning. Additionally there are a host of processes that have been developed locally. These local processes are often unnamed and usually are a blend of the better known processes. However, the label

of the process is not an indicator of the utility or integrity of the plan. When done well, what unites all of these efforts is a commitment to learning what is important to people and a commitment to implementing what was learned. They all require partnerships between: the person; those who know the person; those who develop the plan; and those who implement the plan.

What has been learned
Where careful planning and implementation have been done we have learned that:

When we listen with skill and respect, we can learn what is important to each person regardless of severity of disability;

Planning is a continuous effort, what people want tomorrow is different from what they want today;

Growth and learning occur naturally when people have the opportunities that they want, opportunities that make sense in the context of what is important to them;

Providing structure inside those opportunities helps people with severe disabilities access and learn more from those opportunities;

Most of the behaviors that we have labeled as non-compliance, as challenging, or as problem behaviors, go away when what is important to people is present;

Regardless of severity of disability, people are able to take positive control over their lives as we learn to listen and trust develops; and

Building community, a network of self-sustaining reciprocal relationships, occurs but it usually takes years not months.

We have also learned that while what is most important to people is modest, implementation is affordable only if we change the way we do business. Unless we begin to fund people rather than capacity, individuals rather than houses, we cannot afford to implement plans where people are asking to change who they live with or what they do. We have learned that it is our own structures that are the barriers and

that many of the reports of high costs reflect the rigidity of our responses.

Person centered planning is also a promise

Shifting a system cannot be done by fiat and it cannot be done overnight. It requires the development of capacity, changing the structures that define where the system is going and what it should pay attention to, and it requires political courage and political capital. Some of the ingredients needed to change the system are:

Training in person centered thinking for all of the people involved in planning and implementation;

Requiring that those who do the plans demonstrate competency in person centered planning and that some of their plans be periodically reviewed;

Training for that those who license and inspect and requiring that they be able to determine that plans meet criteria and that the plans are being implemented;

Changing the rules for services and requirements for funding so that they support person centered planning and implementation;

Support (training and technical assistance) for agencies that want to change their practices and structures;

Helping people with disabilities and their families build community before they are desperate, while families have the energy and resources to form a partnership; and

Leaders who understand what real person centered planning is, the changes needed for their implementation, and a willingness to build support while defending the changes from those who feel threatened.

At its core, developing and implementing person centered plans is about shifting power and control. It is about sharing control with the people supported and their families. To many people this is an opportunity to be embraced but to others it represents a serious loss of power. Person centered planning should be done with everyone only where there is the willingness to

make the investments and changes necessary. However, those who lead must also sustain the change in the face of resistance and attacks. Those who wish to initiate the change need to develop the strategies necessary to sustain the change. In learning what is important to people we make an implicit promise to act on what we have learned. We should not make the promise unless we believe we can keep it.

November, 1996

The Importance of Partnerships

by Michael W. Smull

Across the country, agencies that work with people with developmental disabilities are struggling to change from putting people in programs to supporting people in the lives that they want. Change begins with learning to plan with people rather than planning for them. Agencies struggle to learn what is important to each individual that they support and to help each of these individuals move toward the life that they want. The initial focus for most of the agencies that begin tO convert from offering programs to offering supports is to help people with disabilities get what is important within the constraints of available resources and the presence of any issues of health or safety. As they continue to struggle, they discover that they need to broaden their focus. They discover that people with disabilities cannot be empowered unlees those who are providing the support are also empowered,

The managers of these agencies have discovered the power of partnerships. Rather than accumulating power, they see their role as sharing power. Managers have learned that best practice requires that the people delivering the support feel respected, trusted, and valued. Managers cannot just change the way that they talk, they must change the way that they act. They have to change the practices of their agency to reflect the values that underlie partnership. Some examples of partnership in action are:

At Community Living - Wilmington (a supported living agency in North Carolina), the people who are supported get to select who works with them while the people providing support get to select who they work with. There are boundaries and limitations in how this works. Neither the people receiving nor the people providing support

need to have "cause" in order to make a change. However, team leaders are responsible for insuring that a request does not just reflect transient irritation and to insure that the people supported are not left without the support that they need.

At the pubic provider agency in **Manchester, England**, pilot efforts to build partnership begin with staff learning what is important to them and then learning what is important to the people they support. A manager then facilitates the development of a plan where the staff seek to get more of what is important both for the people supported and for themselves. Schedules and responsibilities have been changed. A person eupported gets to go to her church with a staff member from the same church. Staff who are "morning people" have swapped coverage timee with staff who are "evening people". one ataff member, who was going to a music club on her own time, is now taking someone she supports (who also loves music) to her mueic club as part of work time.

Hope House Foundation, a supported living provider in Norfolk, Virginia, has been working on partnerahip for the past decade. They make sure that before any policy or procedure can be adopted there are opportunities for all of the people effected to be heard. Staff who want to learn something that reflects their personal interests are supported with dollars that come from fund raiaing regardless of whether or not there is a perceived direct benefit for those supported. The disparity between the pay of managers and the pay of direct support staff is being narrowed on the basia that you cannot say that support staff are the most valued people in the agency and then pay them at a rate that says they have little value.

These agencies, and many others nationally, have found that partnership "pays" in a variety of ways. Practicing partnership not only enhances the quality of life for those supported but also effects other areas such as the rate of turnover for those people doing the support. Agencies like Hope House Foundation and Community Living -

Wilmington report annual turnover rates that are closer to 10% than to the 50% plus reported by many community agencies. If agenciea are going to move from providing programs to providing supports they are aleo going to have to learn to practice partnership. We cannot practice respect for the people we support unless we respect the people providing the support.

December, 1996

Before You Plan
by Michael W. Smull

Be sure to think before you plan. Thinking about a few issues before you get started can help you achieve a better outcome, prevent problems, avoid unnecessary struggle, and save you from public embarrassment. Note that the plans being discussed here are not plans done in training (those issues are dealt with in the ìcriteria for a focus personî) but the ordinary, day to day efforts to understand how someone wants to live and what we are going to do about it. The overriding principle is that a plan is not an outcome, the life that the person wants is the outcome. The only acceptable reason to plan is to help someone move toward the life that they desire. In outline the issues to be understood before you plan are -

Make sure that -

you understand why this plan is being done and that the reason for doing the plan is acceptable; and,

there is a commitment to act on what is learned.

Spend with the person with who you are planning before you start the plan to:

get to know the person and her/his issues;

develop the ground rules for the planning; and,

do any negotiation necessary to have a successful outcome.

Look for opportunities -

to build relationships; and,

help people be a more a part of their communities.

Learn if there are any issues and challenges in developing or implementing the plan and develop strategies to deal with them

In more detail -

1. Make sure that there is a commitment to act on what is learned. Remember that a plan is not an outcome. A plan is an organized way of learning what is important to someone and a description of what we will do to act on what have learned (including addressing any issues of health and safety).

2. More specifically, why this plan is being done with this person - is the purpose:

   to help the person move to a new setting; or

   to help them get more of what is important to them where they currently live; or

better understand how to help us support them in the life that they want while addressing issues such as a challenging behavior or a complex medical need; or

a combination of these things.

Once the purpose is understood ask what you need to learn and how it might best be learned. Remember essential lifestyle planning is only one way to learn. If the person has a clear goal that will take some time to achieve think about using PATH. If the person has a number of people who care deeply, who are not exclusively paid staff, and you have the skills and energy to mobilize these relationships, think about doing a personal futures plan. Keep in mind that you can do part or all of an essential lifestyle plan to support the development and/or implementation of another kind of plan.

3. Try to learn of the challenges/ issues present in developing

and implementing the plan before you begin. If this is a person whose parents or guardians have views of what is important to the person that are different (from the views of the person) try to determine how those differences can be addressed. It usually helps to set aside time to listen, to find common ground, before formal meetings. Always talk with the focus person about her/his options and support her/him in deciding how to proceed. Occasionally the best short term solution is to not to do a full plan but to help the person find the best short term compromise.

Do not forget that there while someone may want something that their parents see as unsafe, he/she may also want to maintain a good relationship with his/her parents.

Do not forget that we all want mutually exclusive things (e.g. to be skinny and eat whatever we want or to be rich and work in human services), that part of your job is to learn

what these mutually exclusive things are and to help the person find a balance that works for them.

Where what the person wnats is not supported by those whose consent or assitance is needed for that person to get it, be careful. Do not engage in a process where hopes are raised, only to be crushed. (Be honest about what you can do.)

Remember that the best negotiation is one that no one notices. If you can learn about likely conflicts before that planning starts you can design a process where:

Everyone feels that they were listened to and that they participated in a respectful process.

Common ground is identified and nurtured (often starting with agreement that all of us have the same ultimate goals - for the person we are planning with to be happy and safe). A dialogue about a balance that will work for the person

(and the compromises that will work for others) is initiated and supported.

4. Do not forget the most important part - spending time with the person with who you are planning before you start the plan to:

> get to know the person and her/his issues;
>
> develop the ground rules for the planning; and
>
> do any negotiation necessary to have a successful outcome

Develop the ground rules about who to talk with, what can and cannot be discussed, and how to keep the person informed. Where the ground rules that the person wants would interfere with them getting their life the ground rules are negotiated before the planning starts.

5. Look for opportunities to build relationships and help the person be connected to his/her community. Look for opportunities to:

> to strengthen and extend current relationships, to build new relationships;
>
> build partnerships among those who know and care about the person and with the community; and
>
> help the person find situations where their gifts and contributions are appreciated and used.

Do not forget that an acceptable outcome from ìthinking before you planî is to decide not to plan. If the plan cannot be done respectfully, if there is no commitment to implement, do not plan. If the reason for planning is not acceptable do not plan. If planning is mandated, then the support and monitoring needed to:

> insure respectful planning; and
>
> have reasonable efforts to act on what was learned
>
> also has to be mandated and provided.

April, 1998

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The Structure of the Plan

by Michael W. Smull

Following is a summary of the typical comments that I find myself writing over and over again when reviewing plans. I am using it to insert comments as it makes sense in my reviews. Those of you who review plans may feel free to do the same. While this is not being written as a *stand alone* document you can use it as a brief overview of plans in training. You can also use these comments in reviewing your own plans. This does not replace the longer descriptions such as *Reviewing essential lifestyle plans: the criteria for best plans.* It is also a *work in progress* and I expect that it will change and get longer as I add more typical comments to it.

General comments
Think about essential lifestyle plans as having 4 basic sections - an administrative section, the person's section, the support section and the action plan. Each has a purpose and some guidelines about what goes in them and how they are organized.

However, a plan is not an outcome, the only reason to write plans is to help people move toward the lives that they want. Any plan that helps to make positive changes or helps to maintain important things is a *good* plan. A plan that helps the person maintain a balance between being happy and staying healthy/safe is a good plan. A brilliantly written plan, filled with great information and insights, that is not used is a *bad* plan. Plans that are not read cannot be used and plans that are not used do not matter. Plans with good information that are also easy to read make it more likely that people will get what is important to them and be supported in ways that make sense. Experience has taught us that plans are more likely to be read if they are in outline format and:

- Use complete thoughts but not complete sentences;

- Use simple, every day language and have no jargon

or *human service* speak;

- Each item listed has enough detail and/or enough examples that someone newly present in the person's life would understand what was meant;

- There are no long *laundry lists* of items, those that go together are grouped together, with a space between groups; and

- Where there are 4 or more things grouped together there is a topic statement and the others follow as bullets underneath.

Administrative section
In the administrative section the reader should learn: whose plan; when it was done; who contributed; and anything else that is required. This is also where you would tell the reader why the plan was done/what you want to learn if this is to be included in the plan.

The person's section
In the person's section begins with an introduction to the person (positive reputation, what people

like and admire about the person) and then tells the reader what is important to the person (in 2 or 3 sections - most important, 2nd in importance and - if needed - 3rd in importance).

What people like and admire about the person, positive reputation
This section should list what other people like and admire about the person. It should list things that we might like or admire about anyone of roughly the same age. It should not include things that we only say about people with disabilities or is *faint praise*. Where there are more than 6 or so items listed they should be grouped to make it more likely that they will be read.

What is important to the person
These 2 or 3 sections describe what the person perceives as being important to him or her. It must not include items that others think should be important to the person. It should only include those things that the person tells us are important (with words or behavior). For example, the first draft of a plan done with a 5 year old with severe disabilities said *I must have my food pureed*. As we looked at that we

realized that what she told us with her behavior was that she hated to choke or cough when eating. However, it is very important to her health that her food be pureed. So having her food be pureed was listed under what we need to know or do for her to stay healthy and what was listed under most important to her was that she not choke or cough while eating.

Support Section

In the support section the reader learns what others need to know or do :

- so that the person has what is important to him or her; and

- will stay healthy and safe.

For many people, this is where the balance between happy and safe/ healthy is described. The general rules for support are given with enough specific examples to eliminate ambiguity. Where there are things that are important to those who support the person that are not important to the person, they are described in this section. There are numerous optional parts of this section that are used as needed. The ones most commonly used describe

how the person communicates and what we need to do to help the person stay healthy.

Action plan

The action plan should describe who is going to do what to help people move toward the life that they want and stay healthy/safe. It often describes what needs to be maintained as well as what will be changed. The reader should know what is to happen, who is responsible and the date by when it will happen. The action plan often needs a *bridge* to keep people focused on helping the person get a balance that works for them rather than a plan to do the more of the same old things dressed up with new labels. A section that describes what does and doesn't make sense (what is and is not working) from the perspective of the person and those who support the person is often an effective bridge.

The way the *what does and doesn t make sense* section should work is to begin by looking at what is important to the person. Compare that with the present, with what is happening now. Make a heading that says: What makes sense to ...., what is working, what might need to

be maintained. Make another list. What doesn't make sense to ...., what is not working, what might need to be changed. .Where what makes sense (or doesn't make sense) to the person is different from what does (or doesn't) make sense to staff (broadly labeled as *us*) you need to have 4 sections. This part of the plan should be based on comparing the present (what is happening at the time of the meeting) with what should be happening. It is a snapshot evaluation of the person's life.

Once you are done, have people begin by looking at what does make sense and point out where we can take credit for what has been done and/or acknowledge the good things that are present in the person's life. Then you look at each thing that doesn't make sense, that may need to change, to see if there is something that we can and should do about it. Where the perspective of the person is in conflict with the perspective of the others listed, you look for the balance that will work. You then return to what makes sense. Look for those things that will continue only if we are proactive and for those things that we might change (be lost) in the course of

fixing something that does not make sense. Where something is to be done you should have action steps that say what will happen, who is to do it and by when.

A Plan is Not An Outcome
by Michael W. Smull

Person centered planning is our label for learning how people want to live, to learn what is important to them in everyday life and to discover how they might want to live in the future. But, a plan is not an outcome. The only reason to do the planning is to help people move toward the life that they want and person centered planning is only the first part of the process. Whether anyone can *get* the life described is also determined by their access to resources and the *rules* for using those resources.

When you put these two things together, planning for your future and control over resources, you have self-determination. Not too many years ago this was not an issue, most of the groups pursuing self-determination were individual agencies that believed in helping people with disabilities chart their own destinies. They gathered circles of caring people around each person to discover what they might want and used their resources to help people move toward the life that was described. Now some of the public agencies that fund and manage services are mandating person centered planning. They are requiring that everyone get a person centered plan. Whether this will result in people moving toward the lives that they want will depend in part on the quality of the planning but also on the control that people will have over the resources.

Those who are the best at both the planning and helping people have control over their resources recognize that it is as much a journey as it is a destination. It is about helping people find and maintain a balance in their lives. It is a journey because what people want changes over time (sometimes quickly and often slowly). Everyone has to try things to see what they like and what they like changes as they grow and mature. It is about helping people find a balance because real

life is complicated. Most of us want mutually exclusive things (e.g. to be thin and eat all the fattening food we want). Most of us need to take into consideration the desires and preferences of other important people in our lives. Many of us have more that we want than we can afford. Resources are finite, so we have to decide how to prioritize what we want. Good plans are a snapshot that takes of this into account (implicitly or explicitly) at a moment in time. They reflect the current balance that someone wants and give direction for the future.

Good person centered planning requires that you be able to learn what is important to each person, separate what is important to the person from what is important to others, and communicate what you have learned in a way that others understand. Implementing plans is also about supporting a journey. In trendy business terms, it reflects using a learning wheel. We begin by listening and trying to understand what we hear. We record what we learn in a plan. As we act on what we have learned, we see how it works. And then begin again by listening and understanding.

Those who fund and regulate need to change the current reality. For most people with disabilities, who receive services, the present reality is a world of programs. Most of the current resources are fully committed to buy capacity, to buy *slots*. There are people living in group homes and going to segregated day services who have told us that they hate their roommate and are bored during the day. There are high school students attending educational programs they find meaningless because they do not prepare them for the future that they desire for themselves. Where people want change, planning without real action simply creates cynicism for everyone. One of the traps that this creates for planning is that what is available now shapes what is asked for.

In trying to not be limited by what exists we have learned that the kinds of questions that you ask and the order in which you ask them make a difference in the outcome. Ask about what is important before asking where it could happen. Learn what is important in everyday life and then look at all the different ways that it could happen. Look at what is happening in the rest of the

world. We now have enough *best practice*, enough *pilots*, that what people have in mind is likely to already exist. It may not be next door, it may have been developed on the other side of the US, or in the UK or in Canada, but it is likely to exist. Only after people have explored what is possible should they look at what is available now. Where what someone wants is not offered the next question is how do we develop it here? Knowing that it has been done elsewhere gives people the sense that it can be done and someone to learn from.

Clearly this is easier to do with people who are just coming into the community system, people who are leaving their family homes or are leaving institutions. When we plan with those people who are already receiving services we are facing a number of new challenges. One of these is that people are not used to looking outside of their current ways of doing things. Plans that started with what was wrong with someone were typically part of a professional ritual where *good paper* counted more than good lives. These plans were written with those who spent the least time with the person having the greatest input. They were read only by those who wrote them (and those who inspect), and were not used in everyday life. This part of professional culture continues and interferes with implementing person centered plans. To change the culture we have been recommending that those who manage or visit ask some simple questions after the person centered plans are written. Ask those being supported and those providing the day to day supports: How is the plan working? What have we learned? What have we tried? What else could we try? What else do we need to learn? Ask these questions often and in as many ways as makes sense. Write the answers on the person centered plans. Where this is done those who provide the support see what they learned incorporated in the plans. They see that what they do and how they do it changes as we all learn. Those who are supported and those who provide the supports feel respected, and part of a partnership. The plan becomes a living document that is changed as our understanding deepens and as the person changes.

If we want to change the system we need to look for incremental change as well as revolutionary change. At

any moment, we can create best practice for a few people if we put in enough effort and resources. However, if the many are not to be left behind we need to move our entire system incrementally toward best practice. One way to do this is to think of the changes as happening in phases. Start by looking for every opportunity for best practice and seize each one. Then think about how to start incremental change. For many it begins with simple person centered plans where we ask what is important to people in everyday life, compare that with how they are living now, and change what can be changed now. Change what can be changed without having to make major changes in structure or practice.

Making the easy changes is a good way to start, but an unacceptable place to stop. If people with disabilities are to get the lives that they want, change has to continue. Planners, managers, and those who support have to look at what people want and compare that with their capacities to deliver what is being asked for. Where there is a deficit in capacity they need to look at what needs to change. Does the deficit in capacity reflect a deficit in skills,
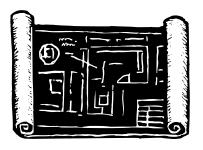
knowledge, or competencies? Does the development of new capacity require changes in policy, practice, or structure? Is the deficit a reflection of problems in how we think or in the unwritten rules for how we act, is there a problem with organizational culture? Again, this is most easily seen as a learning wheel where we are looking at what individuals want and using that to change the system.

Those who mandate the planning will need to make changes in funding, practices, and structures if plans are to reflect what people want and be implemented. They need to invest in the new vision of quality. They will need to build structures that are rooted in values of respect, trust, and partnership. They will have to change a provider agency culture that sees the funding that people receive as the agency's money and uses the language of ownership about people with disabilities. And they need to do this with a minimum of wreckage.

Those who get the support need to be able to say that I am moving and I am taking my money with me. However, those who are left behind need to be able to continue to live as

they wish. The change literature makes it clear that there is no change without loss but we can make change without wreckage. We need to make sure that those who provide the supports are offered the technical assistance to find the win-win solutions. Most will need help to learn the new skills and make the changes in practice and culture needed to move from a relatively static system of supports to one that has the flexibility needed to support people in their evolving visions of how they want to live.

After the Plan

by Michael W. Smull

Excerpted from **Developing First Plans: A Guide to Developing Essential Lifestyle Plans**

Introduction. Learning how people want to live and then doing nothing with the information is a form of abuse. A good plan not only clarifies what each individual wants but creates the perception that those who participated in the planning will do something about it. Planning should only occur where there is a commitment to implement. The challenge in implementation is where to start. The disparity between how people want to live and how they are living often creates a feeling of being overwhelmed, of not knowing where or how to start. The following is an effort to assist those who are engaged in this struggle and to reduce implementation to its essential elements.

Learning how people want to live. The process of implementation of a person centered plan begins with learning how people want to live through a structured process of asking and listening. Honest planning is never finished. People continue to grow and change. As what is important to them changes and as our understanding continues to deepen, the plans should change. Plans are a snapshot of how someone wants to live today, serving as a blueprint for how to support someone tomorrow. They need to be written down so that we have a benchmark of how people want to live. Honest plans also reflect how each individual wants to live, not how we think they should live. Plans should reflect the typically modest wishes and desires of the person and not represent fantasy of the "good life" from the person doing the planning. Person centered planning can be learned by reading and practicing but it is easier (and safer for people with disabilities) to learn from others who have been trained.

Continuously considering issues of health and safety. Doing person centered planning does not relieve us of the obligation to address issues of health and safety. People who are unusually vulnerable need to have safeguards, and people with medical needs must have adequate health care. The challenge is to consider these issues within the context of how the person wants to live. In careful implementation, issues of health and safety are not considered only once, they are continuously considered. The challenge in implementation is to enhance safety and ensure health without compromising those things that are important to the person. Once there is an understanding of how the person wants to live, any compromises in what is important to the person are made consciously, after efforts have been made to think of how the person can have what is important and still be safe and healthy.

Comparing how the person wants to live with how the person is living. Comparing how people want to live with how they are living is a form of discrepancy analysis. The result creates the agenda for action. Knowing what is important to

a person (and knowing how important it is) is followed by looking at how the person is living now and determining to what degree each of these things is present or absent. Careful consideration of the difference between what people want and what they have shows what parts of their lives make sense and what parts do not.
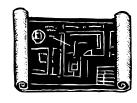
Giving credit for those things that are being done that do make sense (and continuing to do them). It is important not only to highlight the need for change but to highlight those things that are being done well. There is an unfortunate tendency to wallow in blame and guilt when the discrepancies are seen between what is important to the persons served and how we have been supporting them. A sense of urgency is needed but guilt is not helpful. Rhonda's story illustrates these issues. How Rhonda was being supported Monday through Friday reflected a deep caring and understanding of how she wanted to live. Although she does not use words to talk, staff who loved her were listening to her behavior and honoring her positive rituals and choices. As a person centered plan

was developed with Rhonda, it became clear that the weekend staff did not know her as well and were not listening. The reaction of the people who supported Rhonda during the week was dismay and determination. They were pleased at how much they knew and dismayed at how it was not being used to help Rhonda on the weekends. Talking about what was going well validated the efforts of the direct care staff who loved Rhonda and were listening to her. Looking at the discrepancy reframed what had been seen as her "behavior problems" on weekends into a problem with the support she was being given. It gave a sense of direction.

Changes that can be made within current structures and resources. Rhonda's life also provides an example of how needed changes can occur within current structure and resources. Planning with Rhonda made it clear that she must be supported by people who are calm, soft spoken and not "in her face." She must be supported by people who understand how she communicates with her behavior, who listen to what she is saying. Some of the people supporting her on the weekends were not calm or soft spoken and tended to "get in her face." They were the wrong people to support Rhonda. They were not "bad" people, it was a bad match. With some rearranging of where people worked Rhonda began to have weekend support that made sense to her. The staff who know Rhonda also developed a "cheat sheet" that told how to interpret what Rhonda was saying with her behavior. For example, everyone who supports Rhonda now knows she tells you when she wants to get up in the morning by being on her stomach, propped up on her elbows. Her "problem behavior" is gone and someone who was labeled "nonverbal" is now described as "outspoken."

Those that require changes in current structures and/or resources. Some of the issue's in Harry's life illustrate how some changes can be made immediately while others will take time and require changes in structure. Harry will not eat with people that he dislikes and shares his house with a roommate whom he strongly dislikes. He does like eating in his

room, by himself. Using typical "group home thinking" staff used to say: "We eat family style and we all eat together." As staff learned about choice they were willing to support Harry eating in his room-except that it would not be "fair" to another roommate. Harry had another roommate who liked to store food in his room. Staff felt that they could not let Harry do something that another person in the house could not do. They did not feel that the fellow who "hoarded" food could be allowed to eat in his room because it would create a health issue as perishable food aged. In trying to honor choice, staff were saying that Harry did not have to eat with everyone, but there were no in-home alternatives. Harry could, and often does, eat with friends and relatives who live elsewhere but he was also simply not eating some nights.

When we did the planning with Harry, the fellow who stored food in his room had moved, so "fairness" was no longer an issue. (If that roommate had been present the argument would have been made that treating everyone the same in this circumstance is inherently unfair.) As the issues for Harry were reviewed, it was clear that

supporting Harry in eating in his room made sense. Harry left the planning meeting with a "dining" table for his room (that had been stored in the basement) and was going home to have supper in his room. The staff who support Harry had committed to find a way for Harry to live only with people that he chose (and liked). However, helping Harry move requires that the agency figure out the finances involved in closing the group home. While this will take time, in the interim Harry will be happier and will eat regularly.

Harry's story also brings up an issue of health. Since Harry has no unusual medical issues, skipping an occasional meal is not a problem. The concern is that he would skip enough meals to unbalance his nutrition and/or to cause him to lose too much weight. Harry does not have enough money to eat out all the time and he does not eat with his friends every night. He was skipping enough meals to have a noticeable weight loss (although not enough to raise immediate health concerns). Neither depression nor an eating disorder seemed to be needed to explain his not eating at home. Hating one of his roommates and

having no alternative appeared to be sufficient explanation. Eating in his room is the temporary solution. He still eats out when he can afford it and he eats with friends and relatives as often as he is invited.

A life that makes sense to the individual. The desired outcome is a life that makes sense to the individual. How each person wants to live should be congruent with how they are living. This does not mean that everyone gets everything that they want. Some things are beyond our power to provide, some things take time, and some things cost more than we can afford. A woman I met in Chicago told me that the only living situation acceptable to her was to live with her mother. Unfortunately, her mother made it clear that regardless of the supports offered she was not prepared for her daughter to return home. To help this woman achieve a life that makes sense we have to help her deal with the loss of her home with her mother and to develop other relationships.

Many of those things that are important to people take time to achieve. For people living in group settings, the changes that are possible will not work for everyone.

If you hate one of your roommates, not having to eat in the same room helps. However, it does not address the underlying issue that you should be able to pick whom you live with. Because sites are funded rather than people, because having one or two people move may leave a deficit that cannot be covered, helping people leave group settings takes time. Moving to a new place requires that we not only know how people want to live but how we can pay for it. Where group homes are being closed, disposing of the building may require significant effort. Helping people leave group homes can be done and should be done, but it does take time.

Many people say that they want to live by themselves. This is the request that most often challenges the disability system. The easiest way to control costs is to share them. By requiring that people share housing and staff, costs are reduced. Where people live by themselves this economy is absent. If everyone wanted to live by themselves the disability system would never be able to bear the cost. However, if only a small percent want to live by

themselves at any one time it should be affordable. Many people want to try living by themselves, but only a few people like it as a permanent way of life. Further, many people have been forced to share their lives with their roommates and need to experience what just sharing space is like. (When you share lives you do everything together, when you share space you sleep in the same house and otherwise select what you do together.)
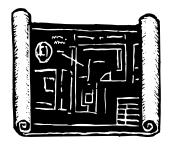
Home ownership is another example of something that appears too costly. The disability system has made it possible for agencies to own thousands of houses but sees home ownership for individuals as too expensive. It does take time, knowledge, and commitment but people across the United States and Canada are finding ways to buy their own homes. It is only too costly when it is seen as something which should be solely financed by the disability system.

Home ownership is also an example of a dream. Whenever a dream for the future is expressed there are a few questions that should be asked. The first question to ask is whose dream is this? Most people need to have a life before they begin to have dreams of things like owning **their own** home. Check and see if it is really their dream or is it the dream that the facilitator thought they should have. If it is their dream, does it really need to happen tomorrow or is it something to work toward? Simple dreams like living only with people that I like, only being supported by people that I trust, or having privacy in the bathroom, should be achieved quickly. Expensive dreams, extraordinary dreams, which are the person's and not the product of a guided fantasy, become something that the person should be supported in working toward.

Remember to keep listening. Whenever people are empowered, a dynamic situation is created. The process of listening and then acting on what has been heard is an ongoing cycle. What people want today will be different from what they want tomorrow. The process is lifelong and interactive. The only thing worse than never listening is only listening once. The process should continuously loop back, comparing how people are living with how they want to live. Where there are differences a plan needs to be developed to help the individual to continue the pursuit of happiness.

Changing from Programs to Supports

by Michael W. Smull

Four of the reasons why changing to self-directed services is so damned hard.

1. ***It requires that, during the change, you run dual systems***; and:
   - Dual systems result in people "layering-on" paper requirements.
   - In the medium to long term you cannot run dual systems – supporting people is another way of thinking, not just another way of doing.

2. ***It requires new skills and new knowledge***:
   - We treat the new skills as if they were knowledge;
   - Acquiring new skills requires mentoring/coaching;
   - In the absence of adequate support people will revert to what they know (do the old process with new labels);
   - Look for the naturals, support the learners, and cope with those who have no talent; and

- Managers make decisions based on their personal knowledge, rooted in their prior experiences –
  - Managers need enough "new" experiences to have enough new knowledge to develop a "translation program" from the old to the new; and
  - Many managers were trained in a "command and control" theory of management and need assistance to transition into a system of sharing power and control.

3. ***It is about sharing power and control and we have a system where power and control are more often accumulated than shared***:
   - At its core, it's about shifting power and control to people with disabilities and their families, but control is never absolute, it is about sharing power and control;

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- For most people exercising positive power and control requires new knowledge, new skills;
- For most organizations sharing power and control requires new policies and practices; and
- There are those who do not want to share, the opposed.

4. ***We say it is about changing practice, but it is even more about changing culture. Those who are successful***:
    - Have a culture where managers consistently view all issues/problems through the lens of helping people get the lives that they want, where they keep their "eye on the prize" -
        - In thinking, problem solving,
        - That deals with requirements, rules, regulations in a way that helps keep people on their journey;
    - Move from a passive "professionals know best" culture to an active, questioning, learning culture;
    - Move from a blame culture to an accountability culture; and

- Create a culture of partnership, rooted in respect, and trust.

Developing strategies for change

1. ***Look for, create, and take advantage of opportunities to establish best practice***:
    - Best practice examples are a necessary but insufficient ingredient in a change strategy;
    - Only doing best practice is the contagion theory of change, change is produced but too slowly; and
    - Local best practice examples demonstrate that it can be done here and produce a clear destination of where you want to go.

2. ***Find opportunities to make incremental change in typical practice***:
    - Create change "inside the box" that demonstrates that –
        - Change is possible, gets people comfortable with change;
        - That moves typical practice toward best practice; and
    - Be ready when a series of incremental changes creates the opportunity to establish best practice.

3. ***Seek ways to change the expectations/creating positive pressure for change among key stakeholders regarding typical and best practice***:
   - The first requirement for change is discontent, the second is pressure;
   - Top down pressure is uneven and inconsistent;
   - Pressure from self-advocates and families can be more constant and consistent; and
   - Where there is top down support, create pressure from those who do the day to day support.

Implementing change
Those who are seeking pervasive change need to remember:
   - Look for opportunities where you can start with success;
   - Start where the people who are doing the work are;
   - Start with listening and observing to see where people and organizations are in practice, in behavior, in organizational culture – not just in rhetoric;
   - Always look for opportunities for best practice while remembering that change "inside the box" helps people become comfortable with change and feel empowered so that change "outside the box" is easier to achieve; and
   - Change strategies that are more ambitious than the resources to support them fail and in their failure confirm the cynics who are saying that this is just a fad.

1. ***Look for the opportunities to initiate and support efforts to change organizational culture so that*** –
   ➢ Leaders/managers consistently view all issues/problems through the lens of helping people get the lives that they want:
      ♦ Remember that this is a part of culture, that you are changing an organizational "habit"-
         ♦ Changing a habit requires consistent efforts where those who participate can remind the leader of the discussion when there is a "lapse;"
         ♦ Finding solutions that reflect what is important to people and address the specific problem may require increased problem solving skills (a training/mentoring issue);

♦ Also remember that you are looking for the best outcome but occasionally need to settle for the "least evil" outcome; and

♦ Where you settle for a least evil solution you also need to let those affected know what you are doing and lobby for change.

➢ Change the planning process to establish/support a learning culture:

♦ Lay the foundation for a learning culture, train those who will implement in the principles of the planning and learning before you start to plan;

♦ Start with simple plans that establish a framework for learning;

♦ Turn the learning wheel –
♦ The person and those who spend time with the person should note what they are learning;
♦ Provide organized time for reflection;
♦ Have the professionals practice their new roles as consultants, synthesizers, and facilitators (who help deepen understanding,

suggest new ways to understand, and solicit/ suggest new things to try);

♦ Continuously teach person centered thinking – look for and use the "teaching" moments;

♦ Develop the skills needed when what is being done doesn't work, e.g., coping with risk, finding new ways to understand behavior, defining responsibilities;

♦ While helping people get what is important in everyday life look for, build and make use of opportunities to help people be connected to their communities.

➢ Go from blame to accountability:
♦ Understand the problems and pervasiveness of a blame culture;
♦ There is no creativity in a blame culture;
♦ In a blame culture responsibility is to be avoided, not accepted.

➢ Build respect, trust, and partnership:
♦ Blending what the Gallup organization learned with person centered planning;

- ♦ It starts with who you select to do the work;
- ♦ Matching talents with jobs, learning who should work with whom;
- ♦ How to keep the people you want; and
- ♦ Measuring respect, trust, and partnership and acting on what you learn – an exercise and a process.

2. ***Look through the attached list for (Measuring the Strength of a Workplace) opportunities for change. Rate the opportunities based on*** –
   - ♦ Effort required (organizational readiness, ease of change);
   - ♦ Talents of those who would lead the effort (naturals, learners, untalented, opposed); and
   - ♦ Potential gain.

Sustaining change

- ✓ Helping managers have the context –
  - • Spending time with one or two individuals who are moving from programs to supports; and
  - • Helping them to stay on their journey, turning the learning wheel;

- ✓ Establish a forum where managers reflect on what is being learned and develop interventions/supports to overcome obstacles and sustain change.

- ✓ Those who participate –
  - • Must meet regularly;
  - • See it as a time to reflect and problem solve (not a time to do crisis management);
  - • Have the support necessary for success (they may require an outside facilitator);
  - • Have a process where they reflect on the success and difficulties and ask what each suggests about issues with -
    - ♦ Knowledge and skills/ competencies;
    - ♦ Policies, structures, rules, management;
    - ♦ Organizational culture; and
    - ♦ Organizational change.
  - • Based on what they have learned, design interventions while supporting success;

✓ Remember that they and the organization must build and celebrate short term successes and have opportunities for renewal.

Measuring the strength of a workplace*, 12 questions that measure the core elements needed to attract focus and keep the most talented employees. (Questions in **bold** are the most strongly correlated with retention.)

1. **Do I know what is expected of me at work?**
2. **Do I have the materials and equipment needed to do my work right?**
3. **At work, do I have the opportunity to do what I do best every day?**
4. **In the last seven days, have I received recognition or praise for good work?**
5. **Does my supervisor, or someone at work, seem to care about me as a person?**
6. **Is there someone at work who encourages my development?**
7. **At work, do my opinions seem to count?**
8. Does the mission/purpose of my company make me feel like my work is important?
9. Are my co-workers committed to doing quality work?
10. Do I have a best friend at work?
11. In the last six month, have I talked with someone about my progress?
12. At work have I had an opportunity to learn and grow?

***Buckingham & Coffman**, *First, break all the rules* (1999) pg 28, 33.

Thinking About the Roles of the Support Broker

by Michael W. Smull

As self-determination and individual funding spread people are looking at the roles of those who have been traditionally known as case managers or service coordinators. The expectations that many had of service coordinators in the late 70s and early 80s has been buried in increasing numbers of people to support and endless paper to complete. As we change from service coordinators to support brokers (or whatever new label is adopted) we have the danger of just changing the labels without changing what happens. Unless managers change (and those who fund support) the underlying structures, including reducing the volume of paper and numbers of people each support broker works with, the changes in the roles and expectations are doomed. Real change needs to begin with an understanding of the desired outcomes and then developing the structures to support it. We need to begin by asking what do support brokers need to know and do?

I could say that the support broker's job is to help people have their own lives where they are supported by and contribute to their communities. While this is true it is also too glib. "Sound-bite" advice is often a good way to help people remember complex ideas but the ideas have to be explained first. If I had the opportunity to briefly explain what I meant I would talk about roles and responsibilities mixed with values, gifts, and talents.

Its about partnership
At its core, the work of a support broker requires partnership and partnership is built on a foundation of respect and trust. Unless people with disabilities and their families feel respected, the trust needed to share what is important and to take the risks inherent in growth will be absent. Without trust there will be no partnerships. Real success is easier with (and usually requires) a series of interlocking partnerships.

Partnerships are needed between people with disabilities, their families, those who provide the support, and those who do the planning and funding. All of these partnerships require effort to establish and maintain. Some of what follows begins to describe what is necessary to create and sustain them.

It begins with listening
Everybody involved in these efforts must feel that they were listened to. There is often compromise and people who disagree, but everyone must feel that the plan facilitator listened to them. While everyone has ideas and important contributions to make, those listening must keep in mind that the person is the expert. They need to listen to what the person says with words and behavior about how they want to live and act on what they say. They have to be careful to distinguish between what the person wants and what others want for the person. And they need to understand that what someone asks for may be limited by what they have tried. What someone is saying that they want is based, in part, on their experiences. People need opportunities to try things to see if they will like them.

After the person, the most important people to listen to are family members. In many instances they were the only advocates who were present before the support broker met the person and the are advocates who will be there after the support broker is gone. Part of the role of the support broker is to help to maintain and enhance their relationships with the person as part of their work in representing the person. They need to understand and take into account the family's perspective. Where what family member's want for the person is different from what the person wants for themselves they need to understand why. Where there are differences that are substantial they need to negotiate a compromise that maintains the relationships while creating a balance that works for the person. While there are notable exceptions, remember that among the things that most people want and need are continued good relationships with their family.

Plans as frameworks for learning
The plan that is developed with the person is where many of these efforts come together and are reflected. A plan should begin with recording the learning that resulted from listening and then describe what will be done to act on what was learned. The plan should -

- Reflect what is important to the person;

- Describe a balance between what is important and any issues of health and safety; and

- Make clear the responsibilities of those who support the person in moving toward their desired life.

The plan should describe the direction of the journey (and the destinations along the way). However, learning is continuous and must be done in partnership, if it is to be used to help the person continue to move toward their desired life within their community. Plans should provide a framework for recording the on-going learning that takes place and describe what will be done that reflects the learning.

Helping find a balance
Few people (regardless of the presence or absence of disability labels) have a perfect life. What we all seek is a life that has a balance that we see as positive. The support broker' job can be seen as continuously seeking a balance that works for the person, a balance between what is important to the person and what is important to those who know and care, between what is important to the person and any issues of health and safety. Remember that this is a journey, not an event. The best outcome, the best balance that can be achieved today is the starting point. As the person grows and changes, as other perceptions of the person change, as our understanding deepens, opportunities for a better balance arise. Self-determination is not about a single effort; it is about pushing for the best immediate outcome, looking for new opportunities, and continuing to listen to the person. In seeking a balance that works for the person the order in which you answer questions matters. Learn how somebody wants to live before you look at where. Learn what would make the person happy and then learn how the person can be healthy
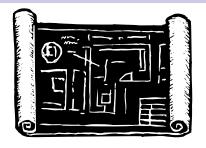
and safe within the context of being happy.

It is about control and seeing possibilities

Support brokers have to be able to do individual budgets. It is about money and how it will be spent, but money is only where it starts. It is really about control. If people can use and move their public dollars as makes sense to them they are more likely to be listened to and achieve a balance that makes sense. Doing this requires that you see the public finding as not just a way to buy services but also as leverage. It is clearly and importantly a way to leverage changes in the services available. However, with enough flexibility in how the money is spent it is also leverage in building community. Some of this is by paying people to "bridge" or connect". There are also people in jobs where co-workers are paid to provide the needed support. But it all starts with being able to see possibilities. The best support brokers are not to be trapped by what is, they lead a process where people go beyond the boundaries of the system and see the possibilities in the community.

It is not about doing all of the work, its still about partnership

The reader's response to this list of responsibilities and activities may well be "this is what we should do but that we will never be able to afford it". If the support broker is the one to do all of this it is true, it is unlikely that there will be the funding to have the enough support brokers. Central to making this happen is to return to the idea of partnerships. If the work is done in partnership, then the broker does not have to be the person doing it all. With support, there are families and service providers who are developing superb plans. There are self-advocates who are developing their own plans. On-going, continuous learning is essential to success and can only happen in partnership. Much of the creative thinking (and learning) about helping people be part of their communities is happening inside existing services. The support broker's role is to look for opportunities to develop productive partnerships, to help define the roles of the partners, and then to make sure that the important work in building a life with each person is happening.

Some Characteristics of a System of Support

by Michael W. Smull

People are more likely to get lives (and the system) changed –

If the people supported (and their families):

- Know what is important to them;
- Know what is conceivable, what others have done, in this sense know what is possible;
- Have substantial control over the public resources available to make it happen; and
- Feel that they are respected and trusted and have a partnership with those who plan, manage, and support.

If the leaders and managers:

- Believe that people with disabilities should have positive control over their lives and should be part of their communities;
- Are committed to do whatever it takes;
- Understand that it is about changing how we think and act more than changing how we plan;
- Support everyone in acquiring the needed knowledge and skills;
- Create and support a culture of learning, accountability, and partnership; and
- Have the skills necessary to be good managers.

If those who license, inspect, and otherwise hold the system accountable:

- Look for outcomes rather than process;
- Understand that change is messy and distinguish between the messiness of change and the absence of acceptable outcomes;
- Require accountability while avoiding blame; and
- While they inspect they also consult.

Those who actually see people and their services need to be sufficiently knowledgeable about person centered plans and the implementation of plans, to be able to meet a person and determine if the plan –

- Reflects what is important to the person;
- describes a balance between what is important and any issues of health and safety;
- makes clear the responsibilities of those who support the person in moving toward their desired life;
- is providing services and supports to help the person move toward the life that he or she wants; and
- Expects that public resources will be used to help the person move toward his or her desired life while maintaining the balance described.

If those who are to do the day to day implementation:

- Understand what they are doing and how –
  - Their work is about supporting people and not about fixing disabilities;

- The people they support have ways in which they are smart, have gifts, and have important ways in which they can contribute;
- The contributions that the people that they support can make to their communities are important to having healthy communities;
- Are active participants in developing the plan, the learning between plans, and in each of the subsequent plans;
- Are acknowledged for their on-going contributions;
- Have the formal and informal times where they participate in the on-going learning –
  - Sharing what each has learned;
  - Reflecting on what has worked;
  - Figuring out what to do next;
  - Celebrating success; and
- Feel that they are respected and trusted, and have a partnership with those supported and those who supervise.

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If the plans –

- Provide a framework for learning, acting and reflecting;
- Reflect what is important to the person and describe what others need to know or do to have a reasonable balance between/among any competing pressures –
  - Between happy and safe/ healthy
  - Between what the person wants and what others want for the person
  - Between what the person wants and available public resources;
- Are accessible (easy to read/ user friendly);
- Are helpful to those who implement;
- Reflect what actually happens in the support that the person gets;
- Are the place to record what is learned day to day (written on by those who do the work as they learn);
- Clearly and simply describe the roles and responsibilities of those paid to support; and
- Are developed in a respectful process where the person

being planned with and those who provide support feels that they were listened to.

If the planner/facilitator keeps the process alive by considering the issues of the person, and the resources available for support and the goal of helping each person be a part of their community. Then, starting where the person is, with a pace that reflects the opportunities and resources –

- Helps the person get what is important in everyday life;
- Using what has been learned about what is important, helps the person to be welcomed by and connected to their community;
- Using the resulting associations, looks for opportunities to build relationships;
- Uses the relationships to build a circle of support; and
- All of this is done with the person and results in an ongoing, evolving vision of desired future

If all of this happens where efforts are made to build –

- A learning culture;
- A culture that moves from blame to accountability;
- A culture of partnership built on a foundation of respect and trust; and
- Having all of these present at the same time is extraordinarily rare and that not all of them need to be present to have plans implemented.

Some Thoughts from the Field: Invited Commentary on Articles on Self-Determination

by Michael W. Smull (from *Impact*)

The articles that form the core of this issue were reviewed through the lens of my current experiences with the service system for adults with disabilities. My reactions reflect what I have been learning from the people I plan with and those who support them. The adult service system is talking about rapid change while engaging in glacial change. It embraces the language of each new trend while largely maintaining its old practices. However, if as Kantor suggests, a key requirement for change is dissatisfaction, it is a system that is overdue for change (Kantor, Stein & Jick, 1992).

In embracing the language of self-determination the readiness discussed sounds remarkably like the readiness about deinstitutionalization twenty-five years ago. In the early 1970s the people who lived in institutions were discussed as being divided among those who were *ready* and those who were *not ready* for life in their communities. As self-determination is currently being discussed in most communities, people are talking about it from a *readiness* perspective, as something for articulate self-advocates but certainly not something for people who have severe cognitive impairments and do not use words to communicate. While the authors of the core articles are not talking of readiness neither have the discussions matured to the point where we are also talking about building community capacities, of helping our communities be ready. Despite the absence of pervasive recognition of where the onus for development lies, self-determination is happening with people with severe disabilities in scattered places across the United States, the United Kingdom, and Canada.

As noted by Wehmeyer (1998), the roots of self-determination can be found in the principles of normalization as articulated by Nirje

(1969). However, despite Nirjeís articulate call, normalization has largely happened inside programs. Those who plan and manage start with what is wrong with the person and then they place people in a program that matches the disability. It is only after they have *placed* the person that efforts may be made to help the person have more control. Therefore the changes that we need are larger than those most systems have either made or anticipate. Further, with today's concerns about the effects of managed care, self-determination clearly provides the best alternative (Nerney & Shumway, 1996). Among the lessons that I have learned from those who are struggling to make self-determination a reality for people with severe disabilities are that:

- The first 'assessment' is to listen to the people who are being supported and to learn what those who love the person already know;

- Self determination is about control but it is also about partnership and struggle;

- Having self-determination become the dominate

paradigm in our service system requires that we change more than practice, it requires changes in thinking, values, culture and support; and

- If self-determination is for everyone what is written about it has to be accessible to everyone.

1. The first *assessment* is to listen to the people who are being supported and to learn what those who love the person already know For any one who lacks substantial control over their life self-determination begins when people listen to what they are saying about how they want to live and then act on what they hear. For people with severe disabilities who do not communicate in traditional ways the first *assessment* is to listen to the behavior of the person and to gather the knowledge that those who love them have. The experiences of those of us who do planning is that where there are individuals in the person's life who love them, much of what is important to the person is known but not recognized. The individuals who love the person may or may not be related and they may or may not be

paid. What they have in common is that they have a personal relationship with the person, spend time with the person, pay close attention to how the person responds to what is being done and thus learn what is important to the person. Part of what is new in self-determination is that we are listening to people to whom we have traditionally given instructions. Where they are paid they are paid the least. They are the individuals who help people with severe disabilities eat, get dressed, and have fun. Because they are rarely listened to and because what they have to say is almost never systematically collected the resulting *collective* wisdom is often greater than anyone was aware of.

Once this *collective wisdom* is gathered and organized the people who know and care about the person are asked to compare what has been learned about what is important to the person with what is happening in the person's life. They are asked to think about what needs to be maintained and what needs to change. They are asked to reflect on what else should be learned. The resulting plan initiates a *learning circle* (Senge, 1990; Handy, 1994).

The circle begins with listening and understanding (Greenleaf, 1977), continues with planning and acting on that plan, and closes the circle with reflection and more listening. Those who are involved with the person are challenged to enter into a partnership of active dialogue and struggle.

It is in this context that formal teaching strategies and formal assessments can provide invaluable assistance. Any time we listen and act on what we hear we have created a context in which communication will become more effective. However, as we seek to help people be a part of their communities we should also look for ways make it easier for them to communicate with people who do not know them as well. We should look for ways of communicating that they might like to use and that people in the community will easily grasp. Where it is not clear what the person enjoys or where they only have a few things that they like, a formal assessment organizes our efforts and makes it more likely that we will learn about what their preferences are. The danger is having the assessments take control over what happens in the person's life rather than their

being seen as just another way of listening and of helping the person to learn. However, the danger in emphasizing a more informal approach is that pointed out by Brown et. al. (1998), that we will make assumptions about meanings that are not correct. We will project our meanings on to those of the person and the 'voice' of the person will be lost.

We need to strike a balance. We need to guard against reinforcing the image of the person as broken with assessments as a way of defining what is wrong and teaching strategies as a way to fix them. The voice of the person must be in the foreground. Assessments should be seen as another way of listening and understanding the person. As is suggested in the articles reviewed, teaching strategies and goals need to be linked to what the person might like to learn and have a benefit that the person sees. For self-determination to become a reality for people with severe disabilities, those who develop education or support plans need to become skilled at listening and to see the need to listen on a continuous basis rather than as an annual event.

2. Self determination is about control but it is also about partnership and struggle.
For all of us control and choice are at the core of self-determination but control is always shared and choice occurs inside boundaries. Living in interdependence means that what we want must be balanced against what others want. Everyone also has mutually exclusive desires (e.g. to be rich and work in human services) between which we need to find a balance. All of us have boundaries imposed by society's rules, our resources, and the resources of our families and communities. The challenge in self-determination for people with severe disabilities is how we share control, struggle with where the boundaries are (breaking through the artificial boundaries of the disability system), and seek an outcome that reflects a balance that works for the person. One sign of success would be the end of *placement*. People would no longer be *placed*. We will learn how people want to live before we talk with them about where.

When we are supporting people who are not articulate self-advocates, who do not use words to talk and who need extensive

physical assistance the challenges increase. We are challenged to 'listen' so that we are hearing the voice of the person and not our voice speaking for the person. We have to try things and see what happens. We have to balance desires, risks, and resources with the person. For all of us, what we want is shaped by what we have known, what we have experienced. For people who have had few life experiences, we have to think of what new opportunities they might try. When we have concerns because someone hurts themselves or others, we have to try to understand why this happens. One difference is where we start. We have to start with understanding how not being listened to for decades can effect behavior. We have to start with the assumption that acting on what we hear will change the behavior. If we are committed to doing this over time with the person then there is partnership as well as struggle. Denise's story in the article by Bambara, Cole, and Kroger (1998) is an excellent example of both partnership and struggle. By listening to Denise they struggled with (not against her) to help her have control. They used their skills and understanding to listen to what Denise was saying and only after they began to understand did they apply their other skills to help Denise learn and grow. Within this framework Denise provided continuous feedback which was used to correct the course that they were taking together. The ways in which she communicated reflected her wounds from her past and instead of simply trying to 'fix' her they struggled in partnership with her. They showed understanding and compassion as they were helping her develop less painful ways of telling us what she wants.

When we continuously listen and act on what we hear there is a partnership and control is shared. We must struggle to have the voice and the desires of the person in the forefront while also encouraging growth and addressing any issues of heath or safety. We will have to continuously ask questions such as: *What is the person telling us with their behavior? If what we think the person is saying is true, how will we know, how will the person tell us? If the person wants a change how will we know? Given what the person likes now what would make sense for them to try next? In helping them try new things, where is the line between*

encouragement and coercion? What could they learn that would help them get more of what they want and would they like to learn it?

3. Having self-determination become the dominate paradigm in our service system requires that we change more than practice, it requires changes in thinking, values, culture and support.

One of the myths in self-determination is that it is just a change in practice. Making self-determination real requires changes in thinking, in values, and in culture. Sharing control with the people we support, having a culture of respect and trust, and operating through partnerships are all the exceptions and must become the norm. We have to stop being the experts and begin to see each person as the real expert in their own life. We have stop telling people how they will live and what they will do based on our formal assessments and learn new ways of listening. As we help people with severe disabilities have their own lives we have to learn to listen more to the people who spend time with the person. We have to recognize that we are asking people to acquire new skills, that learning to

listen and learning to share control will take time and require support.

Wherever people with disabilities need support, we need a culture of respect, trust, and partnership. Unless people with disabilities and their families feel respected the trust needed to share what is important and to take the risks inherent in growth will be absent. Without trust there will be no partnerships. Without a series of interlocking partnerships between people with disabilities, their families, those who provide the support, and those who pay it will not be possible to provide supports to all of those who want them nor will it be possible to build community.

Unless the people who provide the direct support feel respected they will not be respectful of the people they support. Unless they are trusted they will not will not be empowered to provide the flexible support that is needed. At the same time, increasing the trust placed in the people who provide the direct support increases the need to know who is being trusted and to establish clear expectations and boundaries (Handy, 1995; Smull, 1997).

Respect begins with listening, everyone must feel that they were heard. Trust is built on acting on what was heard, on honest promises about what will and will not be done, what will and will not be attempted. Trust comes from seeing actions taken and from honest acknowledgment of what we do not know. Partnerships arise from shared responsibility, shared struggle, and shared actions. Everyone must understand what is being done and why. Everyone must feel included. Respect, trust, and partnership are linked, each to the next. When I ask people with disabilities, their families, and those who do the day to day work of support whether or not respect, trust, and partnership are present the answer is typically no. Each of these needs to be consciously built into the processes by which we assess, plan, and act.

Whenever people are in paid services the challenges are compounded by the issues around control of the funding. People with disabilities get trapped by funding packages and staffing ratios. For example, the first response to hearing that someone dislikes who they live with is that we cannot afford for that person to leave and take their money with them. Those who are paid to support need assistance in thinking beyond the traditional program response and need an incentive to learn new ways of thinking. Change will not occur without pressure, without what Kotter (1996) refers to as a sense of urgency. For many who provide services that pressure will only come when those who get services not only know what they want and what is possible, but have sufficient control over the funding to take their money elsewhere when they are dissatisfied.

Finally, if self-determination is to become the norm we need to recognize that it requires new skills and that learning those skills takes time and support. When I ask those I visit about person centered planning I often hear that they have been doing it for years. When I observe what is happening I see the old practices dressed in new rhetoric. Learning to listen and act on what is heard is a skill and it is not in common use. The teaching strategies most needed are not for those with disabilities but for the people who assess, plan, and support. They need to have

opportunities to learn new ways of: listening; understanding what they heard; and communicating it to others. While there are some notable efforts to produce descriptions of the currents processes more efforts are needed and research on their efficacy is absent (Sanderson, et. al.1997, O'Brien & Lovett, 1992).

4. If self-determination is for everyone then what is written about it has to be accessible to everyone.
If self-determination is to be the norm, the people who receive services, their families, and those who support them need to understand what is being written about how to implement it. This is a challenge when writing for publication and runs counter to the training that most people have. Those who truly wish to see people with disabilities have control must strive to write so that those without graduate educations will understand what is written. Research results need to be presented in a manner accessible to those who can implement what was learned. Each new technique, assessment, or process needs to be evaluated to determine how it can be implemented in a world without graduate students as resources. Research needs to focus as much on at how the system and its organizations need to change as they do on how we need to change our practice in supporting individuals.

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Listen, Learn, Act

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