

# **Never Give Up**

## **Assets Inc.'s Commitment to Community Life for People Seen as "Difficult to Serve"**

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with

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Preparation of this publication was partially supported through a subcontract to Responsive Systems Associates from the Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through a cooperative agreement (number H133B980047) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

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This report results from the desire of Assets' senior staff to more clearly articulate their approach to supporting people who are seen by most mental health and developmental disabilities service providers as difficult to serve. They wanted its preparation and dissemination to serve two purposes: to summarize their own learning and to share what they have learned with others. They invited John O'Brien to visit from 23-25 June 2003. He listened to their reflections on their work, conducted a focus group with staff, read documents, and wrote this report, which each of the other contributors reviewed and corrected.

**Kathryn Carsow** is Assets' Director of Mental Health Services. She came to Assets from the Alaska Division of Mental Health, where she was CMH/ARP Project Manager, in 2001.

**Matt Jones** is the Deputy Director of Assets, responsible for the Community Services Team. He has been personally involved with the people who are the focus of this report since he helped to found the supported living program as a direct support worker in 1986.

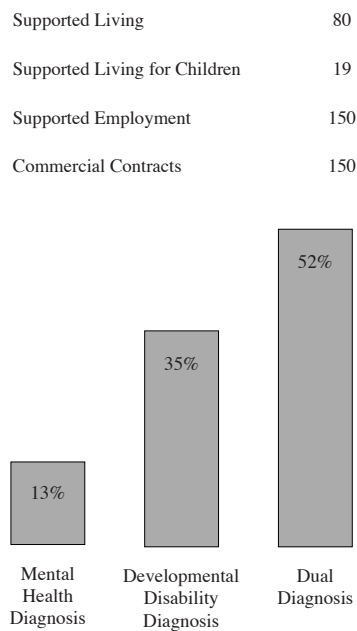
**Maxwell Mercer** was Assets' Director of Mental Health Services from 1996 to 2001. He initiated the effort to document Assets' approach to services and wrote a description of the foundations of Assets' practice that shows its connections to the literature of community services to people with developmental disabilities and the field of psychiatric rehabilitation.

**Laronsia Reynolds** is Co-Director of Assets' Community Services Team. She has worked with the people who are the focus of this report since she began as a direct support worker in 1995.

**Diana Strzok** has been Assets' Executive Director since 1995.

*We act as if the practitioner’s knowledge and technology are more important than the interpersonal relationship between the practitioner and person getting help. We know this is not the case from listening to what people tell us. When asked, a majority of people who are recovering from severe mental illnesses will mention that a critically important contributor to their recovery is other people –people who listened to them, believed in them, and supported them in numerous ways... Today it is fashionable to argue for... the removal of choice with the phrase, “people are dying with their rights on”. But I would also remind us that, “people are both living and dying with their dreams turned off”. We cannot be seen as the field that walls people away from their hopes and dreams.*

—William Anthony (2002)



Assets, Inc. supports people with developmental disabilities or psychiatric disabilities or both disabilities to live, work, and learn in Anchorage, Alaska. It serves about 250 people, offering each person one or more of these services: supported living, supported employment, and contract work. About 25% of the people Assets supports were referred by the Division of Vocational Rehabilitation (DVR) and about 75% were referred by the Division of Mental Health and Developmental Disabilities (DMHDD).<sup>\*</sup> (For a brief description of Assets; organizational structure, see page 36.)

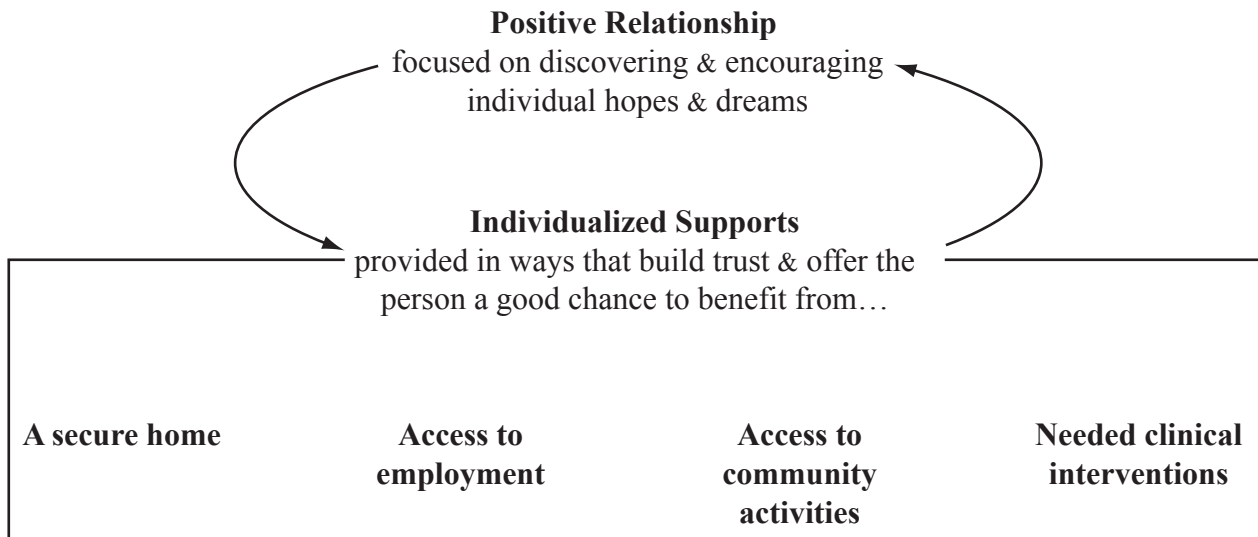
For nearly 20 years, Assets has systematically developed its staff’s capacity to assist people that other community services were unwilling to include because they present challenges and risks that seem excessive to other providers. Assets’ accumulating experience demonstrates the importance of an individualized approach to supports delivered within a positive personal relationship with staff. While some approaches to people who challenge services rely on separate and distinct facilities or service programs, Assets does not. The foundation of Assets’ approach is a positive long-term relationship between the person and Assets’ staff which allows the person to make the most possible use of the opportunities in their community. This relationship focuses on discovering and re-discovering each person’s hopes and dreams and assisting each person to pursue those hopes and dreams in the context of a secure home and access to opportunities for employment and community participation. As need arises, staff develop and apply specialist knowledge and clinical skills so that people whose disabilities present unique barriers can benefit from

<sup>\*</sup>On 1 July 2003, Alaska’s human service system was reorganized. This report reflects the organizational structure in place before the reorganization.

## **Assets' Mission Commits Its Staff to People Who Need Substantial Supports**

The Mission of Assets, Inc. is to consistently improve the employment opportunities, home environments, and community connection of individuals with developmental disabilities or mental illnesses who need substantial supports, so that their independence and self-worth are enhanced and the community in which they live and work realizes the benefits of their citizenship.

### **A Schematic View of Assets' Model for Support**



**Assets' experience shows the effectiveness of individualized supports created through a positive, long-term relationship with staff.**

the same variety of supported living and employment opportunities that Assets offers each person it supports.

Practitioners who are committed to community life for people who are difficult to serve sometimes describe people as having “severe reputations”. This ironic label economically communicates three important ideas: 1) the way services have labeled and responded to this person has amplified their difficulties; 2) there is far more to the person than indicated by their diagnoses and negative stories about them; and 3) it is important to get to know the person by getting past frightening or pessimistic accounts before deciding on what supports will work best for the person.

Assets' staff know the importance of these ideas. They also know that the people they assist are whole people with both light and shadow in their make up; whole people with both capacities to build on and dangers to safeguard against. They know that people's history often includes patterns of behavior that have, in some sense, earned them a severe reputation. They know that at least some of this difficult, dangerous, or frightening behavior may well endure into the new and positive relationships, opportunities, and individually tailored support that they are prepared to offer. They also know that the container for all of their efforts must be a relationship based on an appreciation of the person's hopes and dreams and a willingness to be on the person's side, offering encouragement, advice, and practical help as they take steps to pursue those hopes and dreams.

Over years, Assets has maintained most of its relationships with people who present significant challenges. Some who received supported living services as children or young people have moved on with their lives without Assets' support and some continue to receive assistance from Assets as adults. Most of the people who joined Assets as adults defined as “too difficult to serve” still receive support from Assets. While Assets has failed occasionally –over the years two people returned to prison after violating their parole and two people have left Assets services to return to a psychiatric facility– most people who came to Assets as “too difficult” have jobs, many are actively involved in some aspects of community life, and all have the support they need to live in their own homes.

Assets is not alone in its search for ways to dissolve the category of “too difficult to serve.” The field of psychiatric rehabilitation (see Anthony,

- 1980 — Founded as *Employment Training Center of Alaska*  
Sheltered workshop employs people in printing, bindery, & other contracts
- 1984 — Name changes to *ASETS: Alaska Specialized Education & Training Services*  
Supported Living Services begin, including 8 people referred by the DD Division with dual diagnoses (primary diagnosis: developmental disability) turned down by or discharged by other providers  
Contract Services (work crews) begin
- 1988 — Supported Living Services for Children begins; referrals of adolescents diagnosed as severely emotionally disturbed from Alaska Youth Initiative
- 1989 — Inappropriate Sexual Behavior Services initiated in response to one person's need; includes 8 people by 1992; 25 people by 2003
- 1991 — Include people referred by the Division of Mental Health with dual diagnoses (primary diagnosis; mental illness) and histories of assaultiveness and treatment resistance
- 1995 — Name changes to *Assets, Inc*  
Include people referred from Corrections with psychiatric diagnoses in collaboration with DMHDD: 6 people by 2000  
Collaboration with the recently formed Center for Human Development (UAP) to provide clinical services for people with inappropriate sexual behavior
- 1999 — Include people referred from the Katmai Unit (long stay) at Alaska Psychiatric Institute (API): 7 people by 2001 with diagnoses of chronic psychotic disorders with non-remitting symptoms and personality disorders
- 2001 — Include people participating in Recovery by Choice, a Mental Health initiative for the most frequent short stay users of API: 3 people by 2003 with multiple difficulties including substance abuse, involvement with the police and courts, and resistance to treatment as well as psychiatric diagnoses

Cohen, Farkas, & Gagne, 2002) is systematically expanding the options available within the mental health system by focusing on “processes such as collaborative goal setting, skills training, developing a person-centered plan, building the relationship between practitioner and service recipient, providing environmental accommodations, and coaching” (Anthony, 2003). Developmental disabilities services have invested substantially in creating positive approaches to behavioral support (see, for example, Koegel, Koegel, & Dunlap, 1996 and Lehr & Brown, 1996). Services to children and youth have created the teaching family model (Fixsen, Phillips, & Wolf, 1973) and wraparound services (Burchard, Burchard, Sewell, & VanDenBerg, 1993) to make institutional placement unnecessary. Assets draws from each of these streams of service innovation in developing individualized supports.

### **Assets’ Evolving Role in Alaska’s Service System**

Assets has developed its competencies incrementally, over nearly 20 years, as the time line on the facing page shows. As one senior staff member, who began work as a direct support worker when Assets’ supported living services began in 1986, put it, “Our niche has remained the same. We respond to the people others see as ‘too hard to serve’. As other agencies become willing to accept more challenging people, we keep stretching ourselves to include new people who bring us new challenges.”

**“We keep stretching ourselves to include new people who bring us new challenges”**

Alaska has chosen to redesign its developmental disability and mental health services to eliminate institutionalization and minimize the number of people who have long stays in psychiatric facilities. Harborview, the state’s institution for people with developmental disabilities, closed in 1997 and by 2000 Alaska ranked first among the states in its focus on small (<6 person) residential settings. In 2000, 97% of Alaskans with developmental disabilities who receive residential supports lived with 5 or fewer others, 3% (25 people) lived with 6 to 15 others, and >1% (6 people) lived in nursing homes (Braddock, Hemp, Rizzolo, Parish, & Pomeranz, 2002). The Alaska Youth Initiative organizes wraparound services for children and young people at risk of out of state placement or placed in specialized facilities out of state with the aim of strengthening their families or re-unifying them with their families or offering stable foster care. Mental Health services are at work on strategically developing community supports across the state; downsizing the Alaska Psychiatric Institute, the state’s single public mental health facility; and developing alternative services for people who would otherwise live for an extended

period of time in a psychiatric facility (Alaska Department of Health and Social Services, 2001).

Determining the quality of an effort to make public institutions unnecessary calls for answers, over time, to at least three questions:

- What opportunities and experiences are available to people who otherwise would have been institutionalized?
- Are financial savings invested in either increasing the numbers of people who benefit from services (e.g. by reducing the waiting list for residential supports among adults with developmental disabilities who live at home) or in improving the competence of services (e.g. by raising the wages of direct support workers)?
- Are people who challenge the competence of services exported from the restrictions of institutionalization into other very restrictive settings such as nursing homes, long stay psychiatric facilities, jails, homelessness, or community settings that control people through routine application of physical or chemical restraint?

One of Assets' contributions to the redesign of Alaska's service system –and the primary focus of this report– is its ability and willingness to create opportunities for people at risk of ending up living highly restricted lives to live in their own homes and hold jobs and pursue their personal hopes and dreams.

Assets supports its staff to make long term commitments to people avoided by other service providers as “too difficult to serve”. This judgment has attached to some of the people Assets now supports because, in addition to diagnoses of developmental disability or mental illness, they have shown persistent patterns of difficult behavior, including: persistent non-compliance, violence to others, self-injury, property destruction, fire-setting, substance abuse, sexually inappropriate behavior (including pedophilia), probation and parole for criminal offenses (including homicide), persistent psychiatric symptoms that disrupt daily routines over long periods of time, and a history of poor response to or rejection of services and treatment interventions.

This daunting list of challenges indicates the scope of Assets' commitment and the possible applications of its learning to other agencies and service systems, but it is false to Assets' practice in three important ways. First, Assets sees and deals with whole people whose lives include

- See whole people and value their hopes and dreams
- Design and deliver support in an individualized way
- Focus on all people as an asset to their community

challenging or risky behavior rather than focusing first on symptoms or problems. Second, Assets sees and deals with people as individuals and not primarily as members of a problem or symptom identified group. Differences in referral sources do make a difference to the way public funds flow to Assets, but these differences affect only the way billing is done, not the practice of the staff who provide support according to a pattern tailored to fit each individual's whole life situation. Third, though the service system recognizes Assets' willingness to assist in complex situations, Assets does not publicly identify itself as a specialized service for people who are difficult to serve. Assets positions itself as a resource to the Anchorage community with a particular emphasis on the people it supports as workers contributing to the local economy. Publicity materials and annual reports emphasize individual accomplishments. Assets does not take public credit for responding to the complex difficulties faced by some of the people it supports (for examples, see [www.assetsinc.org](http://www.assetsinc.org)).

It can take years to establish the trusting relationships and individually tailored assistance necessary for people to achieve reasonable stability and security in their lives, reasonable productivity in their work, and reasonable levels of engagement in community life. However some notable results were apparent within three years to outside evaluators of one of Assets' recent efforts.

*The overall success of the Extended Care Services Project has been remarkable. The fact that eight individuals who had previously spent most of their adult life institutionalized were able to live outside an institutional setting is one predominant indicator of success. While overall clinical diagnostic indicators for measuring the success of these individuals remained relatively unchanged; quality of life, additional freedoms, and increased participation in social and community activities was achieved. Census at API was decreased from 25 beds to 20 beds on the Katmai Unit assisting API in the reduction of overall capacity from 79 to 74 beds. Furthermore, the cost of providing services to individuals in a community-based setting, as opposed to an institutional setting, was also decreased with substantial savings to the state.\* (Alaska Comprehensive and Specialized Evaluation Services, 2003, p. 1).*

**Quality of life can improve considerably even if clinical indicators of disability do not change much**

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\*The report computes a potential annual cost savings of about one million dollars for the group of eight people involved in this project (p. 30)

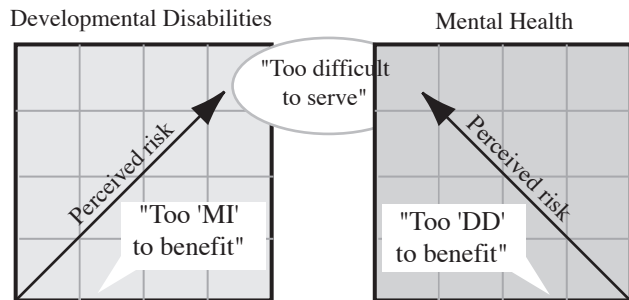
## **How people become “too difficult”**

As Assets’ staff see it, people become “too difficult to serve” when their real life situation generates lasting contradictions with ordinary service practices. Each field of human service shares some common assumptions about what falls within its boundaries and each agency has a distinct organizational culture. When policy and common assumptions that shape those service cultures don’t encourage the creation of individually tailored supports that stretch familiar practices, people who challenge the ordinary become a threat to avoid.

Typical developmental disabilities services are most comfortable offering long term assistance to people’s daily living and occupation and teaching everyday skills. These practices work acceptably well for most of the people who use developmental disabilities services, but people become difficult when behavioral problems or psychiatric symptoms can not be managed with easily implemented environmental controls or medications. Assignment of a psychiatric diagnosis in addition to developmental disability often decreases staff confidence that they are equipped to deal with the person and can invoke stereotypes about psychiatric disability. Developmental disabilities service providers can conclude that people fail to benefit from their services because of their mental illness.

Typical psychiatric services are most comfortable offering interventions that target symptom relief and specific skill development. Usually these services expect that intensive services will be of short duration. Except for some transitional housing and transitional employment services, people’s work lives and home lives are mostly left to them to sort out. These practices work acceptably well for most of the people who use psychiatric services but people become difficult when symptoms persist and people require long-term assistance to maintain themselves. Assignment of a diagnosis of developmental disability often decreases staff confidence that they are equipped to deal with the person or leads to the judgement that the person lacks the ability to respond to anything other than medication and can invoke stereotypes about developmental disability. Mental health service providers can conclude that people fail to benefit from their services because of their developmental disability.

People who don’t fit usual service practices become “too difficult” when perceived risk rises past a service provider’s threshold of confidence. People who frequently assault staff, or have a strong desire to engage



in high risk behaviors, or are addicted to drugs or alcohol, or have a history of such dangerous behaviors as pedophilia or fire setting raise important questions about legal liability, threats to an agency’s public reputation, and extra costs (such as extra clinical services, workers’ compensation, liability insurance, and increased staff turnover). A history of offense against the law compounds the

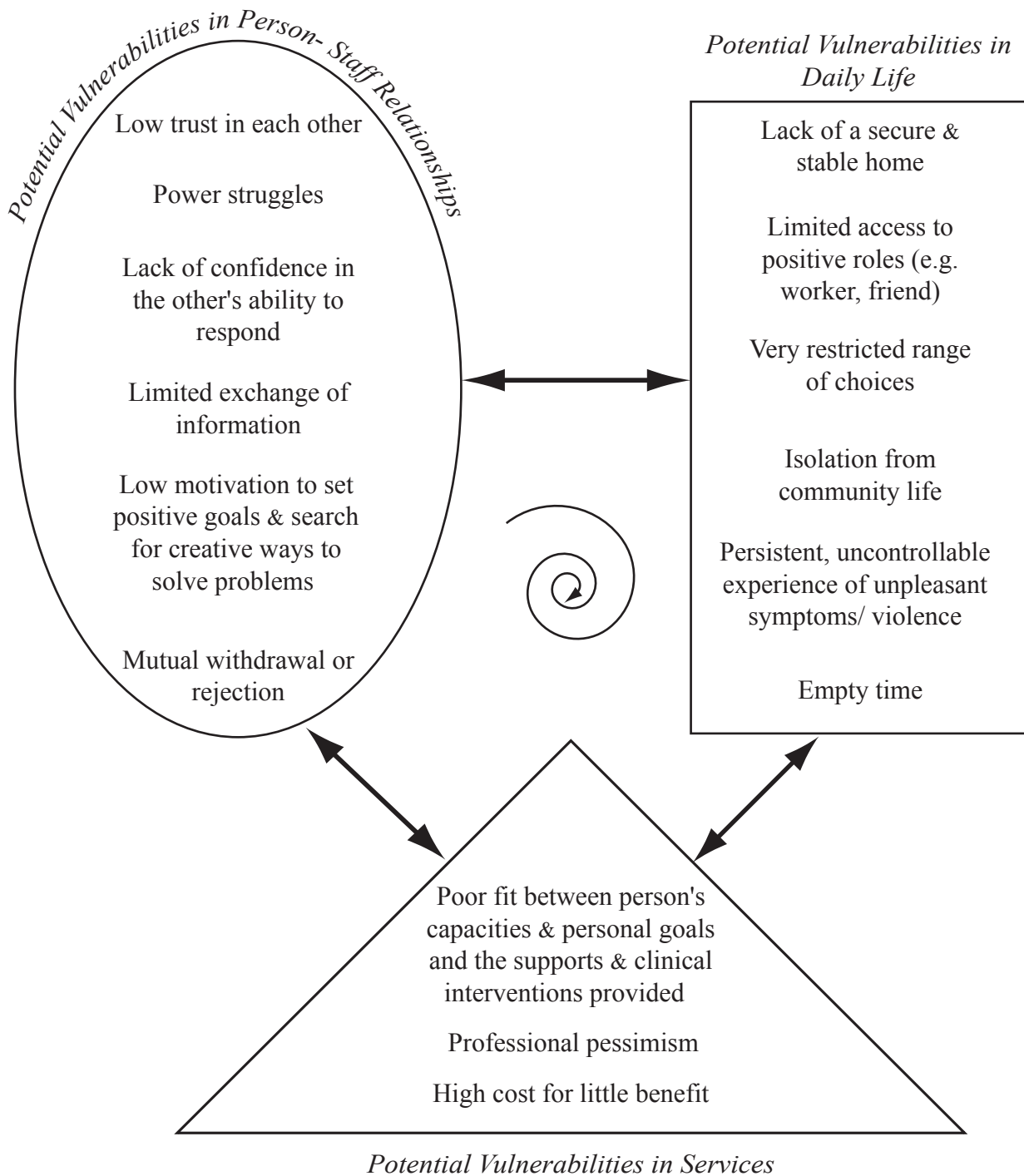
sense of difficulty and risk, in part because it engages the person with a third system, which also sees the person as a poor fit with its culture and competencies.

From this perspective, “too difficult” is a role created by the way a service system organizes its resources. The different grids of mission, definition, knowledge, technology, accountability for funds, methods of risk management, and policy that distinguish the organizational cultures of developmental disability services from mental health services and both systems from criminal justice services create a group of people who look anomalous from within all three perspectives. To the developmental disabilities system a person looks “too mentally ill” or “too much at risk of (re)offending” to benefit from what they can do. To the mental health system, a person looks “too mentally retarded” or “too much at risk of (re)offending” to benefit. To the criminal justice system a person looks “too mentally disabled” to manage effectively. When their perceived risk to an agency is high, people who don’t fit neatly within the grid of an organizational culture become “too difficult”.

People get locked into the “too difficult” role by interconnecting social processes which can create a trap for people with disabilities and those who serve them. Those currently responsible for serving the person can become emotionally engaged in...

- ...working to move responsibility for the person away from themselves and across the boundary of some other agency or system
- ...blaming the person for failure to respond to repeated applications of the approaches that usually work with most of the people they support (often blaming takes the form of multiplying diagnostic labels that do not so much shape more effective interventions as they express staff frustration and justify restrictive practices such as restraint, near sedative levels of medication, or aversive behavioral intervention)

# The Negative Spiral That Can Trap People and The Staff They Rely On



...avoiding personal involvement with someone who seems threatening to staff's sense of confidence, if not their personal safety

This investment of emotional energy in banishing or shunning the person who doesn't fit in –which can be masked by clinical language, objective professional discussions, and formal procedures– communicates rejection and disrespect to the person. Such messages inhibit the development of trust, which in turn hinders the flow of information between the person and those providing services, and retards both the person's and the staff's motivation to set and seek meaningful goals. Combined with the consequences of continued exposure to poorly focused supports, the lack of a positive relationship makes the person even more difficult to serve.

### **Getting Out of the Trap**

Over time, a poor fit between a person's life situation and available supports can result in a negative relationship between the person and professional and direct support staff. Mutually reinforcing difficulties in daily life accumulate, sometimes to the point that the person spends full time or nearly full time living an institutional life, whether in a large or a small facility. This increases the chances that the fit between the person and supports will grow even worse, sending the spiral through another cycle and further decreasing the person's opportunities. The diagram on the facing page summarizes the vulnerabilities risked by a person who occupies the "too difficult" role.

When they are caught in the trap created by this negative spiral, people can end up leading very restricted lives. While not every person identified as "too difficult" will have all of these negative experiences, it is likely that each person will have some of them and...

#### *Vulnerabilities in daily life*

- ...lack a secure and stable home of their own
- ...have limited access to the satisfactions and respect that attach to positive social roles such as being a worker or belonging to a community organization
- ...be subject to control of most of their daily routine by others
- ...be isolated from community life and unlikely to be seen as citizens
- ...frequently and persistently experience unpleasant symptoms or act violently and suffer the consequences with little or no sense of being able to exert control over these undesirable happenings

*Vulnerabilities in services*

- ...face many hours and days of empty time
- ...continue to receive services that are poorly matched to their situation
- ...be seen by most professionals as having little hope of a positive or productive future
- ...be seen as using large amounts of resources for little benefit

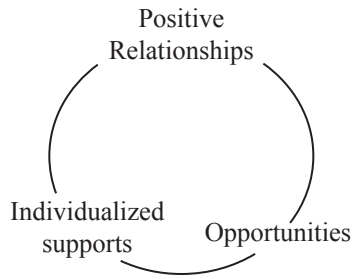
*Vulnerabilities in relationships with staff*

- ...distrust many of the staff they rely on and are not trusted by most staff
- ...frequently get entangled in power struggles with staff and often see no alternatives to attack or extreme passivity
- ...have little confidence that staff will be able to respond effectively to them and enjoy little confidence among staff that they will respond positively to staff efforts
- ...communicate guardedly about a limited range of topics
- ...rely on staff who have low motivation to set positive goals and engage in creative problem solving to deal with barriers to goal attainment
- ...withdraw from or reject staff and possibly experience withdrawal or rejection by staff

The longer people and staff are caught in this trap, the more its negative effects can become part of the person's sense of self. People's sense that they can make a positive difference to their own future decreases and they adjust their expectations for their life downward as they adapt to restricted circumstances. This makes the trap, and their place within it, seem familiar to people and this familiarity can make positive changes a source of anxiety. It can take some time and living through many ups and downs for people to build up a life outside the trap.

This metaphor of a trap does not suggest that people who are cast in the role of "too difficult" are not disabled. Many of the people Assets supports experience cognitive disabilities, many have psychiatric disabilities, some have neurological or physical disabilities, most people have a combination of these disabilities. In some form, these conditions are likely to endure throughout people's lives and continue to call for well organized, individualized assistance. The extent to which these disabilities negatively affect the quality of people's lives depends in important ways on three things that Assets can do to reverse the negative effects of the trap:

- Offer a positive relationship with staff that allows people to discover and take action to pursue their hopes, dreams, and personal meanings
- Provide sustained opportunities for a secure home and access to positive roles



- Offer individualized support that justifies people’s trust and allows people as much autonomy and participation in community life as possible, consistent with their own safety and other’s safety

### **Creating Opportunities**

Assets holds the same aspirations for each person it serves. Young people who have chosen Assets as they grow out of their school years deserve individualized support to succeed as a worker and a community participant; so do people moving after many years of psychiatric hospitalization. People whose behavior poses no particular challenge deserve to enjoy a positive relationship with staff who are genuinely interested in being allies in pursuing their hopes and dreams; so do people with a history of inappropriate sexual behavior. People who are able to manage daily routines independently deserve a home of their own; so do people who require a high level of structure or assistance to deal with daily demands. All of the people Assets supports can make a valuable contribution to their communities (Review Assets Mission on page 4.)

These aspirations are encoded in Assets’ statement of beliefs, reproduced on the next page. These beliefs commit Assets’ staff to respectful relationships that honor people’s choices, promote people’s sense of themselves as powerful, recognize the importance of working for change in community prejudices, and serve people’s participation in valued community roles as friend, family member, tribe member, contributor, employee, neighbor, association member, and advocate.

#### *Some opportunities develop more slowly*

Because Assets implements these beliefs by approaching each person as an individual, there is no need for programmatic distinctions based on a person’s diagnosis or the amount of time and shared effort that might be necessary for a person to move into one or more valued social roles. For some people who were extracted from family and village life as children to receive services hundreds of miles away in Anchorage or even thousands of miles away in another state, recovering family and village roots may take years and include the time it may take to recover from disappointments or rejection. For some people who grew up in an institution, a sense of confidence and efficacy may grow slowly. For some people, it may take many trials to find ways to manage distressing emotions that overwhelm the desire for community involvement.

### **We Believe The Individuals We Support Should:**

Have a stable home of their choice.

Be employed in rewarding jobs with benefits, growth opportunities, fair wages and flexible schedules.

Determine their service and define what improvement means for them.

Experience discreet, non-intrusive, individualized supports of their choice.

Be good neighbors who actively participate in their community and belong to community clubs, associations, leagues, etc.

Have access to affordable, accessible, flexible transportation.

Have opportunities to return to their roots (village, family).

Experience community acceptance on a day-to-day basis.

Be respected and heard.

Have a reputation and identity free from the human service system.

Make their own decisions based on informed decisions.

Be seen as givers/contributors to the community.

Be self advocates – network with each other for support.

Experience a sense of confidence and empowerment and control.

Have a variety of friends.

Understand the obligation of service providers and expect it to be fulfilled.

Get only the services they request.

*Establishing a stable home and a job lays the foundation for success*

It takes much less time for Assets to assist people to live in a stable home and have a job than it takes to support the developmental process that allows people to recover from all the negative effects of being placed in the “too difficult” role. Locating affordable housing that reflects a person’s choice is not always easy in Anchorage, but Assets’ staff have learned how to help people move into their own places. Finding a job that accommodates a person’s need for structure and flexibility can be difficult, but Assets’ staff have learned how to help people find jobs. Because Assets provides people with long term support, first homes and first jobs are just that. As staff earn people’s trust by accompanying them through the ups and downs of first (and sometimes second and third and fourth or more) homes and jobs, they build the knowledge to find better and better matches with people’s growing skill and confidence. A reasonable level of stability at home and at work can take months or even years to establish. But the opportunity to learn by being at home and at work is where Assets begins. There is no sense in continuing the failed practice of trying to get people ready for a stable home and a job, especially when coping with the disruptions that will almost certainly come when people begin to move from restriction into greater choice.

Meeting staff whose mission is to work with you to move into your own home and find a job, and who begin their relationship with you by listening to what you have to say about your hopes and dreams, and build their relationship by asking you about your preferences, and look for ways to help you realize those preferences creates a change for people who have been caught in the “too difficult” trap. When people move into their own place and collect their first paycheck they experience real benefits that strengthen their relationship with staff. When staff stick with them and look for positive ways through the inevitable difficulties and disruptions that threaten the benefits of living in one’s own home and working a real job, the relationship grows stronger.

Assets’ past investments provide some people with options. Assets was founded to provide contract work and still operates a successful printing and binding business in its building. Its early efforts in supported employment include a number of crews that work in community sites, including several well paid crews who work on contracts in federal facilities and military installations. Assets’ contract services are

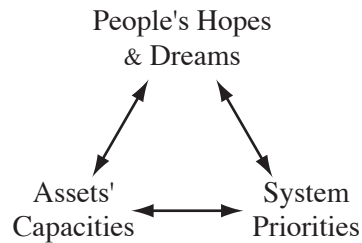
economically successful enough to employ both people with disabilities and some people without disabilities and offer a measure of flexibility and security that allows some people to make the quantum leap from full time patienthood in a psychiatric facility to at least part time employment more quickly than they might otherwise.

Assets acquired HUD funds to develop a nine unit apartment building in 1994 and a triplex in 2000. These apartments are not transitional housing: people can live in these properties until they choose to move to something better. And, people do find places that they like better and move. This occasional turnover provides places for people who may need an exceptionally accommodating landlord in order to establish themselves outside an institution.

Assets' staff and board are familiar with accepted principles of good practice. It would not be news to them if someone pointed out the disadvantages of congregating people with disabilities for work, or in an apartment building built for people with disabilities. They understand the dilemmas of offering individualized support while operating congregate service sites and they are clear that the future lies in the direction of expanding their capacity to offer individualized supports through individualized and community integrated service arrangements. However, they can point to positive outcomes consistent with their belief statement that balance the disadvantages for a number of people, especially people that other providers define as too difficult to serve.

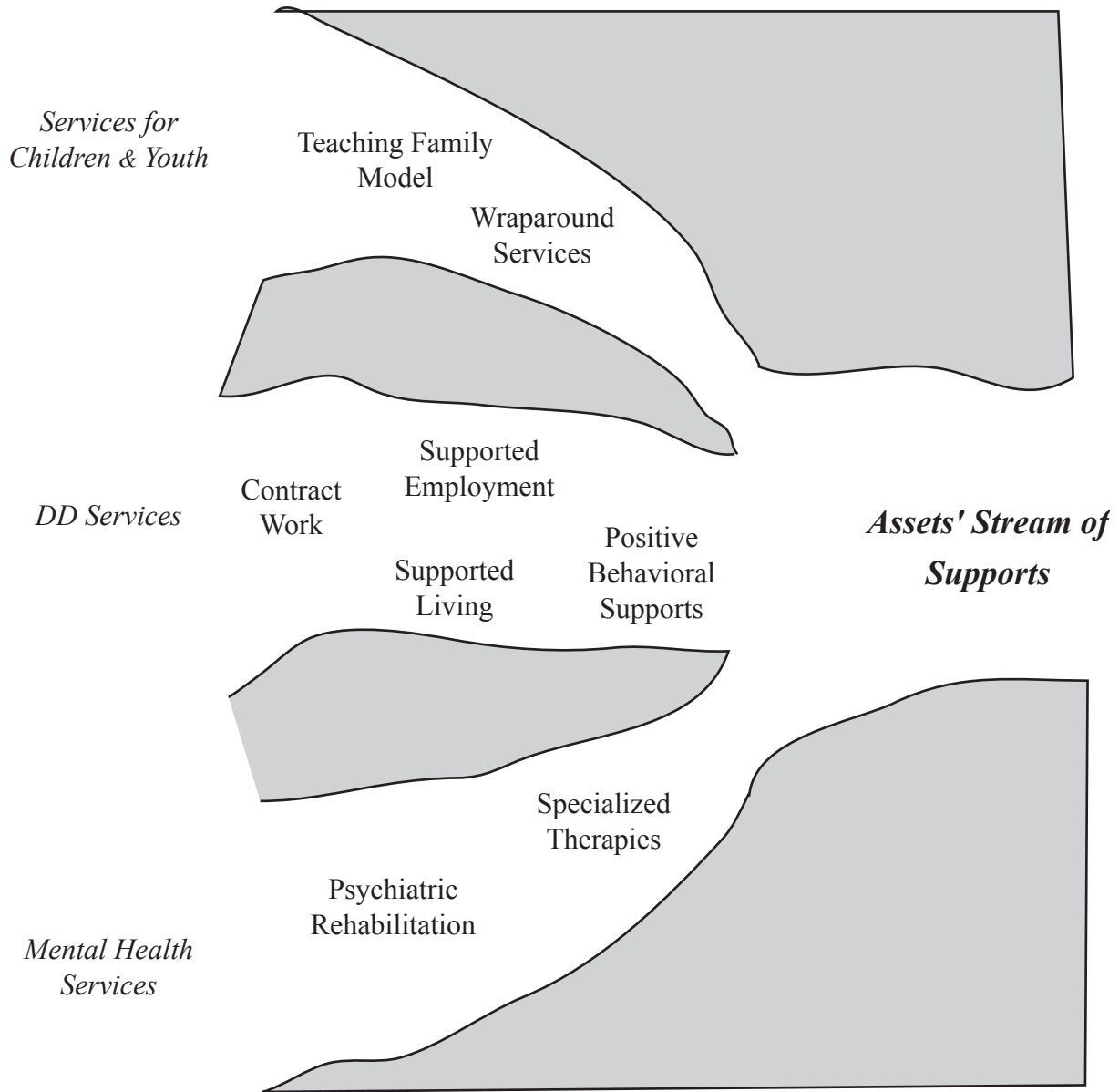
*Assets creates lessons about effective processes, not replicable programs*

Does Assets' experience suggest that an agency in another place needs congregate living and working sites in order to support people who are seen as "too difficult"? The incremental growth of Assets' engagement with challenging people over 20 years makes any answer to this question speculative. Assets has grown its capacity by committing whatever resources it has available to assist individual people to realize lives that reflect its mission and beliefs. What others can learn from their efforts is not in the form of a replicable program design. It is in the form of a learnable set of processes for offering opportunities, building relationships, and individualizing supports (for more on the idea of developing, evaluating, and transferring effective processes, see Anthony, Rogers, & Farkas, 2003).



Assets has been shaped by the interaction of its own beliefs and capacities with the emerging hopes and dreams of the people it supports and the demands of an evolving service system. Assets' efforts on behalf of people who have lived much of their adult life in psychiatric facilities were not, from Assets point of view, an exercise in adding a new program. From the point of view of participants, the project was an opportunity to live outside the institution, which initially may have seemed like a move into the unknown. From Assets' point of view it was a question of how to include eight new people, each with their individual hopes and dreams and challenges, into its ongoing search for effective ways to support people. From the point of view of the direct support workers involved, it was a matter of creating a positive relationship with the person who had helped select them as an assistant and finding ways to assist them to be secure at home and productive at work. From the service system's point of view, Assets was part of a project with a definite identity and location. The title of the state's evaluation study makes this clear: *Assets Enhanced Extended Care Services Katmai Project* (Alaska Comprehensive and Specialized Evaluation Services, 2003).

There are potential tensions in this interaction. People were selected by the state, based on their pattern of hospital use. Their increased opportunity to exercise choice began with their engagement with Assets. Until people found their feet in their new homes and got to know staff, they had to depend on hospital staff judgements about what was necessary for their safety and what meaningful goals for them might be. Change in state priorities or policies could affect Assets' ability to provide the type and intensity of support people need to keep developing. However, these different perspectives can be reconciled. The evaluation shows that the state is getting what it wants from the project. Direct support staff report satisfaction at helping people navigate their individual difficulties at making the move to community living despite some hard times and continuing challenges. Assets has begun to realize its mission for eight more people and strengthened its capacity to make a distinctive contribution to Alaska's human service system. Overall, the people involved report growing satisfaction with their new lives, despite the persistence of some troubling symptoms and periodic crises.



## Providing Individualized Supports

Designers of some programs for people seen as difficult to serve begin their task by adopting a clinical technology that they believe will control the target group's difficult behavior or eliminate troubling symptoms. For example, programs have been designed around applied behavior analysis, or skill training based on social learning theory, or particular drug regimens or focused psychotherapies. The choice of technology sets criteria for admission and discharge, defines the sort of staff necessary, and strongly influences the program's schedule and physical environment.

**“As far as clinical approaches go, we are masters of eclecticism.”**

To these program planners who start with technology, Assets might look like it was designed upside down. Rather than begin with a specific technology aimed at remediating what is deficient in a person, Assets begins by offering people opportunities and situation specific assistance to establish a home of their own and to go to work. Instead of admitting people into a specialized environment for a time limited course of treatment, Assets offers people long term relationships and flexible individualized supports aimed at assisting them to join and play an increasingly active part in Anchorage's communities. Instead of selecting staff based on the technology they are already qualified by their professional training to administer, Assets hires staff based on their willingness to build relationships and learn new ways to support people.

### *Many approaches inform Assets' individual supports*

The diagram on the facing page uses the metaphor of a stream and its tributaries to suggest the approaches that shape the individualized supports that Assets offers. Each of the approaches that feed this stream have come from Assets' search for effective ways to implement its mission. The confluence of these ways of understanding people, teaching skills, adapting environments to improve the chances of safety and success, and assisting people to increase self-control gives Assets a growing repertoire of ways to tailor supports to an increasing variety of individual circumstances.

Assets values clinical interventions. Indeed, over the years senior staff have invested substantially in learning new approaches that have a chance to decrease the particular barriers people experience to their enjoyment of community life. They have developed strong connections with local universities through joint projects and graduate study. They have sought

training and case consultation from national experts in specific disabilities. They have applied what they have learned by incorporating a variety of clinical approaches into people's individualized supports, either through changes to people's routines and environments or by arranging or offering individual or group therapies. As one senior staff member puts it, "As far as clinical approaches go, we are masters of eclecticism."

Some decisions about clinical interventions can be made as Assets begins to work for a person. Assets' psychiatrist will decide to continue or modify a person's current medications. Participation in the university based clinical program for people with inappropriate sexual behavior may be a condition of a person's probation. Other decisions come later, when the effects of access to opportunities and positive relationships with staff allow a somewhat better understanding of who the person is and what works in assisting them. Sometimes Assets' repertoire already includes an effective response or a response that can be adapted to meet a new need. Sometimes staff will have to search for new approaches.

*Assets' pattern for learning new ways to offer individual support*

The development of Assets' capacity to support people with inappropriate sexual behaviors provides an example of the organization's learning process. It begins with a commitment to specific people who are excluded from their right to community life by a poor fit between their situation and available supports, as Karen Ward and her colleagues (1992) describe:

*...In 1985, a group home resident exhibited inappropriate sexual behavior toward children, or pedophilia. Continued residence in the group home exposed the staff's small children who were living in the home, other residents, and the community to an unacceptable risk, since the home was located near an elementary school.*

*At that time, because existing support service agencies for people with developmental disabilities were unprepared to manage inappropriate sexual behavior, the community offered no alternative living arrangement. The individual was placed at Alaska Psychiatric Institute (API), a state psychiatric hospital. While API offered sex offender treatment, their program made no provision for people with developmental disabilities. Yet, by law, people cannot be committed to psychiatric institutions*

*indefinitely, without a treatment plan for improvement. The solution to this paradox arose from a change in ASETS [the agency's name in 1992] philosophy of residential service delivery... (pp. 3-4).*

This commitment to creating an opportunity –initially by implementing stringent environmental controls and very close monitoring within Assets’ supported living and employment for the person whose “too difficult” status caused his confinement without treatment– led staff to a more extensive search for knowledge and skill. As Assets’ capacity grew, the service system and the courts acquired alternative ways to assess risk and respond. In 1995 the Center for Human Development (UAP) at the University of Alaska Anchorage assumed responsibility for delivering clinical services to people with inappropriate sexual behavior. (For a description of some of these services, see Ward, et al, 1992) Available to the whole community, their service now includes about 25 people that Assets supports.

Experience with people whose sexual behavior made them ‘too difficult’ validated and extended lessons staff were already learning from people whose violent behavior led other agencies to refuse to serve them.

- It’s important not to let one threatening aspect of a person’s life overwhelm the person’s whole identity. Staff must be able to see a whole person with both the potential for dangerous behavior and the capacity for a productive life.
- Taking responsibility for making careful judgments about risk is a necessary part of supporting community life for people whose behavior threatens and repels others. Sexually inappropriate behavior that results from lack of information or lack of opportunities for appropriate sexual expression poses less threat than sexual arousal by children or by committing violent acts does. It is not enough for professional staff to know such things. They must also commit themselves, and their organization, to judgments that carry liability for the safety of others. That final decisions may be made by judges or authorities responsible for hospital discharge does not reduce this responsibility. Unwillingness to accept this responsibility (and the concurrent responsibility to seek consultation if necessary) leaves a person’s future in the hands of whatever authority is willing to make a judgment.

- Prevention is essential and can be effective. To reduce the likelihood of hurting others, some people have to live with stringent controls that restrict some of their possessions, activities, and movements. These restraints need not take away the possibility of a person having a home and work life and pursuing some of his hopes and dreams as long as restrictions are consistently and rigorously enforced by staff who want to assist him to have a community life that makes sense.
- One limit to Assets' willingness to include people is this: Assets will not agree to imposed conditions that are so restrictive that they would be replicating a prison or a locked psychiatric ward in an apartment.
- Positive change is possible. Most if not all of the treatments that are effective with other people are also effective, or can be effectively adapted, for people with intellectual disabilities. People who display inappropriate sexual behavior have as much potential to respond to positive relationships with staff, opportunities to have their own home and a job, and effective clinical interventions as any other person does. Despite the possibility of positive change, some people require continuing assistance to control inappropriate arousal. Community safety and quality of life can improve even when some clinical conditions endure.

Assets' pattern for learning new ways to understand and assist people to deal effectively with behaviors and emotions that interfere with their pursuing a satisfying life can be summarized like this. First, **learn from** each person who they are, how best to communicate with them, and what matters to them. Then, **learn for** the person which clinical interventions offer the best chance of improving the quality of their life. This pattern for learning continues to increase Assets' repertoire of individualized supports.

#### *Triggers for learning*

Realization that staff are drifting from the kind of positive relationships that are fundamental to Assets' way of serving people frequently triggers new learning among staff. Signals of this drift include: losing sight of the whole person and focusing exclusively on the person's negatives; not making time for conversation about a person's hopes and dreams; not following-through in assisting the person to take positive steps forward; not being able to imagine a more hopeful future for the person; avoiding the person; feeling victimized or manipulated by the person; repeating

person-blaming explanations for poor outcomes; wanting the person to be punished; feeling unable to make any positive difference in the person's life; not being able to have productive problem-solving discussions with the team, with the person, with family members. A great strength of Assets' leaders is their ability to notice signs that staff are drifting into a trap and redirecting attention toward more positive possibilities.

Some people experience very frequent crises, impulsiveness that can include harming themselves or dramatically threatening to harm themselves, intense and uncontrollable emotions of anger and anxiety, very high sensitivity to abandonment, and great difficulty in forming and keeping stable and satisfying relationships. Life feels empty. Staff who get involved can feel a strong pull toward feelings of helplessness, victimization, anger, personal dislike and pessimism, if not in themselves then in others who deal with the person. When the person also shows signs of a disturbed sense of identity and dissociation and paranoid ideas when under stress, a diagnosis of "borderline personality disorder" summarizes these barriers to a meaningful community life. Dialectical Behavior Therapy (Linehan, 1993 and The Mental Health Center of Greater Manchester, 1998) gives Assets' staff both a hopeful and practical understanding of what the person struggles with and systematic ways to help the person learn to exert more effective self-control of their behavior, experience their emotions with less disruption, discover ordinary happiness, and find a measure of joy in living.

Awareness that a number of people have been victims of abuse or neglect and the possible effects that this can have has led staff to learning how to apply interventions that have proven effective in the treatment of post-traumatic stress disorders. For example, staff are developing their skills in applying EMDR (Eye Movement Desensitization and Reprocessing) (Maxfield, 1999) under the supervision of a local psychologist.

Persistent breakdowns in relationships between Assets' staff, a person, and the person's family and friends combined with a sense that more would be possible for the person if staff had more and better approaches to assisting people recovering from traumatic brain injury led Assets to seek an assessment and continuing consultation from an out of state specialist center. The success of this learning journey has led to further exploration of the fast growing field of applying neurological imaging techniques to

the design of accommodations and interventions.

### **Supporting Positive Relationships**

One of Assets' senior staff has a gift for telling teaching stories. Here are three brief stories that capture some of the qualities Assets prizes in staff.

*Our job isn't to grant people's wishes. It's to take a person's hopes and dreams seriously, however far away we may think they are. That means doing a lot of the kind of listening that is more likely to happen over coffee at Burger King than in an official meeting room. It also means helping the person identify some real step they can take that will move them at least a little bit closer to where they want to go.*

*S told us he wanted a driver's license. Over the years, he took the drivers test 77 times and failed it 76 times. In fact it took almost five months for him to get the process started because it took trying a lot of different strategies to help him overcome his social anxiety enough to go into the driver's license office and get one of the instruction books and an application for a learners permit. We worked on lots of things besides driving, but as long as he wanted to keep working on a license, we were right there with him.*

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*It can take people a very long time to get control of their violence. And some people never completely achieve complete control, even after things have calmed down a lot in their lives and good things happen almost every day.*

*R loved to fish. I like to fish too. And I enjoyed fishing with him. Sometimes things would get difficult and we'd get re-acquainted with the old R. He'd trash his place and work on beating me up. Then he'd get back in control and we'd clean up his place and go fishing together.*

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*A got in trouble for sexually inappropriate behavior. For him it was mostly about not having an appropriate partner. He decided he really wanted a girlfriend near his own age. We heard that. And we worked with him, starting with the idea that he'd have a better chance of getting a date if he didn't smell so bad and*

*if he practiced starting his conversations with something other than crude suggestions. He put in a lot of practice and had some success in creating a social life for himself. You can't let somebody fail just because they lack information. Sometimes what you need is the courage to tackle what's right in front of your nose. If you're not trying to punish people or put them down, they'll usually take honesty pretty well.*

*The qualities of positive relationships*

**Staff move toward people that others move away from**

These stories communicate more than four important lessons about the positive relationships on which Assets builds its supports. First, staff go toward people that service workers in other agencies move away from. Second, staff work to discover what a person finds meaningful, what gives them a sense of mastery and satisfaction, what seems to them worth working toward getting. They expect people to have interests, hopes and dreams that are similar to their own: the freedom to drive; the enjoyment of fishing; the desire for friendship and intimacy that doesn't hurt. Third, staff are willing to help the person identify ways to take at least one concrete step in the direction of their dreams. If need be, they help the person rehearse or accompany the person as they take that step. They tell the person honestly about changes they will need to make to realize their dreams, in terms the person can understand. They find ways to make the way smoother without taking over the work the person needs to do to maintain their dream as their own. Fourth, staff have the courage and skill to be present to the violence or pain a person struggles with. They try to find ways to prevent violence; and if they cannot, they look for ways to protect the person from having to live with doing harm. They can avoid or deal with being hurt themselves. Their sense of a person's dignity and identity is not overwhelmed by the person's behavior. They have honest ways to reconcile with the person.

These enumerated lessons are far less powerful than the stories are. In part, this is because the stories send a crucial message in their form: each story is about a particular relationship with a specific person. Generalization can lead to missing this vital point. The storyteller did not go fishing with R after R trashed his home out of ignorance of the principles and practice of applied behavior analysis. The storyteller understands applied behavior analysis well and finds it a sometimes helpful perspective. The storyteller suggests catching fish in the context

of a long relationship with R, as a good thing for them to do together after they repair the damage to R's place.

*There are people who want to do the work*

**“If a staff person stays long enough to play a part in one positive story in the life of a person they support, we have a good chance of keeping them”**

It is not possible to provide the kind of support Assets has found effective and work at the distance from people with disabilities that is comfortable for many mental health professionals. This is both a source of dilemmas and source of great satisfaction.

Working at Assets demands a lot from staff. People who have lived in the trap created by the interaction of substantial disability with poorly fitting services can be difficult to get to know, may set difficult tests for people they begin to trust, and may continue to experience difficulties for a long time. There can be some risk of physical danger. A lot is at stake: some people can hurt themselves or other people, even with good support. Real positive change is very likely, but can come slowly and crisis may frequently interrupt progress. Because Assets individualizes supports, and because individual needs can change, it can be hard to learn the job by supporting one person and then smoothly transfer to work with another person. There are persistent demands to learn more, not only about new ways to think about people and new ways to do things but also to learn more about oneself. People need to enjoy accepting responsibility for figuring things out, often finding their way with a team through a process of trial and error. Someone who wants a well defined job, with clear boundaries, and predictable workdays would not find working with many of the people that Assets supports very satisfactory.

One of Assets' most important discoveries is that there are support workers whose diverse gifts match the diverse requirements of the jobs people need done. (One manager, made cautious by the time it can take to recruit suitable staff, says there are “almost enough” suitable people who want to work for Assets.) Staff discover meaning in their relationships and satisfaction in helping people claim their rightful place at home, at work, and in the community. Despite the availability of meaningful work, recruitment is a continuing issue, made more difficult by relatively low pay. However, many staff find the work rewarding enough to recommend Assets to their friends and referral from other staff is the single biggest source of new employees.

Assets invests in being a good employer, with high expectations, fair treatment, opportunities for promotion, a number of chances to participate in decision making, and a good work environment. Staff are not left alone without support. Teams, supervisors, and more experienced and skilled staff are available to help make sense of puzzling situations and share in problem solving. There are many opportunities for training. All of this helps to attract and retain good employees.

As important as good working conditions are, Assets has another advantage in retaining staff with a gift for the work. The people Assets supports are effective at recruiting staff into their lives. At root, what is required from staff is openness to the humanity they share with the people they assist. One senior staff member says this:

*Staff need to be willing to identify with the people they support.*

*This means that they recognize three things:*

- *The people we support want the same kinds of things and have the same kinds of hopes and dreams that we have for ourselves and the people we love and care about in our own lives.*
- *The people we support deserve a secure home and a job as much as we do.*
- *The people we support should not be blamed for their disabilities.*

Another senior staff member observes:

*We offer people the chance to work with integrity and make a real difference in the lives of people who have not had many of the advantages that come with people believing in them and supporting them. If a staff person stays long enough to play a part in one positive story in the life of a person they support, we have a good chance of keeping them.*

In addition to rewarding, if demanding, relationships with the people assets supports, relationships with co-workers are an important source of job satisfaction. The opportunity to play a part in a team with responsibility for identifying and making progress on genuinely difficult problems offers many rewards. But sometimes teams can compromise these satisfactions by trying to avoid responsibility for difficult decisions. Because people's safety is often on the line, teams can give away the chance for learning by delegating decisions up to more senior staff. This upward delegation is different from asking other people to join in the

## **Core Values**

### **TREAT EACH PERSON WITH DIGNITY AND RESPECT.**

This means: seeking first to understand the other person. Practicing active listening. Avoiding labels. Bringing out the best in each person. Making courtesies and kindness a part of all interactions. Practicing loyalty to those who are absent. Withholding criticism until you have “walked in the shoes” of the other person. Affirming each person’s unique talents, interests and values.

### **MAKE A DIFFERENCE IN THE LIVES OF INDIVIDUALS WITH DISABILITIES.**

This means: empowering, involving, encouraging, supporting, inspiring, recognizing each person. Being determined to make a positive impact on each person. Thoughtfully planning your actions. Thinking and communicating inclusion. Readily extending trust. Being partners. Managing risks. Increasing knowledge about possibilities and alternatives. Believing in each person. Providing assistance with integrity.

### **CONTINUALLY IMPROVE – FOREVER.**

This means: always looking for ways to do better, be more efficient, be more effective, to make an even bigger difference. Honoring the creative process. Have a high tolerance for ambiguity. Being incessantly curious about the way things work. Encourage learning, diverse opinions and open disagreement. Actively work to decrease fear and anxiety. Be a learner. Share what you learn.

### **ADAPT, OVERCOME, IMPROVISE.**

This means: finding a way when it doesn’t seem possible. Practicing creative and patient persistence. Doing what it takes. Being smarter. Working smarter. Being a responsible risk taker. Creating an atmosphere that encourages risk and innovation. Having a sense of humor. Not taking yourself too seriously.

This Is the Assets Way!

problem solving effort or help a team get untangled from a process snarl that is holding up progress. It is also different from a team informing their supervisor of a decision and asking “Is there anything your experience tells you we should be thinking about before we implement this?” Upward delegation results in the team sitting back relieved, waiting to see what “they” are going to decide. This has at least four bad consequences: it moves decision making about important issues farther away from the person; it deprives the team and its members of the most important educational experience available to them; it reduces staff ownership of their work; and, it overloads the senior staff who accept the delegation. The art of senior management at Assets involves staying in close touch with each team’s work and offering support for high quality problem-solving while avoiding upward delegation of responsibility.

### **Managing for Positive Relationships and Individualized Supports**

Both good management and strong leadership are essential to Assets’ ability to support people who are difficult to serve. Good management assures the resources necessary to do the work. Efficient structures and processes meet the many requirements of being a good employer and satisfying the state agencies that purchase services in ways that allow staff to act flexibly in response to the people they support. Strong leadership engages the organization in the continual personal and organizational development necessary to keep Assets delivering on its mission.

The statement of Core Values on the facing page encourages leadership. It telegraphs the results of staff reflections on how Assets’ staff act when they are most effective. Core Values define expectations necessary for positive relationships and productive teamwork. They inform staff orientation and training and guide supervision. As staff practice these actions they strengthen a culture of service that can support people that other agencies see as too difficult to serve.

Assets’ ability to support people well depends on continuing to develop five organizational capacities:

- Get to know and respond to each person as a whole individual with the right to a community life that makes sense rather than focusing on diagnostic labels
- Offer each person the same basic opportunities for a home, a job, and access to community life rather than treating people differently based on the source of their funding or their primary disability

- Expect all staff to form positive relationships based on people's hopes and dreams and competencies and sticking with people through bad times rather than understanding their role as treating symptoms or providing supervision and control
- Be inventive and flexible in individualizing supports rather than offering standardized services
- Keep looking for new ways to improve the quality of people's lives at home, at work, and in community life

Assets' ability to develop these capacities depends on the talent and commitment of Assets staff. It also depends on Assets' ability to manage its relationships with a changing human service system. The three paragraphs below each identify potential changes in the system that could require substantial adaptation if they are implemented. The fact that by the time this report reaches readers these issues may have dissolved and been replaced with concerns now unforeseen makes the point: Assets' functions in a shifting service environment. Monitoring and working to influence potential changes in two systems demands time and energy from Assets' leadership.

Financial stability makes it possible for Assets to innovate. Negotiating adequate rates for services, generating income from Commercial Contracts, and close attention to financial management has kept Assets financially strong for most of its recent history. The pressures of a bad economy on the state, combined with rapidly rising costs for insurance could thin the surplus that Assets has been able to invest in innovation and staff training. Assets' budget could face increasing pressure from the Mental Health system's practice of paying significantly less for services it defines as providing supervision than it pays for services it defines as treatment. Because this distinction does not make sense in terms of the way Assets provides services to people who have not been successful in typical mental health services, it could erode Assets' ability to get adequate reimbursement for the services that people who need substantial support require.

Being able to treat each person as an individual distinguishes Assets' approach. Each person Assets serves is assigned their own cost center, so budgets are individualized. From the point of view of the staff who provide services, it doesn't matter what the source of their service funding is. People who receive intensive services are not grouped by funding

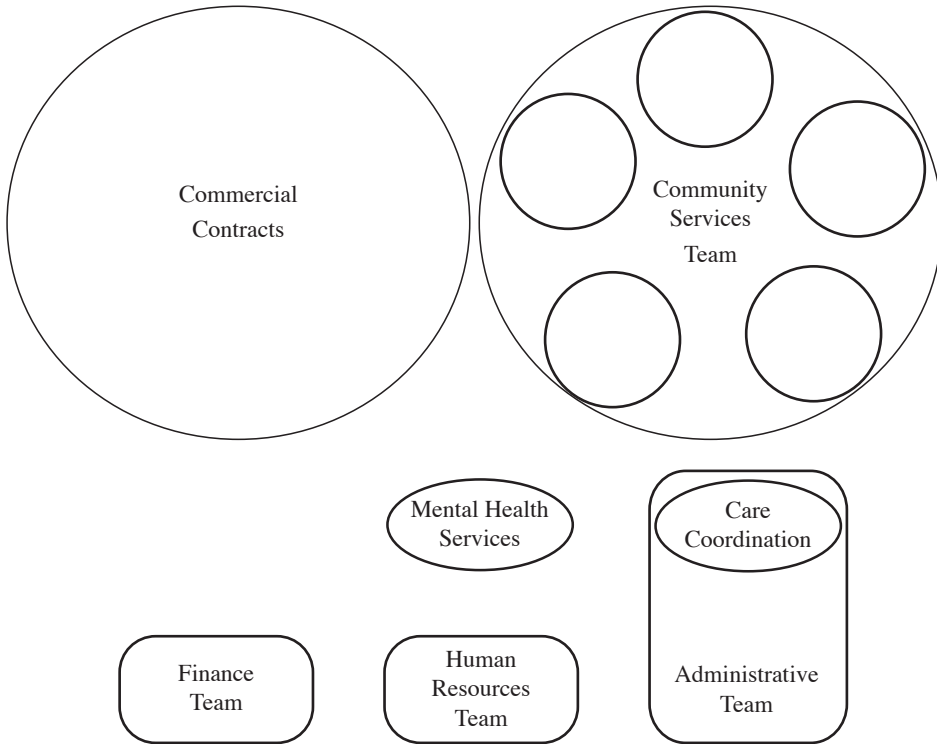
source. Whether a person's supports are funded by Developmental Disabilities or Mental Health dollars, staff keep the same records and follow the same plans. To make this work, records and plans are designed to conform to the requirements of both funding sources. Diverging requirements in both systems for planning, record keeping, and billing could make this unified approach increasingly difficult.

Keeping attention on improving quality of life encourages staff to hold high expectations for the people they support. Assets' Board has set an important strategic direction by directing the organization to grow by improving the quality of its services rather than seeking to substantially increase the quantity of people Assets serves. A rising trend among system administrators in several states favors managing costs by contracting with large lead agencies rather than a larger number of small and medium sized providers. If this trend becomes influential in Alaska it could reduce Asset's control over its own destiny.

Whatever adaptations Assets may need to make to stay on its course, its Mission and Beliefs point the direction and its Core Values identify the habits of action that make for resilience and creativity.

## Appendix: Assets' Organizational Structure

Assets structure is partially summarized in the diagram below. The Contracts Team is responsible for the work life of employees who provide high quality services to Assets customers among local businesses. The



Community Services Team provides supported living services to the people and families Assets assists in their own homes and supported employment services to people employed by local businesses. Mental Health Services provide consultation and training to staff teams, directly provide services to some individuals, and act as liaison to other community mental health service providers. Care Coordinators are responsible to people funded by HCB Waiver for service planning

and assisting in access to appropriate services. Care Coordinators are part of the Administrative Team, which also manages records and provides a representative payee for people who cannot manage their own social security payments. The Human Resources Team recruits, trains, and supports staff. The Finance Team includes quality assurance.

Supported living and supported employment services for people who receive 24-hour assistance are delivered by one of four community services teams, called after precious metals and stones (Bronze, Diamond, Emerald, and Platinum). Each of these teams assists about 26 people and includes seven or eight Assets' staff. Individual supports are provided by a combination of team members and Personal Support Assistants. As much as possible, people have control of who assists them. A fifth team (Onyx) serves 88 people who only receive supported employment services from Assets, many of whom are funded by DVR.

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