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Supporting People with Severe Reputations in the Community

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National Association of State Directors
of Developmental Disabilities Services, Inc.
113 Oronoco Street
Alexandria, Virginia 22314

SUPPORTING PEOPLE WITH SEVERE REPUTATIONS IN THE COMMUNITY

By Michael Smull and Susan Burke Harrison
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This handbook is dedicated to the memory of Jerry Kiracofe and Katie Johnson. Jerry Kiracofe introduced us to person centered planning and always helped us to stay focused on the underlying values. Katie Johnson taught us how to listen to people who do not speak for themselves.

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SUPPORTING PEOPLE WITH SEVERE REPUTATIONS IN THE COMMUNITY

INTRODUCTION

The Handbook

This handbook presents the tools needed to develop better community capacity to support people with severe reputations. For conceptual convenience it is divided into four components:

- How people receive their reputations;
- How to plan with the individual for community services;
- How to recruit and develop the supports needed to implement the plan; and
- How to avoid the most common abuses and perversions in providing supports.

While the material that follows focuses on planning, these are overlapping activities. Recruiting supports begins with the initiation of planning. Inviting those who may provide the support to participate in the planning is part of the process by which supports are developed. Understanding the individual is both the focus of the planning and the necessary prerequisite to have supports that are responsive to the changing needs of the individual.

The planning techniques presented here are called Essential Lifestyle Planning. Partially derived from Personal Futures Planning, these techniques represent one approach to planning for individuals. Anyone using this handbook should feel free to substitute other "person centered approaches" as they seem appropriate.

The authors want to acknowledge some of the many people who have directly or indirectly assisted us in developing this handbook. Our efforts would not have been possible if it were not for the pioneering efforts of John O'Brien and Beth Mount in developing Personal Futures Planning. Herb Lovett has offered invaluable assistance in reviewing and commenting on the many drafts. The staff of the community capacity team have had to implement each version of the planning process and we appreciate their patience and commitment. However, we have learned what does and does not work from the people we are learning to support. They have patiently helped us to learn how to listen to their requests. Their success is our reward.

PART I

CONTEXT

People With Severe Reputations

People with severe reputations are found in every human service system. They are the people who have become famous as a result of their reactions to the services they are offered. They are frequently described as "not ready for the community". Our experience stands this perception on its head. It is the community that is not ready for the individual. It is the absent community capacity that needs to be developed. There are very few individuals who need to be "made ready" for life in the community. Community capacity does not refer to clinical services. While there are acute needs for competent clinical supports in the community, we need to start with the broader context in which the clinical services may be delivered. In listening to what people with severe reputations are telling us, we have found:

- People with severe reputations tell us more about what is wrong with our system than what is "wrong" with the individual; and
- Many people with severe reputations have modest but essential lifestyle choices that are not being met.

Starting With The Individual - Listening To The Individual

Most human service systems develop programs and put people into them. We are suggesting a system that starts with individuals and builds services around them. People need to be provided with settings where their essential lifestyle choices are met. If this can be done, the lives of people with disabilities will improve dramatically and the problems of the service system will be significantly reduced. People who are getting what they are "asking for" clearly have a better quality of life then those who do not. Simultaneously, the need for behavior control programs (and the staff to implement them) will be reduced as we will not be making people conform to a setting which they do not fit. When people are leading typical lives in the community, the degree of community integration increases and the amount of community resistance decreases.

Shifting Our Investments

The process of supporting people in lifestyles of their own choosing requires that we shift our "investments" in service development. We typically spend relatively little time in individual planning and more time in locating or developing a program. This approach requires that we

spend more time in planning. It will also require extra time in helping providers develop services around individuals and in developing a flexible array of supports. Over the long term it means less time spent in trying to make a bad fit work and fewer meetings where everyone tries to avoid the responsibility for another failure.

Essential Lifestyle Planning

The first part of this process focuses on the individual. Any planning that begins with the individual rather than the program is referred to as "person centered planning". There are a number of techniques that fall under that label including "Personal Futures Planning". The specific process described here is a type of person centered planning called "essential lifestyle planning". Philosophically it is rooted in a profound respect for the individual. Essential lifestyle planning helps people to discover their choices and then helps them to have those choices honored. There is no bias for or against a type of service or a predetermination of the number of people who should live together. It is focused on the individuals and what they value.

Understanding Choice

Understanding and honoring an individual's choices goes far beyond simply asking someone to choose where to live and who to live with. We are seeking to understand the interactive set of circumstances necessary for the individual's happiness. The context of our efforts includes the cognitive disabilities of the individuals but is truly made challenging by the nature of their lives. They have had the expression of choice suppressed and distorted by the current system of services that we have provided. Many have had lives of poverty and pain. Few people with cognitive disabilities have ever had any real experience in exercising positive control over their lives.

Common Sense, Not Revealed Wisdom

This is not a new, arcane wisdom. It is a common sense approach to help people with disabilities achieve ordinary lives. We need to illustrate how similar what we are doing is to what typical people do for themselves. We are simply taking "unconscious", learned activities, that everybody engages in, and making them into a "conscious" practice. Bringing together a group to do this is necessary because the people we are helping have trouble doing it for themselves. Part of the difficulty that these individuals have in doing it for themselves arises from their cognitive disabilities. For many people with mental retardation, though, the larger problem is the way in which we have controlled their lives.

We are trying to listen to what people want and to help them get it. The simplicity of this statement is deceptive and potentially harmful. Helping someone else live the life that they want to live requires that we understand them. Understanding others requires empathy and insight. Listening to the surface of what people say is not enough. We have trained people with cognitive disabilities to tell us what we want to hear. Not knowing what is possible leaves

them without the vocabulary to say what they would like. They can only tell us what they believe to be available. Those who are living in circumstances that they acutely dislike and in which they feel trapped will choose the first exit offered.

Discovering What The Individual Values

We need to discover what each individual values and what each individual finds to be a hassle. Some people find a smoke free environment to be very valued and the presence of smoke to be an intolerable hassle. Some people need control over their personal space, over their possessions, and over the order in which they do activities. The focus is not on changing people, but on understanding them. Essential lifestyle planning assumes that we all have an ongoing unconscious balance where we weigh the values and hassles in our lives. None of us achieves a hassle free life. Still, we all struggle to insure that those things that are most valued are present and those that are the greatest hassles absent. In this planning these are referred to as "non-negotiables". Their presence or absence will necessarily make our lives pleasant or intolerable. For most of us, and for most people with disabilities, these non-negotiables are modest needs.

Honoring Choice While Sharing Control

In the current system of service, complete control over all essential choices is in the hands of the professionals. The outcome of this planning process is to rebalance the locus of control. The service system must continue to assure reasonable protection of the individual while supporting substantial freedom. Control is shared through collaboration. People who cannot articulate where they would wish to live or who they wish to live with can tell us of their preferences through their behavior. Those who tell us what they think we want to hear can learn to put forward their own wishes. We will need to assist these individuals to discover what their informed choices are. They will need encouragement and careful exposure to relevant life experiences. We have found that as people gain power over their lives, they often need less control or protection.

Neither the process nor the outcome eliminates the need for skilled professionals. People will still need support for their behavioral, psychiatric, and medical needs. People will still want to learn new skills and will need good teachers. We are not discarding all of our professional skills, we are simply putting them in their proper position. Our skills should be used to help people in achieving the lifestyles of their own choosing. They should not determine that lifestyle.

The greatest challenge for all of us in supporting people with disabilities is finding the balance for each individual. A balance is needed between:

- Freedom of choice and the safety and health of the individual;
- Personal liberty and the expectations of society to conform to social norms; and

- Encouraging individuals while avoiding coercion.

Because the balance achieved needs to take into account the circumstances, the core values, and the complexities of each individual, it is different for each individual. These are the issues that we wrestle with for ourselves and our loved ones. This is why we focus on the ambiguous issues of lifestyle choices. This is why we do not stop with the traditional information such as deficits in adaptive behavior, cognitive disabilities, psychiatric diagnosis, medical issues, and behavioral problems.

CURRENT PRACTICE

People With Severe Reputations As Famous Individuals

In every human service system there are those individuals who are "famous" within that system. Unfortunately, "fame" for these individuals is not the result of valued accomplishments. Their "fame" is the product of our failure to adequately support them in the community. We place people in programs that do not meet their needs or preferences. While we label them as not being "community ready" it is we that have not been ready for them. They are asking for support which is responsive to their needs. We have a rigid service system whose narrow range of responses is unable to meet their diverse needs.

> ***Colleen's story is a nearly archetypal example of the response of the service system creating the reputation of the individual. Colleen is a woman whose tough exterior masks a gentle, caring person who is easily hurt. She is someone that Lovett would refer to as a steadfast social critic. She cannot tolerate systems that are rigid, rejecting, and uncaring. She will do whatever it takes to get someone who is "in her face" to "back off". She demonstrated a capacity to out escalate the entire human service system. She began with hitting a nurse with a couch in a psychiatric hospital and ended wearing a paper gown in the infirmary of the state prison. In this process the system gave her a severe reputation. Rather than being seen as someone who needs settings that are accepting and caring, with positive limits, she was seen as someone too violent to ever live in the community.***
>
> ***Because some people got to know Colleen rather than her reputation, she is now living in the community. While her life is still a struggle, none of the behaviors of her reputation have surfaced. She has not hit anyone, she has not thrown furniture. Her life also has many positive aspects. Colleen's gifts have been allowed to blossom, she helps others and has a number of caring friends. She even received an award from the governor for her success.***

This has been a learning process for Colleen and those who support her. She sat down with those who were going to support her and planned for her move to the community. She had a list of questions for them, including whether they would "let her go" when she no longer wanted their support. They asked her how they could give her the support she needed without Colleen feeling the need to hit her staff. The simple solution was to give her the authority that all of us want. When she felt that staff were not treating her with respect she could fire them. In her first year in the community, Colleen fired two support counselors.

She has found that living with others is a challenge for her. She and her supporters wrestled with this. Colleen agreed that she does need people to talk to. She needs people who will offer support and advice. But, she does not want to share her life with these people and she wants this support to be on her terms. She does not need "supervision", she does need support. Her system of support now consists of staff who wear "beepers". Colleen is in frequent contact but it is on her terms. Will this be the system in place next year? Probably not. However, the system will continue to be the product of a collaboration between Colleen and those who support her.

The Label Trap

The current system of services is rooted in a program model. We look at "needs" which are defined in terms of deficits and disabilities. We develop programs to remediate deficits and accommodate disabilities. We then group people who share disability labels by our perceived need for their supervision. This begins with funding capacity rather than individuals. We start with the program and end with the person. Service providers with "capacity" come shopping for people to put in their "slots". They are looking for people who will "fit". "Fit" means that the individual has labels that conform to the labels of the program (e.g. - "dual diagnosis", or "non-ambulatory") and that their need for "supervision" and "specialized services" conforms to the staffing model of the program. Good providers try to select people who they believe will be "compatible".

What would happen if we applied these good intentions to college students. (The following was originally published in AAMR News and Notes.) If the disability system ran the university, the first thing that we would change would be how people are housed. Freshman would be assigned roommates, floors, and dorms based on SAT scores. We would have separate dorms for each of these groups:

SAT Score	*Classification*
1600 - 1451	*Profoundly Clever*
1450 - 1301	*Severely Clever*
1300 - 1151	*Moderately Clever*
1150 - 1001	*Mildly Clever*
1000 - 850	*Borderline Clever*

While each dorm would be required to be restricted to one group, e.g., the severely clever, within the dorms roommates would be within 15 SAT points of each other. We would debate whether those in the "borderline clever" group are really college material, but we could call them athletes.

Having solved the problem of selecting dorms and roommates we would turn our attention to the next issue, that of choosing major areas of study. We know that freshman really do not know what they should study. Instead of the inefficient process of having freshman pick majors and change majors, we would simply review the SAT results and select the area where they demonstrated the poorest performance. As the disability system we know that what is important is remediating deficits. This will also make course registration more predictable as many seniors will still be failing the same courses that they began taking as freshman.

The next issue where we can be of assistance to college administrators is in the area of behavior. Freshman are notorious for the frequency and severity with which they exhibit maladaptive behaviors. It seems that all of the behaviors that parents had suppressed for 18 years emerge during the freshman year. Colleges have attempted to tolerate all but the most outrageous of these behaviors. As the disability system we can do better. Freshman will have to earn points in activities of "daily university living" (in areas such as personal hygiene and dorm room maintenance) in order to have privileges such as having pizza delivered to their rooms. Where we face more challenging behaviors, we can make attendance at football and basketball games a contingent reinforcer. We can introduce the idea of the IDP (Individual Dorm Plan) and revolutionize the management of the behavior of college students.

Where students have roommates that they do not like (despite our scientific method of matching) we have the answer. The old method of simply allowing students to select and change roommates at will is appallingly inefficient. We know that there is no real necessity to change roommates. With our technology we can introduce behavior programs and structured interactions. We will not need to allow students to change roommates simply because they want to. We will not listen to the students who say that this means that they have to spend more time with people that they hate.

If we were to actually attempt such a system in a college setting it would only be a matter of days or weeks before the students rose up in revolt. People with disabilities have been extraordinarily tolerant (or simply more suppressed). Many of them have been reinforced into acceptance. Those individuals who have continued to object have been the subjects of powerful interventions for "maladaptive behavior". Many of the people with mental retardation who are living in psychiatric hospitals are those who refuse to adapt to the systems that we have in place. These people are steadfast social critics.

The Symptoms Of A Broken System - Listening To Behavior

People with mental retardation who are living in psychiatric hospitals tell us what is wrong with our system. Rather than looking for what is "broken" about the individual we can see the individual as telling us what is "broken" about the community system.

There are a number of individuals whom we have taught that merely complaining about a program produces no change. "Non-compliant" behavior (otherwise known as non-verbal complaining) results in behavioral control programs. We teach these individuals that we will only listen to extraordinary displays of aggression or property destruction. We then say that they "failed" in that program and move them to another program. Ironically the "failure" often reflects the success of the individual in learning what it takes to get our attention and cause us to change the placement.

> *Kathy is famous across her state. She has lived in a number of community programs and state institutions. Kathy has found that no one listens to her complaints but everyone listens to her behavior. She has punched and kicked, but one of her gifts is to display her anger in ways that everyone notices and talks about for years. When "streaking" was popular she ran naked down a city street to tell people that she wanted to live in the country. She put a staff member's desk drawers in her desk upside down so that everything would fall out when this hated person opened the drawers. She "poisoned" a fellow resident's food with soap powder to punish him for stealing her food. When one staff member complained of being punched, she told her: "It's your job. I am a patient. I get to hit staff."*
>
> *We have always listened to Kathy's behavior but never offered her what she was asking for. She insists that she be taken seriously. She wants to be listened to. Her requests are modest. She needs to have control over her space and her "stuff". She wants people to not only ask permission before they come into her room but to wait until permission is granted. She wants to be able to cook for others and celebrate the holidays by entertaining others. She has difficulty in being close to men and wants to have control in her relationships with men. As we honor her requests Kathy will not be transformed. She will continue to struggle and those who support her will continue to be challenged. But she will live in the community with a lifestyle compatible with her basic wishes.*

Blaming The Individual Rather Than The System

Our typical response to a "placement failure" is to have meetings where the primary goal is to blame the individual for the failure rather than any of the system representatives. Avoiding blame substitutes for problem solving. We do not ask what the individual was telling us. Was there a bad match between the person and the setting? Were critical elements missing from the setting? Were there aspects that the individual simply cannot tolerate? Did the people supporting the individual have the attitudes and skills needed to be successful?

Instead of problem solving we repeat the same process over and over again. We look at the old and new labels that we have given the individuals, convene more meetings, discuss the best "program options", and ultimately place people with anyone who will accept them. We recognize the growing fame of individuals by having larger meetings with more and more system managers in attendance.

Rather than broaden the lifestyle options available to the individuals, we develop more sophisticated behavioral control programs. In essence we review the past failures and plan for the next failure. As the "failures" continue, the person first develops the reputation of being "difficult to place" and then "not community ready". These individuals develop "severe reputations" which drastically limit the lifestyle options that are available to them. Their institutional placements become indefinite sentences because of the system's failure to address their needs as individuals.

Where our goal is to control people within our programs rather than to accommodate them within our communities, we see the past as reflecting the need for increased control. The need for control translates into the need for more direct care and professional staff and the accompanying costs. We then conclude that we cannot afford to serve these individuals in the community because of the cost of the staff needed to control their behavior.

Learning From The Past

The "sins of the past" become a daily reality for people with disabilities. We need to learn from the past to prevent it from becoming prologue. We need to use the past to build a better future. We do not need to use the past to rationalize a future of progressively more restrictive efforts. If we were to treat typical citizens as we treat people with severe reputations we would have them followed 24 hours a day, recording every embarrassing moment, every "wrong" move, taking data on the spectacular and frequent "bad" behaviors and then summarizing everything negative about the behavior in group meetings. We would make certain that the "best" of these "bad" moments are transcribed from record to record so that even a decade later these events are still reviewed by each new person who enters their lives.

Changing The Way We Think - Disputing The Reputation

Helping people with severe reputations find community settings that make sense begins with changing how we think about these individuals. If we recognize that a "severe reputation" is only gained when the available programs will not accommodate the individual, it follows that we must look outside of what has been available in the past. We must have a system that starts with the individual and which insures that no more "placements" are made. We need to dispute the reputation by:

- seeking to understand the person;
- helping others meet the person rather than the reputation; and

- facilitate "person centered" planning to support the person's entry into the community.

We know that non-traditional settings and services are going to be required. We must insure that they can be located and secured. We know that these individuals are often volatile and require flexible supports. We must be prepared to do what ever is required to meet the changing needs of the individual. We must keep in mind that those who are doing this for the individuals will themselves need support. We must build a system that will work for the individual after we (and our enthusiasm) have moved on. We must build systems of supports that will last for the lifetime of the individuals supported.

PART II

ESSENTIAL LIFESTYLE PLANNING

The Headings

In "essential lifestyle planning", as in the other forms of person centered planning, we conduct the meeting using "wall paper". A series of charts are placed on the wall with headings that help organize the information needed to implement community services for the individual. The headings for the charts are:

- Non-negotiables
- Strong preferences
- Highly desirables
  - People who really know and care about _____ say -
  - To be successful in supporting _____ -
  - _____'s reputation says -
  - If this is going to happen we must -

The first three categories - non-negotiables, strong preferences, and highly desirables - ranks what people like and dislike. Keep in mind that while these distinctions can be very helpful they are artificial, good sense should prevail. The next set of headings serve a number of purposes. What people who really know and care say about you is your positive reputation. This begins to counter the reputation found in the record. The heading that says "to be successful in supporting ____" is where the issues of those people who are essential to success and the essential clinical issues are noted. The reputation heading serves two purposes. It gives those who are compelled to recite the past a place to do it, but it also insures that attention will be paid to issues that can be glossed over in the positive focus of the meeting. The last heading on the chart is where action steps are described. The "who, what, and when" are described in order to sustain the momentum of the planning process.

Non-Negotiables

Non-negotiables are those lifestyle choices which are essential to a reasonable quality of life for the individual. Positive non-negotiables are essential for a person's life to be tolerable and

pleasant. Negative non-negotiables make life so unpleasant and intolerable that their presence will make people act out or withdraw. Non-negotiables represent the core values and characteristics of individuals. Examples of non-negotiables in plans that have been done are:

- not living with smokers
- having lots of friends
- living where I grew up
- living with people who do not mind clutter
- living with people who "love me the best"
- not living in the city
- control over my own space, my own possessions

All of these requests are modest. The non-negotiables we find for people with disabilities are rarely honored and yet readily available to typical citizens in our communities. We refer to these preferences as non-negotiables because they are essential to the individual's well-being. They are the choices that we must honor. Providers who cannot (or will not) meet these are not considered.

Most non-negotiables are stable over time but some of them do change. Where change occurs it typically reflects learning. We find that core values and the choices they reflect evolve over time. As we mature we find that what we value shifts. Often we want more stability and less change. We also make choices that do not have the anticipated results, that do not give us the increase in our quality of life we expected. The cliche for this is "learning from experience". When ordinary people make a particularly bad choice we call it "learning from the school of hard knocks". In the disability field, when we are angry with someone and "let them fail", we call it "suffering the natural consequences".

Strong Preferences

Strong preferences are the middle ground between non-negotiables and highly-desirables. For example, there are people who simply cannot stand to be around cigarette smoke, those who have a strong dislike, and those who simply find it irritating - people with a non-negotiable, a strong preference, or a highly desirable. Strong preferences reflect those choices that make a major contribution to a reasonable quality of life but are not critical to it.

Highly Desirables

Choices that are the highly desirables represent those things we would like to have. We are not interested in a Christmas list of things that someone might like. We are seeking to discover

those things that people know that they want in their lives. Most of us have lists with a pyramid shape - we have a few non-negotiables, more strong preferences, and lots of highly desirables. Where there is a short list of highly desirables we either do not know the individual very well or the individual is living a very impoverished life. Just as in the other areas, most highly desirables are typically quite modest. We should be able to support people in having many of their highly desirables met.

In Thinking About Choices And Planning

Where services that honor these choices do not exist, we need to plan further. Can we find the setting and then build supports around the individual? How long will it take to develop the setting that meets the non-negotiables? If the answer is months then we need to see if there are interim efforts that will improve life while the individual waits. We must guard against having interim become permanent. Too often the interim efforts remove the pressure needed to develop the setting that meets the non-negotiables. We must ensure that the non-negotiables will be met.

Where we are planning for others we need to take into account that our understanding is always less than perfect. We are often trying to support people whose disability and circumstances preclude a clear vision of a desired future. Difficulties in speaking for themselves, impoverished life experiences and few connections with people who know and care about them increases our challenge. We need to see all of our lists as representing the understanding that we have at that moment. As our understanding changes we need to change our lists.

Quality of life is interactive and evolves over time. There are synergistic effects. The presence or absence of a reasonable quality of life is made up of a complex of interacting issues. The product of the interaction cannot be easily predicted. We need to pay attention to how people feel about their entire life. We need to continue to learn not only about the effects of single choices but the effects of their interactions. In looking at individuals' perceived quality of life we need to account for their personalities. Edgerton has noted that pessimists and optimists tend to stay that way. Assessments of how people report on their quality of life need to reflect the "baseline" of their personality style.

People Who Really Know And Care About Her/Him Say

How would your mother describe you when bragging to her friends? The stereotype of a mother's description is how this section should be approached. All of the positive attributes of the individual that relate to human interactions or valued skills would be listed here. Adjectives such as "charming" or "warm"; descriptors such as "loves to help others" or "makes me laugh"; skills such as being an "excellent baker" or plays a "great game of pool"; are all appropriate examples. Clinical descriptors such as "has all his ADLs" or "expresses anger appropriately" are not acceptable.

Few positive descriptors means that you have not invited (or interviewed) the right people or the person needs to move immediately. People who know and care about someone always have reasons why they care. Their stories carry the positive descriptors. If you have sought out these people and have not found them then the individual is living without people who care. Anyone living without people who care needs to leave as quickly as is possible.

To Be Successful In Supporting Her/Him

If we are to be successful in supporting people with severe reputations we must do more than honor their choices. We need to address their clinical needs. We need to address all of the prerequisites for the individuals to achieve their desired lifestyle in the community. We cannot assume that behavioral issues will simply cease to exist because people are getting the lifestyle that they are asking for. For an individual who throws and breaks things when he gets angry we cannot assume that he will no longer get angry. There need to be reasonable, positive practice behavioral plans to deal with predictable challenging behaviors. Other clinical support issues may be medical, psychiatric, or neurological. Any essential clinical supports needed should be listed.

This is also the area where the issues of other essential people are addressed. In one instance it was critical that an individual's mother be enlisted as an ally before the individual moved. This is an individual who has a close relationship with his mother and she has correctly perceived that we have not done well in supporting her son in the community. For another individual, whose living arrangements crossed funding jurisdictions, officials from both county services boards had to agree before the individual could move.

His/Her Reputation Says That He/She

Reputation needs to be approached with caution and judgement. When you are planning with people whose reputations are the primary barrier to achieving their desired lifestyle, the reputation must be confronted. But you must also keep in mind how difficult this can be for the individuals who are experiencing this public parade of past sins. Consider whether this section is needed. It can serve a number of purposes.

First it provides the facilitator a place to consign all of the negative attributes that some people have a compulsion to emphasize. Second, it can be used as a contrast with the positive attributes of the individual and demonstrates how we blame individuals for system problems. Finally, in the process of describing the reputation, we can be alerted to issues that we must account for. Occasionally people feel that the positive emphasis of this planning process precludes raising issues of real concern. For example, someone who has set fires presents a public safety issue that we be adequately prepared for.

The reputation listed in the preliminary plan needs to be shared with the individual and a strategy developed to assist the individual in coping with it. The terms used should be carefully considered to see if they impart the necessary information while they are as respectful of the

individual as is possible. Alternatives can be considered as well. Where the planning is being done with people without severe reputations, you need to consider whether this section is needed at all.

If This Is To Happen We Must -

As the planning meeting ends the momentum that has been created must be sustained. A set of concrete action steps should be developed. They are listed under this heading with the action, the date by which it is to be accomplished, and who is to accomplish it. A list which includes everything up to the move of the individual is unusual. It is more important to establish realistic time frames for moving forward with the plan and to make the planning participants responsible for its execution. The last step is typically a date to get back together to report on progress and continue the planning.

PREPARING FOR THE MEETING

Disputing The Reputation - Understanding The Person

Understanding the person is not a "Polyanna" process where the difficulties are glossed over by denouncing the service system. Understanding the person suggests that all people are complicated and require more than simple assessments of splinter skills or isolated behaviors. Understanding the person also suggests that people with severe reputations have positive attributes. They have gifts, skills, and potential contributions. Understanding the person requires that we look beyond the reputation to the whole person.

First, we must get to know the whole person. We must move from traditional, deficit oriented assessments to understanding the person as a real person. We must go beyond simply identifying strengths and needs and discover what the core values are for each person. It is not enough to focus on preferences, we must know each person's dreams and nightmares. We must remember that we can easily make someone's nightmares reality.

It is critical that we know what the values and hassles are for each person. There are few relationships, jobs or situations that are totally hassle-free. We choose to continue in these situations when the values outweigh the hassles. We choose to leave when the hassles outweigh the values. We must recognize that a major difference between ourselves and people with disabilities is that they do not get to "walk" when the hassles outweigh the values. They only get to leave when we allow them to leave.

Meeting The Person - Not The Reputation

We must meet the person rather than the reputation. Find a setting where the individual is comfortable, where the behavioral norms of the setting are not elicited. It can be private space where the individual lives but it might be a hillside where you can sit with a picnic. It might be a restaurant in the neighborhood. It may require that you go along with the person on an

outing. We need to keep in mind that the norms of congregate settings are powerful and seek alternatives where the individual is relaxed and comfortable. We also need to keep in mind that many people are shy and will not let you get to know them until they get to know you.

Getting to "know" someone is a social skill more than it is a professional skill. Typical professional skills will elicit social histories or determine mental status but will not help you find out who the whole person is. You need to talk about the good times in the individual's life. When did things go well from the individual's point of view? What are their favorite activities? Who do they feel close to? Who would they like to have involved in their lives? What do they like, what do they really enjoy? What annoys them, what makes them angry?

How much people can share verbally depends on their abilities as well as the relationship you establish. Regardless of the verbal skills there is much that can be shared and learned. We need to take the time to get to know them as individuals and not rely solely on informants. However, because many people with disabilities are poor historians and because we have given them extensive training in telling us what we want to hear, we also need to interview others.

Selecting "Informants" - Recruiting Allies

We typically find no shortage of professionals who can tell us what is wrong with an individual. To understand the person we need to be able to talk to people who know the person rather than their disabilities. We need to talk to the people who know what is right with the individual, who can tell us why they like the individual.

Find the people who enjoy spending time with the individual. There are no rules about who these allies can or cannot be. For individuals who live in institutions they may be from housekeeping or be from the professional/management staff. The only rules for selection are that these people must like the individual and enjoy spending time with him (or her). Look for people who spend extra time with the individual. If there is no one at this moment, start going back in time. Where someone has lived in a facility for years there are almost always people who really know and care about the individual.

Look for family or friends who are available and interested in the individual. They are typically the best historians for the individual's likes and dislikes over time as well as for information about the times when things went well. Unless they appear to be a destructive force in the life of the individual, encourage their involvement in the planning for the person as well as the eventual supports. The key word is encourage. Do not coerce, use guilt, or otherwise manipulate family into promising involvement that they will not be able to sustain.

Ask:

- What do people generally like about the individual?

- What are the individual's gifts; what does he/she do well; what does he/she enjoy doing?

- What makes the individual unique; how is he/she different from other people; if we were to characterize the individual in two or three words what would they be?

- What does the individual find to be a hassle; what doesn't he/she like doing; what makes him/her angry; what does he/she find to be annoying?

- What motivates the individual; what is important to him (e.g., money, praise, personal appearance, family, church, friends)?

- When have things gone fairly well for the individual? Describe the circumstances, speculate on why things went well.

- Who is important to the individual and what is their relationship (e.g., mother, son, sister, friend, special member of the staff)?

The responses can be as short or as long as the informants would like to make them. These are areas to cover as much as they are questions to ask. Just as much of this planning process is adapted from personal futures planning, interviewers should adapt these questions to their own style and circumstances.

Using Professional Information - Looking Beneath The Labels

We need to look beneath the labels that the individual has acquired to determine if they contain any helpful information. Some labels tell us very little that is useful while others provide critical information. No label tells us where people live or what work they should do. Where they are accurate, they can tell us where someone should not live or what situations we should avoid.

As many labels are not accurate, we need to start with skepticism. Some people with severe reputations seem to have acquired labels as if they were party favors. They got the labels by simply being at a facility where someone was passing them out. They did not get the label by meeting a set of criteria. They may have exhibited behaviors that were misinterpreted, not examined, or elicited by an atypical institutional environment. Some labels reflect behavior that was present in the past but which is no longer an issue.

People with severe reputations typically have psychiatric or behavioral labels. Some labels give us critical information. If we ignore or dismiss these labels, we can cause the very failures that we are seeking to avoid. Someone with a bipolar (manic-depressive) disorder must have careful, competent psychiatric care. Someone with a history of severe depressions or psychosis will need careful monitoring so that prompt appropriate treatment is given for reoccurrences.

We need to be particularly careful with the labels that are "loaded". People with labels of pedophilia or arson are rarely welcomed. Where they do reflect a real condition, we need to take the precautions necessary to assure the safety of the community. Yet, these labels rarely

reflect a compulsion on the part of the individual. Typically they were not correctly applied and have no current relevance. A number of people have labels relating to aggression, such as intermittent explosive disorder, whose real histories describe someone who is rarely listened to. Labels that are misapplied, or are no longer relevant, are simply another barrier to life in the community.

Mining The Records

While the typical record of an individual with a severe reputation is replete with accusations it can also be the source of significant information. Careful review can yield information about how to help the individual and who else to involve in helping. By reviewing the stories of repeated failures we can prevent errors in our responses to the individual. Reading the record from a "person centered" orientation will tell us much of what the individual does not like or will not tolerate. There are often clues as to the characteristics of people that the individual does like and what the individual finds to be valued. Current and past social histories should be carefully reviewed for clues regarding family or significant others who may be available to provide supports in the future.

Developing Preliminary Lists

As you are collecting information about the individual you should be organizing it. Is this a non-negotiable? Is it part of the reputation? Once all of the pre-meeting information has been collected it should be put on charts. Make charts with the various headings and begin to put the information on them. The most difficult part is deciding what is and is not a non-negotiable. Keep in mind that part of the purpose of the meeting is to review, revise, expand the information on the charts. Keep notes of your questions and uncertainties. Sharing your questions about what should go where is an excellent way to initiate and sustain discussion.

Information on the charts should be free of jargon and in everyday English. The only exception is listing clinical labels on the "reputations" chart. Do not worry about having complete information at this point. The purposes of developing preliminary charts are:

- To organize your thoughts;
- To discover what you know, what you do not know, and what you are not sure of; and
- To provide a place for people to start, to give them something to react to.

Inviting The Right People - Determining Who Is Needed, Who Is Essential

The people who need to be invited are those who know the person the best and those who are essential in the implementation of the plan. People who really know the person can help sort out what is a non-negotiable and what is a highly desirable. You need not invite all who

must approve the plan but you need the people who will be responsible for its implementation. They will be educated by the process. Many of them will meet the person (rather than the reputation) for the first time. If you can move the whole person to the foreground and the reputation to the background, skeptics can be changed to allies through their participation in a good planning meeting.

However, this is another area where common sense and good judgement must prevail. People who have profoundly negative feelings about the individual will adversely effect the meeting process and outcome. Do not invite them. Among those who know the individual there may be some whose schedules just do not allow for them to come when all of the other key participants can come. You will then have to determine whether to rely on an interview to convey their information and insights or to delay the meeting.

Finally there are the key people who are really needed but are "burned-out" on the individual and/or meetings about the individual. The first step in convincing them that this process is different is to spend time listening to them. Most typically they will agree if they feel that you appreciate all of their past involvement with the individual. You do not need to convert them into enthusiasts prior to the meeting you just need them to agree to participate in the meeting.

CONDUCTING THE MEETING

Setting The Ground Rules

Large, interdisciplinary team meetings are a frequent and familiar occurrence in human services. People gather to share their "clinical insights", assessments, and findings in an "objective" setting. Typically, these meetings focus on the individual's deficits (which are labeled as "needs"). The "team's" mission is to "fix" the person. All of the efforts are directed toward moving the individual towards "independence " and "community readiness".

There are several key elements that distinguish an Essential Lifestyle Planning meeting from a typical Interdisciplinary Team Meeting. One of the basic differences is the ground rules that are established and adhered to throughout the meeting. These ground rules should be clearly stated at the beginning of each planning meeting. They are:

1. Use plain English.

Avoid clinical jargon. If we want friends and relatives to participate on an equal footing we all have to use everyday English. Jargon can also serve to distance the individual from the rest of us. Using everyday descriptions, instead of clinical terms, helps to keep the individual's issues in the same realm as our own struggles. It is the job of the meeting facilitator to politely rephrase jargon laden statements into everyday language. Whatever is written on the lists at the meeting and incorporated into the final plan should be in language no more sophisticated than that of the local newspaper.

2. ***The planning meeting should be conducted with as well as for the individual with a disability.***

The individuals who are the focus of the meeting are always invited to the meeting. If they are absent it should be their choice and not for our comfort or convenience. They should be spoken to directly and never talked about as if they were not at the meeting. The respectful inclusion of the individuals with disabilities during the meeting is a key ingredient to the overall success of the meeting. If people are unable to speak for themselves or if it is not clear what they want, a trusted friend or family member may, through the strength of their relationship, be able to speak on their behalf.

3. ***Promises for further action are made to the group and not to the team.***

As responsibility for the action steps are divided among the participants they must understand that they are undertaking a collaborative process. They are making promises to the person with a disability and the other participants, but **not** the "team". It is not unusual in "team" plans to set completion dates that conform to expectations rather than reality. If these time lines "slide" the individual will see this as simply another empty exercise. Individuals who trusted the process will be disappointed and may regress in reaction. Realistic timetables and deadlines should be set and those with assignments should be held accountable to the planning group. It is usually more important that an action step be completed thoroughly rather than quickly. Be sure to avoid the seductive trap of over-commitment when setting up the time lines for the steps.

While these three simple ground rules appear to be quite easy to implement, they represent a major shift in "planning behavior". It is hard to break habits and easy to revert to "team meeting" behavior, lapsing into jargon, ignoring the individual, and making unrealistic promises. The result can be a compromised process which produces a pale imitation of a person-centered plan.

Setting The Tone

In this meeting we are to listen to the individual with the disability. The facilitator conducts the meeting on the behalf of the individual with the disability. In this sense, it is the person with the disability who directs and propels the meeting. This is an opportunity for the person's essential lifestyle choices to be identified. Dramatic behavioral incidents of the past must be placed within the context of the person's whole life. Do not allow the meeting to degenerate into a series of professional "war stories". The reputation cannot become the focus of this meeting. Redirect excessive discussion of negative behavioral experiences. For a person with a disability, the negative experiences of the past can become a daily reminder of the most humiliating moments of their lives.

It is equally important that these difficult times not be ignored or glossed over. Rather they should be treated as holding important information for planning. What does the behavior tell

us? The key is to learn from each experience and not to place too little or too much emphasis on any incident. One sign of a good facilitator is the capacity to reframe negative accusations into positive statements. A man who "isolates himself" may "enjoy being alone". A woman who "resisted doing new and more complex tasks" was discovered to "want to do things that she is good at". Another woman, who was seen as a pest by some staff, was found to "want to have someone who loves me the best". Staff centered institutions, group homes, and services necessarily cast everything from the perspective of the professional. In a person centered process we can recast these statements. By seeing them from the view point of the individual we discover behaviors that are not remarkably different from our own.

Keeping It Moving And On Track

Although the format of the person-centered plan is straightforward and easy to follow, the focus and momentum can be compromised or lost during the meeting. It is easy to become bogged down in excessive detail or psychodynamics. The challenge is to balance process and outcome. We need sufficient discussion to allow people to get past the reputation and focus on the individual. There needs to be enough interaction between the participants so that the synergy of a group process can be tapped. At the same time we need to have a reasonable plan at the end of the meeting and we need to insure that we do not revert to focusing on what is wrong with the individual.

Using the lists as a point of reference will help to keep the meeting focused on the individuals and their lifestyle choices while avoiding the lure of tangential journeys. The facilitator needs to tell people how long the meeting will last and the expected outcomes. Periodically note how the group is doing relative to the remaining time. It is a role of the facilitator to "bring the group back to task" if they get off track. If the group has significant unanswered questions these can be noted and the group can move on. Schedule another meeting to deal with them, where necessary. Typically these questions require additional information as well as additional discussion. The information will need to be collected before there is another meeting.

Building And Sustaining Momentum

During the meeting the momentum for change and implementation is developed as the individual is seen as a whole person. As the modest requests of the individual are identified, they become the foreground and the reputation moves into the background. This can be exciting! A good planning meeting will energize people to support the individual. They will also need help.

The meeting ends with assignments being made to carry the plan forward as the first step in sustaining the momentum. However, without on-going efforts, implementation will cease. Unlike classical physics (where an object stays in motion unless acted on by an outside force), change in human services only occurs where people keep pushing. One of the goals needs to be to build a "personal network" or "circle of support" for the person. People who have others

who care about them in their lives will not have to depend on paid staff to have their choices honored. This is hard to do for most people who have been socially isolated, but for some there are friends or family who only need permission. Where you find that opportunity, give permission.

Collecting Additional Information

At the end of each planning meeting you need to ask yourself if you feel satisfied in your understanding of the individual. It is not uncommon to find that important questions remain unanswered. Sometimes these reflect the absence of someone that we should have invited or questions we did not ask in an interview. More frequently they reflect the process of discovery that goes on during the meeting. Ending a meeting with unanswered questions is not necessarily a sign of a poor meeting or poor preparation. It can be an indication of how misunderstood the individual has been. The questions arise when we begin to look past the reputation to the individual.

Experience can help the facilitator to have fewer unanswered questions. However, what is immediately at issue is getting the information. Where these questions remain the first action steps are to find the answers. There are no rules for who is to obtain the information except those of common sense. People who know the individual are logical choices. The facilitator can be the one who gets the information but this may be an indication that there are too few people who are committed to making the plan work.

Writing Up The Plan

Occasionally writing up the plan is simply a matter of transcribing the lists. More typically, additional information or additional reflection results in changes in the plan. This is the last opportunity to use simple declarative English in describing the individual or the supports. This is also an opportunity to make sure that everything is stated as positively as is possible without misstating who the individual is. This is also an opportunity for reflection. Does the plan capture what we know about the individual? Do the non-negotiables make sense? Include the uncertainties in the written plan. The plan should be seen as a guide rather than revealed wisdom. Remember that it will be implemented by people who were not at the meeting as well as those who were there.

Have the plan typed and distributed within a week of the meeting. If one of the action steps is to get information that is to be included in the plan then the preparation and distribution of the plan becomes an action step with a date by which it is to be accomplished. A key element in sustaining momentum is to put the written plan in the hands of all of the people responsible for its implementation. If they do not get it until several weeks after the meeting it will simply be more paper in an in-basket.

THE PLAN IS AT THE BEGINNING NOT THE END

A successful planning meeting can be the beginning of exciting change for the individual. It is when we stop talking and start doing. Putting person centered plans to work in a program environment is a challenge. It is also an opportunity. System change is easier when done one person at a time. By focusing on the individual's issues you side-step interminable debates over the number of people who should live together and the rules they should abide by. What remains central is meeting the essential lifestyle choices of the individual. Can these choices be met in existing settings? Then the individual should move to that setting. If it requires something new, we need to create it.

It is essential that we not move from trapping people in a program mentality to trapping them in a plan. The plan cannot be frozen in time and never change. Today's plans reflect our present understanding and knowledge. If the plans are accurate, they are a snap-shot of what is important now. As the person changes, as our understanding deepens, the plan should change. We need to make certain that we do not tell people that we will plan carefully once and never again. We have to get into the habit of listening to people with disabilities and acting on what they tell us.

PART III

RECRUITING AND DEVELOPING SUPPORTS

Introduction

This part of "supporting people with severe reputations in the community" focuses on recruiting and developing the supports necessary for people to have the lives described in the person centered plans. Implementation of a person centered plan depends on the commitment, understanding, and efforts of those who actually support the individuals. Plans that are implemented without empathy or insight may appear to offer a reasonable lifestyle but will not support the desired lifestyle. Plans that are implemented without understanding the underlying values may be frozen in time. Plans that do not change with the person will result in the erosion of the quality of life of those who are supported.

Part 3 suggests that we need to change how we organize and deliver services as well as how we plan for services. We need to change how we invest our time and resources if we are to achieve the flexible and responsive services system that is needed. The changes needed are reviewed and briefly illustrated. A complete review of the implications of moving from a system of programs to one of supports is beyond the scope of this handbook. Additional information is found in the suggested readings and in the stories that are being shared among those who are in the middle of change.

Current Practice - Referral By Packet And Provider Shopping

What is being suggested is a complete change from current practice. The two common methods of developing services for people are "referral by packet" and "provider shopping". In "referral by packet", collections of reports which detail all of the deficits and past sins of the individual are sent to all potential providers. These "packets" contain assessments from each of the concerned disciplines and paint a collective picture which rationalizes why all of the prior placements failed due to the deficits of the person. Details are provided about their labels, limitations, and failures. Summaries are included that review everything that person has ever done wrong. This material can be more accusation than information. Its effect is to reinforce the image of someone who is "not community ready" and further limits the options available.

Those who receive packets have received as much misinformation as accurate descriptive material. Most providers decline to serve people who have such a one-sided, negative description. Those who are willing to accept the person propose extraordinary costs based on the perceived need to have one to one, shift staff to make the person conform to the program's

rules and to "protect the public". These providers will come forward with a new "dual-diagnosis" program specifically designed to respond to the descriptions they have received.

The second common practice is "shopping" by providers. Upon hearing that funding is available for a group or class of individuals, providers will come browsing through the institutions where the individuals are living. They will be looking for people who will "fit" in their current programs, for the "easy" people. People are selected on the basis that if they do not "work out" they can always be returned for an "easier" person who will be a better "fit". This also reinforces the tendency of institutional staff to "omit" some of the challenges that these individuals present.

Both of these practices treat people with disabilities as if they were commodities. The funding provided supports capacity or slots rather than the individual. If the first person does not "make it" in the slot he or she is discharged and another person is put in the slot. Discharge typically means that the person returns to an institutional setting. In this process there is little commitment to the individual. The result is a system that does a better job of supporting the service providers than it does of supporting the individuals who are the reason for its existence.

Changing Our Investments

The new process of developing supports does require that more time be invested in planning and developing the supports. Administrators and managers complain that they have insufficient resources to meet their current obligations much less the resources necessary to develop and implement person centered plans. They note that if sufficient funding is available, a number of people with severe reputations can move into the community without these efforts. Disability systems are underfunded and requests for increased funding are reasonable. However, when the only solution is to spend more money we are looking at a system that is conceptually bankrupt.

Even if there were more money, without person centered efforts, people with severe reputations are not likely to stay in the community and are more likely to receive control programs to maintain their stay. There will also be a number of people who will never move. The resources saved by not doing person centered plans will be expended in the endless meetings that are convened when things go badly. The costs of developing and implementing control programs, to make people conform to settings where they do not fit, will exceed the costs of the development of the plans and the careful recruiting of supports.

Moving to a system of supports requires changing our investments. Understanding the person and developing community around the person requires a greater initial investment. As an investment, it will bring a return. For the individual, the return is a greatly enhanced quality of life. For the system, the return is multidimensional. Success is the system's first return. People will be living in the community who were seen as "not community ready". The next return is the reduction of the average long term direct and indirect costs of supporting these individuals. Finally there are the changes that this effort can bring about in the entire system of

services. If we can build community for the most challenging individuals we should be able to build community for everyone.

Finding The Balance For Each Individual

The greatest challenge in supporting people with disabilities is finding the balance for each individual. We are seeking a new balance between:

- freedom and control;
- supporting autonomy and providing protection; and
- encouragement and coercion.

This balance needs to consider the circumstances, the core values, and the complexities of each individual. The input used in determining the balance needs to consider the issues of the family and close friends. As recipients of public funds, providers must also consider the goals of the funding agencies and the expectations of society.

The initial balance should have been achieved in the plan. The planning process gives implicit consideration to all of these issues. In the implementation of the plan explicit consideration of the balance is required. Where there are concerns about potential violence there must be contingency plans. All of the "what if" questions must be answered. Safeguards to assure public safety must be present where they are required. The challenge is to determine what is "required". Giving freedom will often reduce the need for control.

> ***Steven lives alone. He hates to have people telling him what to do. He can cook, shop, and clean. He has lots of friends but he is lonely. He has allowed homeless people to move into his apartment (against the rules of his subsidized housing) and appears to be depressed. He lives with all of his everyday possessions surrounding him in his living room. His diet consists largely of pizza, beer, and cookies. The program response to Steven would be to move him to a congregate setting where he can "get the supervision that he needs". Yet Steven is adamant about wanting to live by himself without staff supervision. Those supporting Steven felt that they were trapped. They did not want to move him against his explicit wishes and could not ignore the issue by using choice as an excuse.***
>
> ***When efforts were made to understand Steven, it became clear that his depression arose from the loss of an important relative. Steven had lost the person who had helped him to maintain his balance. He had lost the person who gave advice with love. This was advice that he was able to follow and love that made him feel valued. The challenge that***

Steven's support provider has accepted is not to decrease his autonomy but to find people who can fill the role of his lost relative.

Before You Recruit And Develop

The efficient and cost effective implementation of person centered plans requires that we recognize that this is part of a paradigm shift. Simply implementing the plans without looking at the other aspects of the paradigm shift can result in increased costs and another failure. Four components of this paradigm shift should be kept in mind from the beginning of the development of supports. These are: the need for individual advocates and "personal champions"; the importance of a "personal network"; the use of a "reliance bias"; and the paradox that "less may be more".

Looking For Individual Advocates And Personal Champions

A necessary requirement for people to achieve their desired lifestyle is the presence of one persistent and competent advocate. Where these advocates become a part of the individual's life they are what Beth Mount refers to as "personal champions". Where you are trying to help people with severe reputations move to the community you need to either be the individual advocate or find one.

Individual advocates are focused on the person. They see the individual as more important than the funding, the program or "the system". Knowledge of the funding mechanisms, the programs, and the system, will make for a more powerful individual advocate but is not essential. Tenacity and commitment are more important. It is essential that the individual advocate not become "bogged down" in the system's issues and lose sight of the individual's issues.

Individual advocates must commit to the individual for as long as it takes for the people they support to achieve their desired lifestyle. Before these advocates fade from an individual's life, they have made certain that there are others who fill the role of individual advocate. While there are people who have this role as a part of their work it cannot just be a job. It requires commitment and passion. The passion needed is not the passion of romance novels or spy thrillers. The passion needed is the "fire in your belly" that keeps you focused on the vision of what the individual wants. While there will be pressures to "settle for what is available" and compromises may have to be made, the individual advocate will persist until the desired lifestyle is achieved. Individual advocates are not stopped by what currently exists.

Colleen was able to get out of jail because there was one advocate who believed she should not be in jail and should live in the community. He could not find community services but was able to have her move to a small ICF-MR (Intermediate Care Facility for People with Mental Retardation). It was several years before she could move from the ICF she had entered after leaving jail but her advocate was persistent. When funds were cut he advocated for the closing of

the ICF. Using a person centered planning process the staff of the ICF found a provider who would meet Colleen rather than her reputation and she was able to achieve her desired lifestyle (for less than half of the cost of services in the ICF). There were 14 people with very severe reputations living there. A handful of people were committed to having these individuals live in the community. Twelve of the 14 people (including Colleen) moved to the community based on person centered plans. They all continue to live in the community in their desired lifestyles.

Individual advocates are not personal champions. A personal champion makes a connection with an individual that transcends any professional relationship. When you listen to someone who is a personal champion you hear descriptions like love and friendship. You hear how the person with the disability will always be a part of the personal champion's life. While the label personal champion could be construed as someone in a superior position, what you hear is profound respect for the individual. The person with the disability is not a cause, but an individual whom you value.

Personal champions cannot be mandated. You cannot mandate the connection and commitment needed. You can insure that there are opportunities for a personal champion to emerge. Professionals may need permission to transcend their assigned roles. Family and friends may need to be encouraged to go forward despite professional resistance. Some people seem to know what to do instinctively while most benefit from assistance and having a mentor. Everyone benefits from support. A personal champion can also serve as the nucleus of a personal network.

Jon first went to court after he tried to have a young girl become his "serious girl friend". He received no counseling or assistance but was placed in a residential school as the response to his "sexual problem". While living at the school, Jon had consensual sex with peers. This was against the school rules and he was discharged from the residential school. He then went to an ICF, where a report sent to the judge noted one "episode of inappropriate touching". (Jon had patted a peer on the "butt" while watching a football game.) This ICF was scheduled to be closed. Once the judge was notified of the closure, the judge decided that Jon should be sent to the state prison.

Sarah had met Jon several months previously and had gotten to know him. She believed that his issue is one of loneliness. He desperately wants to "belong" and feel loved. She said that if he went to prison "his life would be over". Without making a conscious decision she became Jon's personal champion. She insured that a person centered plan was developed. The plan included supervised employment and community living, with enough supervision to insure that the public was safe. Sarah then set out to convince the judge that

this was the better plan. He would not return any phone calls nor respond to any letters regarding Jon. Sarah knew that if she could not get the judge to listen Jon would go to jail. She packed a briefcase with work to keep her busy and sat outside of the judge's chamber door from 8:00 AM until 6:20 PM. When the judge emerged from his chambers, he said that he felt sorry for Sarah and would speak to her for 5 minutes. An hour and ten minutes later, Sarah and the judge left his office. He set a date for the hearing and agreed with the community-based plan.

The Importance Of A Personal Network

It is a cliche that the best protection anyone can have is a circle of concerned family and friends. These are the people who give us the advice that we trust, they support us on a daily basis and rally around us in a time of crisis. As defined in Service Brokerage (Salisbury, Dickey, and Crawford 1991) a "personal network is made up of the people who support, sustain, and enhance the autonomy of the person...". While people with severe reputations have the greatest need for a personal network, many have little family involvement and no friends. When faced with the difficulty of moving people with severe reputations to the community, it may seem absurd to be talking about developing a personal network but it is an investment that will bring a return.

For people who have no concerned family or friends, developing a personal network takes time. While it may take years, we often miss the opportunities to begin the process. It is not unknown for people to have concerned family members who only need permission and support to be the foundation of a personal network. Occasionally there are people from the individual's past who are pleased to be asked and a number of individuals have people from their time in institutions who want to continue to be part of their lives.

Jacob is famous within the disability system and in his home community. He has lived at home, in group homes, in state psychiatric hospitals, and currently lives in an institution for people with mental retardation. His past included a wide array of anti-social acts. He talks "tough", with reference to guns and knives. His reputation says he is dangerous even though he has never hurt anyone. His last placements did not consider his issues as much as they reflected the needs of the system. His predictable "failure" and subsequent moves have added to his reputation. Jacob grew up in a dysfunctional family where most members strove to put as much distance as was possible between themselves and their parents. He has a sister who has recently become involved and is advocating for him. She has demonstrated a willingness to call anyone, including the governor, on behalf of her brother. She has been seen as part of the problem rather than as part of the solution. With encouragement, support, and a sense of partnership she can serve as the nucleus of his personal network.

Unfortunately the disability system often starts out with an adversarial relationship with the strongest advocates. The strong advocates want what is "best" for the individual but may not know what the "best" is. They listen to advice from professionals that is given as if it were revealed wisdom. Over the years they have noticed that the wisdom has changed. Yesterday's advice and today's recommendations may be opposed to one another. This does not inspire trust. Trust is further eroded when it is clear that the system has failed the person. As we have consistently failed people with severe reputations, the adversarial relationship begins with our past behavior. The disability system also distances and alienates strong advocates by acting as if only professionals have worthwhile contributions to make in the planning process.

The best way to offer encouragement and establish a partnership is to involve the advocates in the planning process. Interview them before the meeting and begin to establish a relationship. Invite them to be active participants in the meeting and respect their contributions. Encourage them to take responsibility for action steps that they can reasonably accomplish. Help them to understand what a personal network, or circle of friends does and see if they are willing to be the nucleus of the individual's network.

Personal networks, where they have been developed, are very powerful. People that you can rely on for advice, people who will advocate for the supports you need now and the changes you need in the future, people who will rise to the challenges and crises of life, are the result of a strong personal network. Few people with disabilities have a personal network without significant efforts on the part of a core group of caring people. This is an effort that needs to begin as supports are developed and recruited. We need to look for the opportunities that can be created and used to start the foundation of a personal network.

A Reliance Bias

Community resources must be used with a "reliance bias". The concept of a "reliance bias" is simple. The supports that an individual needs should be provided by the individual or as close to the individual as is possible and reasonable. Each support should be reviewed to see how close to the individual it can be accomplished, i.e. by the individual, the family, a friend, a community association, a generic agency, or a disability agency.

We are speaking of a bias rather than a rule because of the potential for abuse. Good sense must prevail, e.g.-

- Individuals should not get tasks they "could" or "should" do but will not.
- Families should not be asked to do things the individual would prefer they not do or which they are unlikely to do.
- Members of the community should not be asked to provide supports that an individual would prefer to receive from a disability professional.

Susan lives by herself. She enjoys her lifestyle but has difficulty getting to work on time. She just could not get herself moving in the mornings. The typical response would be to say that Susan could not live by herself or to pay a staff member to work a morning "shift" in Susan's home. However, the support provider looked to the community first. Susan and her neighbor are friends. It was not a big step for the neighbor to agree to come to Susan's home each morning for coffee. Susan is now motivated to be up early enough to have the coffee ready and she gets to work on time.

Less Is More, But Less Can Also Be Dangerous

Anita lived in a psychiatric hospital from the age of 16 until she was 26. Every time she broke one of the hospital's rules she was punished by being further restricted. When we met her she said: "I have these 4 walls, one wall has a picture, one wall has a window and one wall has a door. I can go in the room but not out the door. I can raise my window and touch outside. I can smell outside. But I cannot be outside." She was restricted to her bedroom and an area near the nursing station. The perception of the hospital staff was that she needed one-to-one, shift supervision. She is now living in the community with a paid roommate. She is working on her G.E.D. and discussing career options. Life is not without excitement. She tests the commitment of her support provider and has spent some time in acute care hospitals. But someone who "had no ego" and "could not live outside of 24 hour structure" is demonstrating that less is more.

When the system engages in a control struggle with an individual no one wins. The system achieves control by using restrictive environments, behavior programs, increasing numbers of staff, and the use of medications. The expense of this effort reduces the funds available to support others. The restrictive nature of the efforts adds to the reputation of the individual. In the absence of positive control over their lives many people with severe reputations seek negative control. With the perception that they have nothing to lose they will escalate until they are overpowered. Many people are simply saying that they will settle for nothing less than what they have asked for. As the disability system will not listen to their verbal complaints they will make non-verbal statements. All of these individuals see their reputations grow while their options shrink.

For these individuals, the automatic response of the system is to see them as needing the same kind of staffing in the community that has been provided in the institutions. When we are able to see past the reputation to the person we see someone who needs positive control. Many of these individuals need fewer hours of supervision and more resources devoted to meeting their non-negotiables. The only "behavior program" that some of these individuals need is to be treated with respect. They want to live in a place that they like where there are

people with whom they want to spend time. They need to have people in their lives with whom they identify and who they admire.

> *Eric is a very shy but very funny guy who had a run of bad luck. He was placed in a residential school when his grandmother was no longer able to provide the care he needed. He had an immediate need for a place to live at a time when there were no vacancies in the programs in his home community. His luck did not improve as the system attended to the next crisis and did not consider his return. His reputation was his placement. Anyone in a residential school must be challenging. When we met Eric he had "graduated" from school but was still living there with 24 hour supervision. He always wanted to be a cashier so his "training program" was to operate a play cash register with play money. He told us that he knew that this was not real money.*
>
> *When we asked Eric where he would like to live he named five different towns. He was willing to live anywhere, so long as he was able to leave the school. When we spent some time with him it became clear that he wanted to be close to his family. He wanted to be able to visit them when he wanted to and not just when "transportation could be arranged." Eric now lives near a bus line that is no more than one transfer from his important family members (including his grandmother). He lives by himself with staff who come by each evening and spend time with him on the weekends. He is thinking about having a roommate because it is "pretty lonely" living by yourself. As for work, he has a job at Rite-Aid. He started with a full time job coach but he only needed him for the first day. Being a cashier is still a goal but it is now only one of a number of goals for his career in retail sales. The cost of supporting him in the community is approximately one-third the cost that was being paid for the residential school.*

There are dangers in all generalizations. Some people need safeguards. They need supervision to protect them or to protect the community. We can get so focused on looking at someone's positive attributes that we forget to account for the challenges that the individual presents. We are not doing anyone a favor if we support people in settings where their behavior adds to their reputations. One of the traps in this process is advocating for supports purely on the basis of cost. Disability systems tend to see average costs as maximum costs. As supporting people with severe reputations typically has a lower average cost than placing people in programs, there is the assumption that it is always cheaper. As the primary cost of services is the cost of staff, those people who need supervision to protect themselves or to protect others will be relatively expensive.

WHO TO RECRUIT, WHAT TO DEVELOP

The Importance Of Partnership

The thoughtful implementation of a person centered plan requires partnerships. There should be a partnership between those who have done the planning and those who are doing the implementation. Partnerships, like community, should be inclusive. We should seek partnerships with the individual, the planning team, the provider(s), the individual, the family, and the funding and regulatory bodies. In a system whose components have an "us versus them" mentality, this is a challenge. We do not have to like each other to be partners, but we do need to respect each other.

Person centered planning only works when all of the parties are contributing information and creating the synergy found in functional groups. A good plan demonstrates a basic understanding of the individual and understanding anyone requires that we consider the multi-faceted complexities that each human presents. This is not likely to occur without a partnership. The positive implementation of a plan is not a cookbook exercise. It requires creativity, flexibility, and responsiveness. This is unlikely to occur without partnership.

Recruiting And Selecting Providers - Looking For A "Hook", Insuring The Commitment

The success of the person centered plans will depend on the providers who implement them. Remember that while the person centered plan articulates the choices, it is the provider who implements them. Providers must commit to the individual rather than to the program. A desire to be trendy or secure the money that the person represents is not sufficient. However, it can be the "hook" that is used to interest a provider. Those who are seeking someone to implement a plan need to separate marketing from commitment. It is acceptable to get a provider's attention by suggesting that there are financial or ego rewards. After their attention has been secured, we need to insure that providers listen to what the individual is asking for and then commit to helping the individual "get it".

While good intentions are important, they are not sufficient. There needs to be a reasonable match between the desires and challenges of the individual and the skills and practices of the provider. Different providers have different skills, abilities, tolerances, and limits in supporting people with disabilities. This is an area that providers rarely consider but has proven to be critical for some individuals. The process of reviewing non-negotiables will winnow out many providers who have not thought through the issues of implementation. For others it is helpful to look to their current successes and failures. Providers who are successful in supporting individuals needing lots of structure may not be successful in supporting people needing very flexible responses. People who want an active social life need to be supported by providers who will support them in their desired lifestyle. Providers often need to be assisted in not accepting people they will not be able to adequately support.

Looking Inside Large Providers

While the capacities and interests of providers are partially a reflection of "corporate culture" it also reflects the capacities and interests of staff. Large providers are not necessarily monolithic structures. There are often managers of units or sections whose values and practices are congruent with the individuals' plans. Typically the managers of these units have established their own culture. The risk in using these units within the large provider is the potential that the commitment to the individual will leave with the manager. If the manager has been skillful in instilling the values, they will survive the departure of the manager. If the funding agency reinforces these values they will almost certainly continue.

Remember While You Are Recruiting...

Commitment to the individual starts with saying yes to the non-negotiables. It includes seeking to offer as many of the strong preferences and highly desirables as is feasible. The commitment to the individual should include a recognition that the supports need to change as the individual (and our understanding of the individual) changes. Implementation is just the beginning of a process where we have to keep listening to the individual.

> ***Harry is a very famous person in his state. He is a big, strong guy who was always getting in trouble. His tendency to be violent had resulted in an on-going institutional tour. When people asked why he had done something that had resulted in his being in jail (or any other facility) he would reply, "I am Harry Smith, this is who I am". One community provider was willing to give him a chance. A person centered plan was developed and staff were hired who were not intimidated by Harry's size, reputation or behavior.***
>
> ***Harry did better than he had ever done but he continued to have problems. His staff secured six different jobs for Harry in as many months. Most of them were the traditional jobs for people with cognitive disabilities, working in fast food restaurants and doing grounds maintenance. Harry kept saying he wanted to be a veterinarian and the staff replied that you have to go to college to be a vet. Harry had tried basic adult education but without success. He would say "*#!@ college, I want to be a vet."***
>
> ***A staff member finally listened and got him a volunteer job in an animal shelter. The director of the animal shelter (which has mostly volunteer staff) says that Harry is their best volunteer. He does whatever is required. He cleans the pens. He feeds, waters and grooms the animals. Everyone says that he is very gentle and nurturing with the animals. Harry has had a drinking problem for years but has now stopped drinking.***

A number of providers will understand the concept of offering lifestyle choices from the beginning and be excited about the opportunities that this approach provides. Many providers will understand the concept after they have had the opportunity to participate in a person centered planning meeting. Some providers will find the concepts involved in a person centered approach antithetical to their values. This latter group will not provide reasonable supports and should not be coerced into the effort. For a number of providers the structural changes that supports require cause hesitation. These providers need assistance in seeing how they can make the needed changes.

The most typical label for these services is supported living. As supported living is the "latest trend" in service delivery a number of providers will be interested because they want to be current with the latest technologies. Capitalize on a willingness to change, even a willingness to be trendy. Major changes can arise from a desire to see what supported living is about. What is essential is that providers learn that it is more than just another program. Supported living entails a commitment to individuals, not to programs. The best way to help people understand the process is for them to attend a planning meeting.

Implementing the plan using a reliance bias will be challenging to many providers. Most people are used to having the disability system be the provider of "first resort". Only where there are things that the disability system cannot do are the resources of the community considered. Turning this process on its head will take practice. As providers are recruited and the implementation of plans is discussed, time needs to be devoted to looking at the potential resources of the community in meeting the needs of the individual.

The Hazards Of Specialized Providers

The outcome of these efforts must be an individual who is not only living in the community but is part of the community. There is a tendency to measure success purely by duration of stay in a community setting. If we are to offer people their chosen lifestyle we must do better. Too often people with severe reputations are living in community settings that are more isolated than the institutional settings they left.

There are dangers in the "successful" programs that have developed specifically to support these individuals. These programs have a tendency to become self-contained. Their success and dedication coupled with community resistance can lead to a perception that they are the only people who really care, who can cope with the challenges, who will be there for the "long haul". From the perspective of formal agency support they may be correct. No other human service agencies may be willing to support "their people". From the perspective of the community they are missing critical opportunities. There are other individual community members who could be wonderful friends and companions to the people they support. The more positively connected and embedded in the community the individuals are the more likely that they will achieve the lives that they seek.

A byproduct of isolation from the community is staff "burn-out". A number of people with severe reputations are difficult to be with over extended periods of time. In this they are no

different from many ordinary people. Instead of finding a number of potential friends who can spend an evening or afternoon with the person the disability system relies on shift staff who "run programs". Things happen to the individual rather than with the individual. Control struggles are likely. Staff, quickly caught up in the battle for control, forget that one of the few areas where the individual has control is the ability to out-escalate the staff. The staff and the individual tire of each other. The staff member complains of burn-out and leaves. The individual cannot leave but knows that his or her behavior can bring about a change in the staff.

Responses That Account For The Lifestyle Choices

An essential lifestyle plan (and most other person centered plans) provide a skeletal description of the characteristics of the desired lifestyle. While a good plan captures the critical lifestyle choices it does so with stark simplicity. The response to this plan should detail how the lifestyle will be achieved and address any disability issues. The detail in the response to the person centered plan allows those who are supporting the individual to make an initial determination of whether or not those proposing to provide the supports have a grasp of the lifestyle choices and the disability issues of the individual. The amount of detail presented will vary depending on the circumstances of the individual and the local requirements for individual plans.

It is important to supplement these written responses with oral presentations. A discussion, as short as twenty minutes, will reveal, with great clarity, whether or not the person centered plan was understood and the degree to which reasonable implementation is proposed. Where there are multiple providers who are proposing to support the same individual, "options meetings" can be held where each provider sets forth their proposal. The individuals and those who attend on their behalf decide which provider has put forward the proposal that will best address the lifestyle and disability issues of the individual. Some option meetings result in unanimous decisions about who should support the individual. Others result in follow-up visits to existing support settings. Regardless of the outcome, the individual is empowered by the process.

The initial presentation should be seen as a part of a dialogue between partners. Empowering the individual and those who support them does not detract from the contributions that knowledgeable, committed providers will make. Where there is mutual respect, all parties value the contributions of the others. Support providers who are present from the beginning of the planning process start as partners. Providers who join later in the process need to become partners before they initiate services.

Addressing Disability Issues

Throughout this handbook relatively little space is devoted to the disability issues that preoccupy much of the literature on services for people with disabilities. The rationale for this lack of attention is twofold. First, there is adequate literature on addressing these issues and familiarity with this literature is assumed. Second, while the disability issues must be accounted for, they should not determine where people live, who they live with, or what they should do

during the day. Disabilities can and do limit some of the lifestyle options for many people but they should not have the pervasive effect that they have had for people with cognitive impairments. There are people with heart conditions which preclude vigorous exercise. There are people with severe diabetes who must adhere to restrictive diets. Neither group is told where to live or who to live with. Both groups need to account for their disabilities within a broad range of self-selected lifestyles. People with cognitive impairments should have the same options.

One of the keys to accomplishing this is by preventing disabilities from becoming handicaps. Someone who has difficulty learning how to cook can often learn to microwave. Environments can be modified and settings can be chosen which minimize the degree to which disabilities become handicaps.

> ***David inherited many things from his father: his easy-going manner; his blue eyes; and his propensity to develop serious heart disease and high blood pressure. When David moved into a home with two other men he had the opportunity to learn to cook for himself rather than to eat Mom's heart healthy foods. With the freedom to eat anything he wanted, whenever he wanted, he quickly gained 20 pounds. David's blood pressure soared and he was placed on a diet by his physician. David hated it. He said: "Man, this is just like being at my Mom's. People are always telling me what to eat and how to cook. This sucks!"***
>
> ***A psychologist was called in to write a behavior change program that would focus on increasing David's compliance with his diet. Wisely, the psychologist saw this as an issue of personal control rather than as a "problem". We had made his disability into a handicap. Control was returned to David. He now plans his menus with his house counselor and shops for his own foods. Everything he likes to eat has been color coded as red, green,and yellow foods. Red foods are restricted by amount each day, yellow foods are less restricted and green foods have no restrictions. David marks his food, with the counselor's help, after each shopping trip and controls his own consumption. Using a simple chart to match the foods to his diet, he has lost 25 pounds. He is now 5 pounds lighter than he was when he was eating his mother's cooking. His blood pressure is lower than ever and he has the control that he wants.***

Disability issues must still be accounted for. An implementation proposal that does not address the disability issues is just as unacceptable as a response that does not account for the lifestyle choices. Many of these disability issues are embedded in the lifestyle choices. The need for someone who uses a wheelchair to have an accessible home and access to the community is as much a lifestyle requirement as a disability issue. The desire for someone with a cognitive impairment to acquire new skills is also a lifestyle choice. Accounting for the

disability requires that the need for clinical services and the need for supervision to assure the well being of the individual or to protect the community is carefully assessed.

People with severe reputations are more likely to need psychiatric or behavioral services than are people with similar cognitive impairments. They need services that will respect and support their lifestyle choices. Too frequently the providers of these support services have been agents of social control who listen to the complaints of staff more than the concerns of the individual. Where these services are essential to success in the community, they need to be in place before the individual arrives.

Both the person centered plan and the implementation of the proposal must balance the need for supervision against the desire for autonomy on the part of the individual. Skillful plans and carefully crafted implementation responses will minimize the tension between these competing needs. Where the conflict continues, there needs to be a frank and open discussion of the issues. Everyone must accept that there needs to be a balance between safety and satisfaction. The balance will vary from individual to individual. The balance should also be seen as dynamic, with changes expected over time. Negotiation should be the rule. The exceptions are those conditions set forth in court orders. However, even court orders can be changed over time.

Where there are issues of public safety, they need to be carefully addressed. Many people who present a public safety issue need not languish in institutions if the supervision needed to address their issues is present.

> ***The first thing you notice about Mary is her dimples. The second is how soft spoken she is. She rarely speaks louder than a whisper and her head is usually bent forward as she speaks. She does not strike you as a dangerous person but she did set a fire. She burned her family's house to the ground. She was sent to an institution for people with mental retardation and was not allowed to return to her family or live in the community. During a person centered planning process, it became apparent that Mary's "fire setting" was directly related to her situation in the family home. Mary's older sister was jealous of the time and attention that Mary got from her parents. She was angry over constant requests to bring Mary along with her to parties and outings with her friends.***
>
> ***The sisters started to bicker and fight. Mary's sister was stronger and always able to get the last punch in before their mother banished them to their rooms. Mary finally figured out a way to "get the last punch in". Mary set a fire in her sister's room (when her sister was absent) and shut the door. The fire quickly spread and the entire house was burned to the ground. While it was clear that Mary had set the fire to get back at her sister it was not clear as to what Mary might do the next time she was angry with someone. What would happen if***

someone else "picked on her"? We knew that she did not have a compulsion to set fires or an unusual fascination with fire. However, we also knew that Mary and the community deserved to be safe. A community provider was found who liked Mary, was willing to support her in a lifestyle of her own choosing, and installed a sprinkler system throughout her home. Mary has now lived in the home for two years. She cooks, has fires in her fireplace, and barbecues on a grill without any incidents of fire setting. Her neighbors remain safe and she is included and welcomed in her neighborhood.

Have The Support There Before The Individual Arrives

A common reason for community failure is the absence of critical clinical supports. If an individual needs psychotropic medications to live successfully in the community, competent psychiatric services must be arranged before the individual moves into the community. If the individual is receiving a psychotropic cocktail, competent and careful psychiatric support will be required to sort out the medication issues without catastrophe. People who have seizure disorders or other medical conditions need to have the specialized services waiting for them. Individuals who need counseling or therapy should be able to start without delay. Where staff need to be trained in how to support the individual, the training should be completed prior to the individual's arrival.

All of these issues are simple common sense but are frequently ignored. The funding and arrangements for residential supports may be on a different "track". There may be no interested professionals available to provide the services. The pressure to have the person move may seem overwhelming. Recruiting and developing these supports is as critical as the development and implementation of person centered plans. If the clinical services are seen as a priority by the clinical providers, they will be developed. Where they are seen as another unwelcome burden in an already over-committed system they are not developed or are woefully inadequate.

Seeking Allies

Where change is needed it is essential to have allies. Allies in positions of power can protect programs that are vulnerable as they learn new ways of supporting people. Allies in positions of power can insure that changes in regulations or funding mechanisms will be congruent with supporting people. Where these allies exist they need to be supported. Where they do not exist they need to be recruited.

In the bureaucratic tribalism of the "us versus them" mentality, everyone who is not of our group is part of "them". We forget that most people who are in the field of disabilities entered the field to help people. We need to relinquish the odd comfort that this thinking provides and look at each one of "them" as individuals. There are people in each system who have not had a new thought since they left school. There are people in each of the groups who would like to see change. When asked, most people can name those in the other groups who would promote changes to systems of support. Someone simply needs to make the first overture.

Changing The System

Implementing person centered plans will require that we change the system. While this is a laudable goal it is also a daunting prospect. It helps to remember that this happens one person at a time. The system only needs to change enough to implement each person's plan. Some people will require very few changes. What is present can be easily adapted to meet their plans. For others, new services or new providers may need to be developed. Where there is a provider who is willing to change, that provider must be supported (and protected) while making the change.

Implementing a person centered plan appears simple and can be done in a matter of weeks. The simplicity is deceptive. We have found that it typically takes two years for a provider to successfully and fully convert from programs to supports. It often takes a year to complete the process of changing the administrative structures and insuring that the documentation reflects the new efforts. Changing the attitudes and practices of staff takes time. Changing "corporate culture" takes even more time. Learning how to support people (as opposed to programming for them) requires experience. Ironically, one of the key indicators that a provider has completed the process of conversion to supports is for them to acknowledge how much they continue to need to learn.

Where supported living is not a current option, the changes needed to implement the person centered plans for some people will need to be made at the system level. There may need to be changes in regulations, enforcement, or funding mechanisms. These also take time. Often they take too long from the perspective of the individual. Where the individual must wait, interim efforts need to be considered. The danger with interim efforts is that they remove pressure from the system, and without pressure there is no change. It is essential to not let this turn into a "catch 22". There needs to be a balance where the pressure to secure change is maintained while people are not allowed to languish without services.

Because changing regulations or funding mechanisms takes time, these changes need to start as soon as possible. Many states and localities appear to have a compulsion to develop new regulations or amendments to medicaid waivers without considering the efforts that other localities have made. Regulations that facilitate the development and implementation of support services have been developed and are in place in a large number of states. Everyone should be able to find a congenial set of regulations to use as a model.

The lives of individuals will begin to change as soon as the efforts focus on the individual rather than program. Person-centered efforts need to be the first part of the process of systems change. The dramatic improvements in the lives of those people who can be supported in their desired life-styles is its own reward. Confronting the disparity between what others need and what is present provides the spur needed to change the system.

A Cautionary Note

Recruiting providers can become an end in itself. There are always pressures to have people move. Goals are set by external agencies to have a fixed number of people move within

a particular time frame. Individuals with disabilities will say yes to anyone who will get them out of an institution. We must always keep in mind that we are playing "you bet their lives" as we develop these services. A carefully developed and implemented person centered process can result in people having the lives that they have always wanted. A poorly implemented person centered process can result in our having failed the individual once again.

PART IV

PERVERSION PREVENTION

We have written this handbook with concern as well as hope. While we are hopeful that it will be used to enhance the quality of life of people with disabilities, we are also concerned about the potential abuses. The potentials for misuse, abuse, and perversions are vast. In reviewing the application of person centered planning we have found that there are a number of perversions that, unfortunately, are common. We have described these in the following section in hope of preventing some of the more common.

Seeking And Achieving Understanding

Person centered planning is a technology. Properly applied it results in understanding the lifestyle desired by the person and how it may be achieved. Unlike many technologies, person centered planning is value-laden. While each of the person centered planning technologies has a different focus and a different process all of them are rooted in a profound respect for the individual and an expectation that the individual will be included in her or his community. All of the techniques assume that those who are facilitating the planning will spend sufficient time to discover the core values of the individual and to insure that these values are accounted for in the plan. When these techniques are treated as just another process, without regard to their explicit and implicit values, they are perverted.

Abuses generally arise from a lack of understanding on the part of those conducting the planning. The change from a program to a support model has been described as a paradigm shift. As a paradigm shift we are changing the "filters" through which we sort information. It changes the relative importance that we give to different pieces of information. What an individual cannot do is seen as less important than discovering the life-style that individual might like to live. Professionals who have learned to change their words but have not changed how they "filter" the information are not uncommon. It is easier to change the way we talk then the way we act. Most of the misuse of person centered planning results from using program model practices while using support model language.

Not Discovering The Core Values

A good plan develops a vision of the future. The vision that should arise from a person centered plan is the individual's vision, not the vision of the professionals or the system. Describing someone else's vision of their future requires that we understand the individuals and their core values. Understanding an individual is never complete, people continuously change while they remain complex. The understanding that we do achieve arises from what is shared.

We share stories from our past, dreams of our future, and the experiences of the present. Understanding is a process that occurs over time. In the artificial process of person centered planning we substitute interviews and discussions for the time that we have not spent with the individual. We need to recognize the limitations of these substitutes. A person centered plan is a way to begin the process of understanding. It begins with listening to the words and behavior of the individual and continues with listening to those who know and care about the individual. The end of the person centered plan should be the beginning of a lifelong effort of understanding the changing desires and needs of individuals.

The most common misuse of the person centered planning process is to confuse soliciting the superficial expression of choice with discovering the core values of the individual. The core values of the individual are relatively stable over time. They tell us who the individual is and the characteristics of the settings where the individual would like to live and work. If you know the core values you will understand how much privacy the individual requires. You will know where to begin in supporting the individual in the community. You will discover that there is no substitute for taking the time needed to understand the individual.

The people most vulnerable to this abuse are those who wish to leave an institution. People who desperately wish to leave an institution will supply any answer in order to leave. Because they cannot leave without being selected they will agree to any conditions necessary to be selected. The professionals who have conducted the interviews will say that they have elicited the choices of the individual. In reality the professionals have distorted the process and abused their power. They have carried on a form of negotiation where they have all of the power and the individual who is desperate to leave has none. They have not spent the time necessary to discover the core values of the individual. They do not know what is essential in the life of the individual. They know what they have available and obtain the coerced consent of the individual to accept it.

The presence of significant disabilities should reinforce the need to understand the person. However, the profound power of the current model of services allows professionals to assign people to places to live (and who to live with) according to their disability labels. For individuals who do not speak for themselves this becomes even more tempting. Reliance on labels denies the individuality of the people we support. The more severe the disability an individual has, the more time will be needed to understand the individual. Unfortunately, the more severe the disability the more likely professionals will rely on the labels alone.

Implementation With Understanding

Understanding another person is a process and a skill. Participation in the planning activities initiates the process and builds skills. Where those who are developing the supports have not had the opportunity to participate in the planning process, they must have other opportunities to develop understanding. They need to: spend the time needed to get to know the individual; talk to those who know and care about the individual; and make the effort to understand what

is behind the words in the plan. The more skilled you are, the less time is needed to achieve a basic level of understanding, but there are clear minimums.

All people are complex, regardless of the presence or absence of a disability. All people show different facets of themselves in different settings and with different people. Understanding requires that more than one facet be seen. Further, we cannot claim to understand someone if we do not know their core values. Discovering core values requires a picture of the person across settings. By definition, core values are stable across settings although they may be manifested differently in each setting.

> *Kathy is one of the most famous individuals in Maryland. Some of this fame rests on the creativity that she uses in expressing her displeasure with the services she receives and the people providing them. While the manifestations have ranged from practical jokes to aggression to streaking, there are core values that are consistent throughout. Kathy demands that you take her seriously and respect her as an individual. By doing neither we have trapped Kathy in a cycle of community failure and institutionalization.*
>
> *A recent plan for her movement to the community carefully considered how to honor her non-negotiables but had proposed that two staff be on duty with her at all times. The rationale was that Kathy will fabricate stories regarding staff abuse. The second person on duty could dispute those accusations. While the response represented an effort to avoid a real problem, it demonstrated a lack of appreciation of Kathy's core values. First, Kathy is creative enough to develop plausible stories regarding abuse from both of the staff on duty. Second, she would see this as evidence of a lack of trust. Finally, she would see this as excessively intrusive, manifesting a lack of respect.*

Understanding Deepens Over Time

Given the complexity of people, our understanding should continue to deepen indefinitely over time. Our initial efforts should be seen as a beginning, not an end. Sharing experiences with those we support is the best way to deepen our understanding. Sharing portions of our lives also develops the relationships upon which mutual commitment and interdependence are based. Careful implementation of a plan that honors choice is the first part of the process. The understanding that arises from sharing life experiences is the necessary next part of the process.

Understanding is a process that is focused on a moving target. People change over time. People who have lived in impoverished environments may need a period of frequent change. They need to learn what their desired life-style is by trying a variety of settings. We need to keep listening to their words and behaviors while these individuals test the perception of who

they are against the reality of their life experiences. This requires that we support change that occurs at the pace requested by the individual rather than the pace dictated by our review cycle.

Once people are empowered to seek their desired life-styles they will continue to want changes to maintain their evolving perception of a reasonable quality of life. Carol Beatty of Alternative Living, Inc. (ALI) tells how 70 of the 74 people that ALI supports wanted significant changes in a one year period. These were not changes that the agency could not afford, they were the reasonable changes that any group of people might want over the course of a year. Some people wanted to change who they lived with. Some people wanted to change where they lived. Many people wanted to change how they spent their time. These changes did not occur according to an agency review schedule. People's lives changed according to their own schedule. The staff of ALI see supporting these changes as a challenge but they also see it as central to their mission.

Abuses In The Implementation Response

In the essential life-style planning process the development of the plan is only the first part of the process. It needs to be followed by an implementation response. One of the most common perversions is to act as if the development of the plan was enough. It is as if the person centered plan was self-implementing. The plan is treated as a magical activity which will result in changes without further effort. Those who do the planning need to insure that careful implementation will follow. The best way to do this is to establish a partnership with those who will develop the supports.

Person centered plans are not free-standing documents. They represent a snapshot of our understanding of the issues of the individual. Additionally, essential life-style plans are designed to be simple. They use short phrases and words to articulate the key issues for the individuals. While a good plan is a powerful tool for communicating who the individual is, it does not give the detail needed to develop the supports. A person centered plan can be implemented only in the context of the understanding that has been achieved.

Where people have challenging behaviors, the absence of an understanding of their core values is likely to result in failure. For many of these individuals, their behaviors can be seen as a non-verbal critique of the services they have received. If we listen to their behaviors, discover their core values, and act on what we have learned, they will no longer need to express their dissatisfaction through their behavior. These are the individuals who present the "less is more" paradox. The typical response to their "non-compliance" or "maladaptive behavior" is to increase the number of hours of supervision. The belief is that this will insure "compliance" or allow for the implementation of behavior change programs. Where the individuals are asking for control, success will be achieved only when they are given control, not when they have "earned" it.

Not Accounting For The Disabilities

The planning process must account for the disabilities that are present. People who have led lives that were segregated and impoverished may need assistance in learning the patterns of behavior that will enable them to achieve their desired lifestyles. Additionally, there are people who need supervision to protect themselves or others. Giving them less supervision will increase the likelihood that someone will be hurt. In either instance, not understanding the individual's issues will result in an inadequate implementation response and another failure that will be seen as the fault of the individual.

For individuals with severe disabilities, not accounting for their disabilities can cause failure or even be life-threatening.

> ***John is moving from an institution to the community. He is well aware of his problems with alcohol. John said that one of his non-negotiables was "no alcohol, not even one drink". We have to support him in coping with this disability by supporting him in living in a home where there is no alcohol, not even beer in the refrigerator or a bottle in his roommate's room. John is also supported in working in places where employees do not drink or use drugs on the job.***

> ***Ronald is living in the community for the first time in about fifteen years. He does not know how to keep himself safe. He thinks cars should stop for him and therefore does not see why he should stop and look before crossing streets. Ronald also loves to go for walks and does not always want to be accompanied. How could we account for his disability, keep him safe, and honor his desire to be able to walk by himself? Ronald lives on 5 acres in rural Maryland. He knows the boundaries of the property, there are no roads to cross on his routes, and he walks whenever he wants to.***

Where those who have developed the plan are different from those who provide the services there is a need for someone to assume the responsibility of assuring that the plan will be implemented as intended. We have referred to these people as individual advocates. Someone needs to take the responsibility for the translation of the plan into services. This translation can represent another step in the process of understanding the individual or it can represent the devolution of fitting the individual into a "slot". The individual advocate (or personal champion) is present to insure that the desired life-style of the individual is achieved.

Abuses In The Provision Of Services

The single most common abuse that we have seen in the provision of services in the community has been compromising on the non-negotiables. Individuals who are moving from institutions to community settings are the most vulnerable. They desperately want to leave.

They will agree to anything to escape. People who are living without privacy in institutional settings often find that their need for privacy is not honored. A common rationale from the professionals is to point out the relative "improvement" in living situations (e.g., "she was living with seven other people, so sharing a room with just one other person should be great"). If having a room of your own is a non-negotiable, sharing a room is an invitation to failure.

> ***Janet had lived most of her adult life in a psychiatric hospital. Now in her fifties, she finally had an opportunity to move to the community with a life-style that meets her needs. She did not care how many people she lived with but she had to feel that her possessions were safe and undisturbed. As she phrased it... "Nobody should mess with my stuff". As people in congregate settings keep their personal possessions in their bedrooms, this meant that she should not share a room.***
>
> ***As the professionals looked for a place that met her other criteria (e.g., in the country, with people her own age) they found a "perfect house" that had only one flaw. Janet would have to share a room. Those developing the "placement" argued that it was much better than the institution. They asserted that it was fine with Janet as they had asked her and she had agreed. Within a month of her move she was having problems with her roommate whom she accused of "messing with my stuff". Fortunately, those who had found the house realized their error and Janet got a private room. Her "behavior problems" vanished.***

A companion abuse to the practice of compromising on the non-negotiables is to focus only on the non-negotiables and to omit the strong preferences and highly desirables. A danger in the emphasis on the importance of the non-negotiables is to forget that these are artificial distinctions. Assuring that the non-negotiables are met is the beginning, not the end. The absence of most or all of the strong preferences and highly desirables can result in a barren, empty life.

Having The Critical Supports In Place

Having all of the needed supports in place as the individual arrives is a challenge. For people without a place to live, the first focus has to be insuring that they have a home. This focus on residential support often results in having the residential supports available before the other key supports. It is possible to develop more than one support at a time, however. The support needs of each individual must be reviewed and the critical support needs identified. All critical supports must be present before the individual arrives. Someone who has a major affective disorder should not have to wait to have their lithium monitored. Someone who wants structure should not have to wait for something meaningful to do during the day.

Abuses From A Systems Perspective

Broad implementation of person centered plans is not possible without changing from a program model to a support model. While change can be made one person at a time, the greater challenge is in the broad implementation of a support model. This requires an interconnected set of fundamental changes in the system of services. Some individuals can achieve their desired lifestyles within the program model. Careful implementation of their essential life-style plans is possible without radical change. This success is seductive, however, and can lead to the erroneous conclusion that minor adaptations will be sufficient for everyone.

The focus on honoring individual choice is not cost effective unless community resources are used. When choice is imposed on a program model, costs increase as additional staff are required to support the divergent choices of the people who live together. Using members of the community, individual interests can be explored and developed, often at less cost than the original program model.

When people use their behavior to ask for control over their lives, they are asking for less supervision. The typical program model response is to see the behavior as evidence of a need for more supervision. The individual's half understood request results in a proposal to support the individual in a home where he or she lives without other people with disability labels. Because the real request was not understood, there is still the perceived need for shift, round-the-clock staff. The resulting cost is exhorbitant. Failure to receive funding for this unneeded expense is seen as proof that we cannot afford this new way of doing business. The result is that the individual stays (or is placed) in a "high management" group home to live with several other people with challenging behaviors.

Where choice becomes "trendy" within the program model, supporting choice often becomes an excuse. Supporting people in their desired life-styles is more complex than the simplistic response of "allowing" people to do as they please because it is their "choice". Each choice has its consequence and an informed choice is one where the consequence is understood.

> ***Tom and Harry left a mental retardation facility for community living. A phone call was received from their employer saying that they were arriving at work dirty, disheveled, and hungry. When asked, Tom and Harry said that they still liked their jobs and wanted to keep them. However, they had never organized their own lives and enjoyed sleeping late. They were not getting up early enough to shower and have breakfast. They were not organizing clean clothes because they had never had to deal with laundry. The staff response was that it was their "choice". When someone sat down with Tom and Harry and helped them develop a morning schedule, their "hygiene" problems vanished. They still enjoy sleeping in, but they now confine it to weekends and holidays.***

Choice can also be used as a way to punish people. A goal of the program model is to have people conform to the rules of the program. Struggles for control can then escalate. Within a support model the goal is to support the individuals in their life-styles. Behavior that is supported has limits but the general limits are the limits imposed on all the citizens of the community. Accounting for the presence of a disability may result in some limits, but it should not result in restrictions that reflect agency needs rather than individual issues. When staff are required to enforce compliance with senseless rules, they tend to "blame the victim". While staff have all of the power, the individuals with disabilities can "out escalate" the staff. One of the responses from angry staff is to say that they support choice and will let the "natural consequences" of that choice be experienced by the individual. "Natural consequences" is often code for letting the individual be punished by society where the staff cannot act out their own anger.

From the perspective of the system and the individual, the worst long-term abuse is the failure to build community associations and personal networks. Becoming part of the community is more than simply living and working in the community. Building community associations is required. Using the community to participate in the support is not only required for a cost-effective service system, it is required if inclusion is to be achieved. It is not only what is received from the community, however, but also what is given to the community. One of the most pernicious by-products of our program model is its tendency to put people with disabilities only on the receiving side of help and never on the giving side.

If people are to maintain their desired life-style they need to be as independent of the disability system as is possible. The more dependent on the disability system an individual is, the more vulnerable they are to the vagaries of changing staff and the ebbs and flows of budget and policy. Where someone has a support circle or personal network they are much less likely to find their life-style being compromised by the disability system. Personal networks rarely develop without assistance. Opportunities to develop personal networks need to be sought, developed, and pursued. It is unlikely that everyone can have an effective personal network, but it is certain that more people will have them if we make the effort.

In Conclusion

Success in supporting people with severe reputations requires skill in planning and implementation. But skill is not enough. The skills must be matched by commitment and tenacity. The commitment must be to the person, not the program. Tenacity is required as multiple efforts may be required for success. The following stories illustrate the struggles and the potential. The stories were told by Dave Wamsley and Kathleen McNally of eMerge. The names of the individuals and minor details have been changed.

"Tyrone"

Tyrone is tall, handsome and charming. He says that he just wants to "get along" and "be accepted". While Tyrone is aware of his

disability he does not want anyone to see it. Growing up in inner-city Baltimore, Tyrone has emulated his urban peers. He acts macho, tough, and street-wise. As long as he was living with his sister there were no unusual problems in Tyrone's life. Then his sister left for North Carolina. She did not plan to leave him, he just did not want to go. His roots, his girl friend and his job were in Baltimore. He did not leave with her and did not go several weeks later when his sister's boyfriend came to reunite them.

For the first several nights after his sister left, he slept on a friend's couch. Unfortunately, his friend lived in a funded residential home and while having friends sleep over was OK, increasing the number of residents was not. The system's response was to put Tyrone into the suburbs in respite care. At the first altercation Tyrone started talking about his gun and how he would use it. The respite agency's immediate response was to discharge Tyrone. However, the people providing the respite realized their mistake. The gun was symbolic, not real. They kept Tyrone with them even though they were no longer being paid. While this speaks well of the family that Tyrone was living with, it also says how charming and endearing Tyrone is.

The agency that was supporting Tyrone at work agreed to support him residentially. They offered Tyrone the opportunity to live with two fellows that he knew from work. All three were about the same age and liked each other. The counselor in the home was also someone that Tyrone knew and liked. One of the serendipitous discoveries of his stay occurred because the counselor had six year old twins. Tyrone loves children and is very good with them. He and the children would spend hours together. In other ways this was not a good arrangement, however.

When there were disagreements Tyrone would be culturally correct and threaten his roommates. They would back down and all three of them would feel bad. Tyrone was engaging in what he saw as a normal opening gambit. He was staking out a position from which he expected to compromise. His roommates saw someone, who they had thought was their friend, threatening to hurt them. The standard system response would have been to either discharge Tyrone or move him to a "high management, behavioral home". A more enlightened "program" response would be to have the behavioral consultants come to the home, increase the number of staff, and make Tyrone adapt. This was proposed. A number of staff said that he was asking for supervision and structure.

The agency director and program manager had another idea. They got a few people who knew Tyrone together to try to figure out how to support Tyrone rather than trying to change him. He was offered an apartment in a working class, urban neighborhood. While not the neighborhood where he had grown up, it was nearby and identical in cultural norms. A former agency staff member, who knew Tyrone (and who Tyrone liked), lived in the same building and was offered a stipend to be his support staff.

Tyrone is now living in a neighborhood where no one is afraid of him and many of the people who live there look out for him. Life is still exciting. He is still someone who acts first and thinks later. One weekend was particularly bad. First he tried to sell some of his furniture. The store where he took it told him that they had to hold it until the beginning of the week and then called his support staff. He then had a major fight with his girl friend and threw her TV out the window. The fight ended with Tyrone yelling at her from the sidewalk outside of her window in the early hours of the morning.

On Monday the agency began to sort out the weekend's activities. Tyrone said that the TV was his sister's fault. In a sense he was right. He felt abandoned and his behavior reflected that. Staff told him that he still had furniture, it just needed to be picked up. Tyrone said that while he had wanted the money, in the calmer light of day, he was relieved to discover that his apartment would still be furnished. The discussion regarding his altercation with his girl friend began with Tyrone saying that he was still angry but that "his girl friend was in his will". He and his girl friend began talking and then decided to go out to dinner. Tyrone left several bemused staff behind.

When inquiries were made through his support staff, it seems that Tyrone's neighbors would like him to calm down but do not see him as being too different from a number of other young men who live around them. In fact they say that Tyrone is more charming and friendly than most men his age.

Tyrone is maturing rather than being controlled. He is being supported rather than being programmed. The disability system knows how to control the Tyrones in the system. He could have been sent to a home that "specialized" in people with challenging behaviors. All that it would have required is several professionals, lots of staff, and lots of funding. Instead of the typical response Tyrone is being supported rather than being programmed. He is being supported by the community as much as by the disability system. He is being offered the

opportunity to grow up rather than being controlled into perpetual childhood.

"Maurice"

Maurice has been with the agency longer than the director. For most of that time he has been telling us how unhappy he was. He would ignore most people and be nasty with others. When you passed him in the hallway he would refuse to say hello. His unhappiness was reflected in his health. Maurice has diabetes and refused to follow his diet. In general, he was contrary. Wherever there was a way to demonstrate his displeasure he would use it. He would not keep his place clean, would scream and yell at people, would refuse to go to work, or refuse to do his work when he was there. Despite the drama of his behavior, nobody was really listening to him. He even tried hitting people and running down the street naked but that did not work.

Maurice wanted to live with his fiancee, while his family was adamantly opposed to any move. Part of their opposition was rooted in a devaluing skepticism. Maurice's fiancee does not have a labeled disability. They felt that no one, who did not have a disability label, would really want to spend the rest of her life in intimate partnership with Maurice. The family would threaten the agency with vague actions that would be taken if they allowed him to move. The harder his family leaned on Maurice and the agency the less compliant Maurice was.

For a year and a half the agency held meetings where everyone fought and there were no positive outcomes. The agency finally asked Maurice what support would be required for him to live with his fiancee. His requests were modest and reasonable. Agency staff then turned to his family and said that while they could not guarantee that the relationship was permanent they could guarantee that if Maurice ever needed another place to live, they would provide him with that place.

The change is remarkable. Maurice is now seen as a charming guy. His diabetes is under excellent control, he enjoys his job, and is a valued employee. Visiting his house is visiting him at home. Once he had control over what was important to him he did not need to use his behavior to register his displeasure. Once the family was assured that there would be a home for Maurice regardless of the outcome of his relationship with his fiancee they were willing to let him try.

"Susan"

When you meet Susan you are impressed with how direct she is. She will always tell exactly what she thinks and believes. When she got an award from the governor for her achievements she said thank you and then told him that he should close the local institution for people with mental retardation, saying "No-one should live there." Susan has had a tough life, which one person described as "a lifetime of rejection". She is a very intense as well as a truthful person. When she tells you she is going to do something you can count on it. She has her own standards and lives by them. Unfortunately for Susan, her standards and those of the system are often at odds. As a friend of hers said, she is simply "not Betty Crocker or Suzy Homemaker".

Her collision with the system was assured when it attempted to impose its standards on her. She needs lots of support but always wants to be in control. Susan hates being controlled and will out-escalate anyone who tries to control her. When she feels "low" she can either feel better by buying a new dress, having her hair done, or by "pushing the staff's buttons".

Five years ago, Susan was living in an agency apartment in the community. However, Susan's standards of cleanliness were not those of the agency. A control struggle began with a behavior program to increase Susan's "compliance". The struggle escalated when she stopped taking her medications. The agency countered with the need for live-in staff. Susan said, "If you move someone in here I will burn it down". They did and she did. As a result Susan was institutionalized with one of the most disabling behavioral labels, arsonist.

A community provider met Susan rather than her reputation and made the commitment to support her. Susan made it clear that she needs a lot of support but also has to be in control of her life. She picked her own one-bedroom apartment. Staff said that she needed a two-bedroom apartment to accommodate the staff who would have to supervise her. The program director said,"No, we have to listen to Susan". So an apartment was rented in the adjoining building for the staff. (The costs were shared with another individual who was being supported.) Staff are with Susan as she wishes and are available on short notice. Initially she requested that staff sleep on the sofa in the living room, as she did not feel safe at night. After several weeks she felt that she could do without this and staff could sleep in their own apartment.

Susan is in control. She can fire staff from her life (not from the agency) and determines the pace at which she enters the community. Susan does not want staff who either "push" or "mother" her and she has "fired" two staff members who did not listen. At first she wanted staff to meet her at the van when she was dropped off from work. They would walk her into her apartment. Now she wants to be met at her apartment. Initially she wanted staff to go shopping with her and stay at her side throughout the process, then she told them to wait outside, now she does not need them at all.

When plans were developed for Susan to leave the institution, staff of the institution said that unless she was constantly supervised she would set another fire. If the agency had followed this advice they would need to have one-on-one staff following Susan around to prevent her from acting out her rage. Instead, Susan sits down with her staff every week and she tells them what support she wants that week. She is in charge of the staff's schedule and her own life.

Last Thoughts

People with severe reputations can be supported, in lifestyles of their own choosing, in the community. The efforts are complex but can be reduced to seeking the answers to five questions. We need to know:

- What is the individual's desired lifestyle;
- What supports are required to achieve that lifestyle (with reasonable assurances that the safety of the individual and those around the individual are accounted for);
- Who can provide those supports, looking to community resources wherever possible;
- How can the necessary supports be paid for; and
- How will we know if our efforts are working?

These questions take less than a page to ask but require life-long efforts to answer. Success requires a commitment to the individuals and tenacity in their support. Success occurs one person at a time. Some people can achieve their desired life-styles with adaption to the current models of services, while major changes in the systems of services are required to achieve success for everyone. We have tried to communicate what we have learned in our efforts and in our observations of the efforts of others. We have not found all of the answers, however. The users of this handbook are encouraged to not only use what is described here but to seek

their own answers. We need to remember to keep listening to what people are asking for and to keep struggling to help them get it.

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Susan Burke Harrison
Baltimore, Maryland
July, 1992

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APPENDIX A

ESSENTIAL LIFESTYLE PLAN FOR CLARE

NON-NEGOTIABLES:

MUST live in a quiet, relaxed atmosphere.

MUST be given lots of love and attention!

Must **NOT** share her personal items, especially her clothes.

MUST have time to be alone and not "bothered" by staff.

Clare will know that staff care **IF** they give her hugs when she wants them.

MUST have chocolate milk with all of her meals **OR** she won't eat.

STRONG PREFERENCES:

Loves long bubble baths **BUT** do **NOT** pour water over her head!

Likes to eat slowly and enjoy her meals.

Loves to go bare foot.

Likes to play keyboard for fun.

HIGHLY DESIRABLES:

Chocolate pudding!

Prefers "semi-dark" rooms.

Likes to go on short walks.

Does want to spend much time watching T.V.

Likes soft music. (ie. classical, elevator music).

PEOPLE WHO KNOW AND CARE SAY:

She is real cute!

Very loving.

Has the cutest smile.

She brightens my day!

She almost always gets her way!

She can be very funny.

HER REPUTATION SAYS:

If she's ignored in the bathroom; she may smear feces.

She will strip if you try to "force" in a new situation.

If you don't let her pour milk on her food, she'll put the food in her hair.

She might bang her head if things get too hectic.

Can be stubborn.

TO BE SUCCESSFUL IN SUPPORTING HER:

Remember: she is a solitary person so, she will **NOT** tolerate "forced socialization programs".

She enjoys her current day program and if possible, should be "allowed" to stay there.

Clare responds best when she is spoken to in a clear, firm voice. Do **NOT** raise your voice at her or you'll get into a big power struggle.

If she is not given chocolate milk with every meal; she **WILL NOT** eat. She has gotten dehydrated in the past because she was stopped from pouring milk on her food. **SHE DOES NOT NEED A LOT OF HELP AT MEALTIME.**

Because Clare has limited vision, furniture and accessories should not be moved around frequently.

Clare **HATES** to have her hair washed so, this should be done as quickly and gently as possible. Do **NOT** pour water over her head!

Clare hates to have her hair brushed when her hair is long. She seems to like a short haircut.

Clare is very aware if anyone is wearing a piece of her clothes. She will get very upset if someone is wearing her clothes **OR** if she thinks someone is wearing her things.

Clare has learned to make herself "heard" if she is ignored or not taken seriously. Listen to the language of her behavior!

ESSENTIAL LIFESTYLE PLAN FOR RICHARD

NON-NEGOTIABLES:

Quiet/calm environment.

No Noise! No Loud Voices!

No Chaos!

Privacy.

Must have staff working with him who really care about him.

STRONG PREFERENCES:

Television.

Radio in his own room.

1:1 staff attention.

Outings of all kinds.

Likes to sing and dance.

Hamburgers and french fries.

WORK!- at least initially at MVTC.

Relaxing in a comfortable, reclining chair.

Being outside.

Walks!

HIGHLY DESIRABLES:

Attending sports events (especially Basketball and football).

One or two room mates, only.

PEOPLE WHO KNOW AND CARE SAY:

Funny.

Friendly.

Polite.

Pleasant.

Quiet.

Sense of humor.

Develops close and friendly relationships.

Talkative.

HIS REPUTATION SAYS:

Can be aggressive.

Threatening.

Chokes people.

Kicks others.

Makes statements.

TO BE SUCCESSFUL IN SUPPORTING HIM:

Because Dick is so perceptive about who likes and doesn't like him, who is intimidated and who isn't- It will be **VERY** important that staff build a rapport with him.

House staff need to spend time with him before he leaves Great Oaks.

Develop a positive approach behavior management program.

Staff need to be trained in the Management of Disruptive Behaviors before Dick leaves Great Oaks.

Part of knowing Dick is knowing when he should wear his helmet.

A major part of supporting Dick is understanding his seizure disorder.

Staff **MUST** be in-serviced and knowledgeable in recognizing and managing Dick's seizure disorder and seizure related emergencies.

Keep environment "safe" which would include having a chair with arms, when seated.

Check medication blood levels.

Staff need to be aware that in the past he has become aggressive prior to a seizure. His "signs" are: he becomes moody, argumentative, loud, aggressive and then has a seizure.

NO stairs in his home!

Staff need to be sensitive that home has been Great Oaks for over 15 years. He will need a slow, predictable transition.

Staff need to be firm kind and patient.

Richard **LOVES** food. He enjoys eating **BUT** remember: his calorie intake is controlled. (He **HATES** and can not drink milk.)

A medically approved daily exercise program should be a part of his daily routine.

While he enjoys work and keeping busy, he will also need alone" time each day.

Must have competent medical services.

- psychiatric
- neurologist
- general health care

ESSENTIAL LIFESTYLE PLAN FOR LINDA

NON-NEGOTIABLES:

Must have space to move around, at home at work.

Carry a pocket book.

Must feel safe and secure.

NO NOISE -- NO CHAOS.

STRONG PREFERENCES:

Being outside.

Eat outside at restaurants.

Long, hot bath.

Comfortable clothes (kind of baggie).

Likes to have a quiet place to lie down.

Likes brightly colored rooms.

HIGHLY DESIRABLES:

Having her hair combed.

Having her nails done and wearing lipstick.

Music.

Movies.

Shopping.

Likes to sit by the window.

PEOPLE WHO KNOW AND CARE SAY:

Gentle.

Sweet.

Affectionate.

Patient/puts up with a lot.

Wonderful smile.

Very helpful.

Has a strong intuition for those around her. Knows what staff care about her.

HER REPUTATION SAYS:

Severe PICA.

Hyper.

SIB.

Head banging.

Gets upset.

Autistic-like behaviors.

TO BE SUCCESSFUL IN SUPPORTING HER:

Linda does best when things are consistent and the routine is predictable.

She needs a lot of supervision and prompting.

Linda's behavior (SIB/PICA) will increase when her environment lacks structure and/or consistency.

Because she will put non-food items in her mouth, Linda's living & work environment should be free of small items/bits and pieces.

Linda has difficulty sleeping.

Linda will need 24-hour awake supervision.

Mom must know when medication is prescribed.

Build breaks into her daily schedule, i.e., walks outside.

Scheduled visits with Mom.

Linda's diet should be low in sugar, high in veggies--little or no red meat.

She simply seems to feel better with this type diet. Minimal dairy products (does not have allergy to dairy products).

She becomes more relaxed when the area is open/bright.

Staff needs to be firm, but kind.

Take her out of the environment when she is upset. Give her a chance to calm down. Give her juice/water.

Will do much better in a home with three or fewer residents.

Mom is very involved & will remain so--keep her informed and involved

Linda has sensitive skin--must be kept clean and cream applied (with Vitamin E).

Do not use harsh soap.

Ongoing behavior plans in place regarding PICA/SIB.

Current GOC psychologist to meet with agency consultant prior to Linda's move.

ESSENTIAL LIFESTYLE PLAN FOR JOHN

NON-NEGOTIABLES:

Being involved with his family.

No alcohol, not even one drink.

Working with Nate!

Privacy.

His own room.

Having coffee when he wants to.

Smoking, when he wants to.

A full-time job where John can earn money.

HIGHLY DESIRABLES:

Going to the movies.

Shopping.

Attending sports events.

Eating at Wendy's -- especially the hamburgers.

Going to car dealers and looking at the cars.

"Riding around" talking and listening to music.

STRONG PREFERENCES:

Music!

Playing drums.

Having money in his pocket.

Joking and "fooling around".

Continue to see his girlfriend, Dorothy, **BUT**...also have chances to meet other women.

Going to Knights of Columbus dances.

Continue car washing business.

PEOPLE WHO KNOW AND CARE SAY:

Likes to help others.

Has a good sense of humor.

Can be a good friend.

Hard worker.

Has a great laugh.

HIS REPUTATION SAYS:

Non-compliant.

Steals.

Teases.

Verbally abusive.

Manipulative.

Destroys property.

Hits and pushes.

Abuses alcohol.

Easily lead astray.

TO BE SUCCESSFUL IN SUPPORTING HIM:

Keep John's **MOM** involved and informed.

Let John know, up front, exactly what the boundaries and rules are.

Set firm limits and expectations with John and his mother regarding visits and his money.

Always take the time to listen to him when he says there's a problem.

Live and work in a drug and alcohol-free environment.

Staff must learn "John's ways" -- what he likes and hates and what makes him "tick".

A good rule for supporting John is: "Treat him like you would like to be treated".

Realize that John will test the limits in the beginning.

All forensic issues must be addressed before he leaves Great Oaks.

Continue to work in his car wash business.

John models after the people who are around him. If he's with "good role models" he'll model their behaviors, if not...

Staff need to know that when John gets furious he may be vengeful.

ESSENTIAL LIFESTYLE PLAN FOR PATRICK

NON-NEGOTIABLES:

Patrick cares about his appearance & wants to look good-- wearing nice, stylish clothing.

No smokers; including staff!

Meticulous about his personal appearance.

Continued involvement with his family.

Must get hugs, backrubs and pats on the back to know that people really care.

STRONG PREFERENCES:

Lots of healthy snacks.

Housemates who are similar to him.

Favorite chores include: stripping beds, mopping, moving furniture for cleaning.

Second and sometimes third helpings at mealtime.

Live in house, not an apartment.

HIGHLY DESIRABLES:

Exercise (like using a stationary bike and weights).

Swimming.

PEOPLE WHO KNOW AND CARE SAY:

Sweet.

Helpful.

Good-looking.

Energetic.

Friendly.

Cooperative.

HIS REPUTATION SAYS:

Self-injurious.

Aggressive.

Hyperactive.

Bolts & runs.

Doesn't sleep through the night.

Gets up early.

TO BE SUCCESSFUL IN SUPPORTING HIM:

Keep him busy. Patrick doesn't like to sit around & watch TV! Also, he tends to sleep better when he's involved in physical activity during the day.

We need to help keep Patrick safe. Fenced yard, away from busy streets. Rural area preferred. House and yard--not an apartment.

Patrick has asthma and will need ongoing treatment.

Arrange for competent nursing services.

All staff trained in giving nebulizer treatments (9 pm, and PRN).

Recognize Patrick's "signs"--need for nebulizer treatments. Because of his asthma, it doesn't make sense for him to be involved in activities/chores that involve dust, mold, etc.

Allergic to grass, dust, mold.

No smoking in Patrick's house--either by his housemate or staff.

Remember Patrick's limited vision. Approach him from left side so as not to startle him.

Time to transition. Patrick will let us know when he is comfortable.

When giving Patrick instructions, remember to use verbal as well as gestural questions.

Realize when Patrick is anxious. His physical activities increase (jumps up & down).

Hire **ENERGETIC** staff.

Must have competent podiatry services.

Good hair care--dandruff shampoo.

Seems to respond better to firm/low pitched voices.

Remain calm with him. He does not respond well to hysterical/loud voices.

Will need awake overnight supervision.

Staff needs to know his signs for nebulizer and bathroom.

Continue with sign language program.

APPENDIX B

Training Exercise #1

Explanation: Essential Lifestyle Planning is an inclusive process that encourages everyone who knows the focus person to contribute during the planning meeting. Often friends, family and some "team members" feel excluded from the process because "we" use jargon and phrases that are unfamiliar.

Directions: Listed below are some of the most frequently used terms. Translate the jargon in Column A into plain English and write it in Column B.

COLUMN A	**COLUMN B**
leisure opportunities	_____
SIB	_____
community connections	_____
"the retarded"	_____
verbally abusive	_____
sexually inappropriate	_____
"wheelchair bound"	_____

Training Exercise #2

Explanation: We all have a variety of friends and relationships that affect and are a part of our life. The intensity and importance of these relationships vary from person to person. The picture below represents the various levels of friendships that surround the focus person.

Directions: Place the names of friends, family and other people in the corresponding circle that makes sense.