

Risks and Opportunities

from Patterns of Supported Living



Introduction

There are many dimensions which shape a *life of quality* for members of any community. When considering how to support people with developmental disabilities in living a life of quality we need to think about those elements which add quality to our own lives. For example, a local family doctor frequently gives lectures about how to live a balanced life. He suggests that the characteristics of the "best possible life" are: good health; reasonable wealth; family; peace; security; friends; time; and, growth. He feels so strongly about this advice that he lists these qualities on the back of his business card and hands them out to anyone who will listen. People with developmental disabilities want the *best possible life* as well and supported living services can help achieve that goal.

One quality of the best possible life that was not included on the doctor's list is having personal power over one's life. This is a characteristic of a good life that people with developmental disabilities have not often experienced. This denial of personal power combined with low status in the community creates a situation where people are at high risk for exploitation, abuse, neglect, and making risky choices. So, it's critical for supported living services to recognize and understand the vulnerability of people

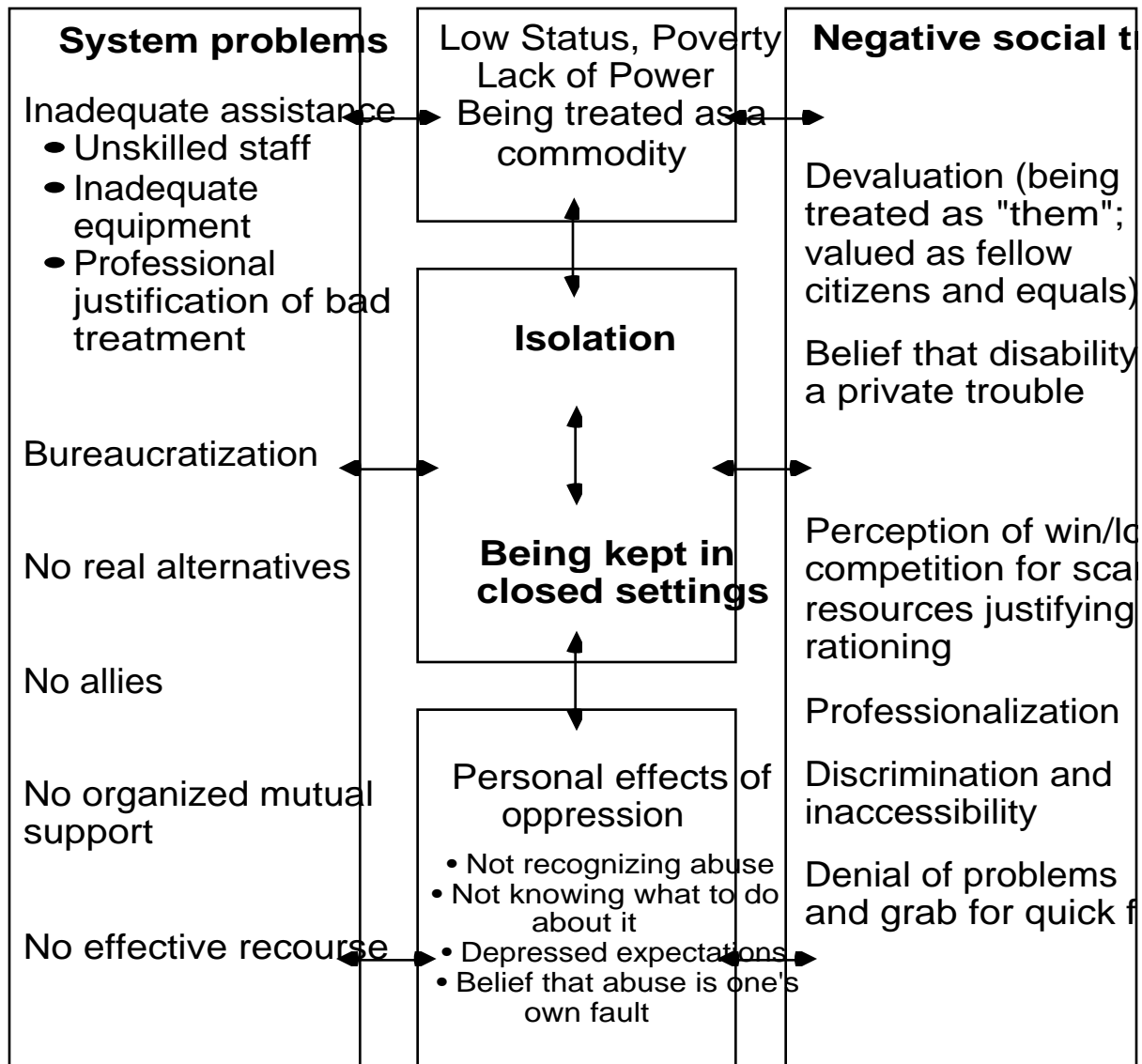
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and to spend time figuring out how to help people be safe in their homes and communities.

Understanding Vulnerability

The following diagram was developed by John O'Brien (1990) to visually display the sources of people's vulnerability. The low status given people with disabilities often

What Increases People's Vulnerability?



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puts them at risk within the community and the service system designed to protect them. People often accept living in abusive conditions because they don't feel they deserve a better life.

The Tension between Choice and Neglect

A major challenge in providing supported living services is walking the tightrope between supporting people to make their own choices and intervening to prevent choices that put people at risk. There are no answers here on where to place your next foot on the tightrope. Ultimately it must be the person with disabilities who makes the decision with support from friends, family, paid staff and community members.

Supported living is about making a serious commitment to stand by a person when life gets tough and there are hard decisions to make. It's also about power sharing and negotiation. Finally, it's as much about interdependence as it is about independence. John O'Brien advises that respecting choice can't mean avoiding a personal commitment when you're supporting someone who makes a decision that negatively affects them. At those times, you need to work on ways to form even stronger alliances with people.

Choice is not a reason for a person to live in an unsafe place.
Choice is not a reason for a person to live in filth
Choice is not a reason for a person to smell bad.
Choice is not a reason for a person to inflict self-harm.

John O'Brien, 1989

When California agencies started providing independent living services, many regional centers and ILS agencies placed a very high value on *independence*. Professionals prided themselves in not influencing people's decisions, and when someone made what seemed like a bad decision, people would say *people learn best from experience* or *natural consequences are the best teacher*, or they are experiencing the *dignity of risk*. While such values are an important part of any

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consideration about providing support to those who are learning how to make decisions for themselves, they are not enough. Far too often a person does not learn from natural consequences or does not feel dignified in making a bad decision.

Regulations for Protection

Our attempts at regulating health and safety have often resulted in patterns of relationships between people with disabilities and the people who support them which promote a dual status (the protectors and those who need to be protected) and power hierarchy. We need to be aware of this phenomenon when developing policies and regulations regarding supported living. While service accountability is important, it can also inhibit natural relationships and the creativity of developing support networks.

How One Agency Looks at Risky Decisions

Options in Community Living, Madison, Wisconsin, has been providing supported living services since 1974. One of the unique features about Options is their commitment to "stand by people over time." We provide you here (adapted with permission) questions that they ask themselves when considering additional support for people who are placing themselves *at risk*. Any of the Options staff can convene an At Risk Meeting whenever it is felt that someone they support is at risk in any quality of life areas (listed on the pages that follow) or there's a drastic change in lifestyle or there is feedback from community members or the person's family that indicate a concern for well-being, safety or health.

Considerations for Increased Staff Support

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in the Face of Risky Decisions

If someone is making decisions which are putting him/her at risk, the following considerations should be addressed at an *at risk* meeting to determine whether more staff support/intrusiveness is justified.

- A. *What is the person's history of decision making?*
 - previous experience or practice in exercising autonomy and rights
 - ability to learn from the natural consequences of poor decision making
- B. *What are the possible long and short term consequences associated with poor decision making? (What is the worst that could happen?)*
 - death
 - illness, injury
 - involvement with law
 - financial difficulties
 - exploitation
 - isolation, rejection by others
 - substandard living conditions
 - lack of enriching experiences
- C. *What are the possible long and short term consequences of increased direction and control by staff or system?*
 - decreased confidence or self esteem
 - likelihood of increased dependence on staff
 - improvement in person's quality of life
 - possibility of person refusing to work with Options. If this is likely, the following issues should be reviewed:
 1. Under current circumstances, how is the person benefiting from Options involvement?
 2. What would be the impact of Options terminating services if the client refuses our increased involvement?
 3. Does the client require protective measures to be taken, i. e. guardianship, protective placement, other?
- D. What are the trade offs of continuing the current situation?
- E. Existence of safeguards to protect person's rights
 - Is the person sufficiently assertive to advocate for his/her rights?
 - Is there the presence of an advocate, friend, or guardian to represent the person's interests? If not, should Options locate such a person?
- F. Should more control and direction be provided? If yes, list proposed support.

A Policy on Risk and Opportunity

Introduction. *Options* developed this policy on risk and opportunity and it has been used by many supported living programs throughout California. The California

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Department of Developmental Services even requires its use by agencies providing supportive living services through the CSLA program. This policy can be used to communicate to people with disabilities and their families, advocates and others the principles that guide supported living services. It also provides supportive living services with standards for evaluating a person's well-being and for identifying areas where more support may be needed.

The policy addresses nine major aspects of community living. Each area is divided into two sections: 1) a list of those conditions which must exist to ensure that people are not at risk in the community; and, 2) a list of further conditions that supported living programs can promote to help people achieve a valued lifestyle. Some people may need intensive and long-term support to maintain these standards.

Risk and Opportunity Policy

I. Autonomy/Choice

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
 1. The person has opportunities to make decisions and express preferences in all areas of life. The right to make these decisions shall be respected by others in the person's life (e.g. service providers, parents, roommates). The person also has the right to refuse interventions initiated by providers.
 2. The person has a method of expressing preferences and a method of acting upon these preferences in all areas of life. For example, a person who has a physical disability and is non-vocal might use a communication board to express preferences and have a personal care attendant to act on those preferences. Preferences can be expressed in non-verbal ways, such as by a change in behavior.
 3. The person has access to information and experiences that assist the person in making decisions about his/her life.
 4. The person has people in addition to service providers for support and information needed to make decisions about his/her life.

II. Personal Income

- A. Conditions that must exist to ensure that a person will not be at risk in the

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community:

1. The person has a stable source of income that covers basic living needs, including shelter, food, transportation, clothing.
2. There is effective management of this income to ensure that basic needs are met. (Support can be provided when needed through a double-signature bank account, representative payee, or assistance with budgeting.)

B. Conditions that will further promote a valued lifestyle:

1. There is sufficient income for items and activities that enrich one's life experience, such as vacations and other leisure activities, home decorations, and items that enhance one's personal appearance.
2. The person is able to participate as fully as possible in decision-making about the use of personal income through the development of money and budgeting concepts and values that encourage financial responsibility.
3. The person can maximize income through wise investments and purchases, and through subsidies for which the person is eligible.
4. The person has a means of earning income through employment as a supplement to or in place of government benefits.

III. Housing

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has housing that meets community building codes, is secure and has adequate heat, water and electricity.
2. The person has the basic furnishings necessary for daily living, including a bed, chairs, table and lighting.
3. The person lives in a neighborhood where s/he feels safe and where there is access to needed resources.

B. Conditions that will further promote a valued lifestyle:

1. The interior and exterior of the home is maintained in a safe, clean and attractive fashion.
2. The person is able to exercise control over the home environment, including the choice of location, personalized furnishings and decor, and control of temperature and lighting.

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3. The home furnishings are attractive and complete.
4. The person is able to have maximum influence over his/her housing situation through such means as participation in a tenant association, cooperative housing or home ownership.

IV. Physical and Mental Health

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
 1. The person's health is maintained through adequate nutrition, exercise, safe behavior, medical monitoring, and appropriate medications when needed.
 2. The person receives prompt and up-to-date treatment for physical and mental health problems.
 3. The person employs a personal care attendant if his/her physical disability limits the person's ability to provide self-care.
- B. Conditions that will further promote a valued lifestyle:
 1. The person has established relationships with and easy access to health care providers (e.g. physicians, nurses, dentists, counselors and therapists) that know the person and monitor his/her health needs on an on-going basis.
 2. The person's lifestyle encourages wellness. For example, the person eats nutritious meals on a regular schedule and maintains an appropriate weight; does not smoke; does not drink in excess or use drugs; has coping mechanisms to relieve stress; has people to provide emotional support.

V. Safety

Conditions that must exist to ensure that a person will not be at risk in the community:

1. Potential dangers in the person's environment are minimized. For example, his/her home is free of fire hazards and is locked and secure; the person does not walk alone on dark streets at night.
2. The person receives prompt and appropriate emergency services when needed, such as police, fire department, ambulance, crisis line.

VI. Appearance and Hygiene

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
 1. The person minimizes health related problems through adequate personal

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hygiene and clothing choices that are appropriate for weather conditions.

2. The person maintains acceptable hygiene and appearance so as not to restrict where s/he can live, work and socialize.

B. Conditions that will further promote a valued lifestyle:

1. The person has a choice of attractive clothing for different occasions.
2. The person maintains his/her hair in a manner that is becoming.
3. The person's hygiene and appearance serve to enhance self-esteem.

VII. Relating with Others

A. Conditions that must exist to ensure that a person will not be at risk in the community:

1. The person has the means to communicate on a daily basis with primary people in his/her life. (This may include speech, signing and adaptive devices.)
2. The person has support people, including Options staff, with whom s/he are able and willing to maintain contact.

B. Conditions that will further promote a valued lifestyle:

1. The person has the means of communicating in such a way that encourages interactions with other members of his/her support system and community (e.g., clarity, assertiveness, appropriate affect.)
2. The person has supportive relationships with family members that encourage independence.
3. The person has relationships with friends and peers which provide companionship, intimacy and support.
4. The person has the opportunity to responsibly engage in sexual relationships and marriage based on his/her personal beliefs and values.
5. The person's relationships include people who are non-disabled.

VIII. Meaningful Activities

A. Conditions that must exist to ensure that a person will not be at risk in the

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community:

1. The person has a daily routine that is designed around his/her needs and capabilities and that resembles as closely as possible a typical adult routine. Such a routine is likely to include vocational, domestic and leisure activities.
- B. Conditions that will further promote a valued lifestyle:
1. The person's activities provide opportunities for personal growth and increased life satisfaction.
 2. The person receives wages for work.
 3. The person takes part in culturally-valued leisure activities, such as parties, trips, concerts and shows.
 4. The person's activities take place in community settings that are integrated with non-disabled people.
 5. The person has the means of developing and achieving short-term and long-term goals (e.g. vocational planning, vacations, retirement).

IX. Mobility

- A. Conditions that must exist to ensure that a person will not be at risk in the community:
1. The person has the means to move about his/her home and community environments to the extent necessary to satisfy basic needs.
- B. Conditions that will further promote a valued lifestyle:
1. The person has physical access to a wide range of community resources for work, leisure, shopping, etc. Modes of transportation can include bus, car, bike, walking, vehicles equipped for wheelchairs.
 2. The person, when needed, has adaptive devices that will enhance mobility, such as canes, motorized wheelchair, three-wheel bike.

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Armistice

Written by Julie Nichols-Younes; reprinted with permission from *Options*.

For over a year now I've resisted a recurrent urge to write a story about Carol and her ongoing struggle with a mental illness and with defining Options' role in her life. I've often thought there was an important message in Carol's story, but I could never find a way to express it, probably because it was not yet complete. Looking back, it now seems as though Carol and I have come full circle, in many ways we are back to the place we started. Yet, in others, we are light years away.

The past two years of struggle and conflict could have looked to an outsider like a battle of wills to determine who would have ultimate control over Carol's life. I have to admit that in times of frustration and despair over Carol's situation, I often felt like Carol's adversary in a war of wills that I was destined to lose. But now it looks for all practical purposes like I have won. I have Carol's monthly benefit checks sent to me at the office. Options' staff are now co-signers on Carol's bank account. I accompany Carol to the grocery store every Monday, not for the purposes of training, but to be sure she buys what I consider to be nutritious food. Every Wednesday I meet Carol at her apartment to sign spending checks, contingent on her apartment first passing "inspection", and once a month I escort her to a psychiatrist's office to obtain a prolixin shot. Yes, the battle is over, but did I win? No, I don't think so. I don't think I was ever really a combatant in the war. Carol's struggle was really an internal one. Her need for independence and autonomy was battling it out with her need for structure and support from Options. Carol was unable to see that she could only have independence and "be her own boss" in her words with certain supports and assistance from us. The more control that Options relinquished, the more out of control Carol became.

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She went for months without bathing. I'm sure many of you remember the lingering olfactory evidence of Carol's visits to the office during those times. She rarely changed or washed her clothes, appearing in the same menstrual bloodstained outfit week after week. Her diet consisted primarily of Oreos, Coke, and M&Ms since she preferred to spend her grocery money on dolls and toys rather than food. She was noticeably losing weight. Carol never cleaned her apartment or took out the garbage, letting garbage and spills pile up on the living room and kitchen floors. For some reason she preferred living with the stench of her own feces rather than simply flushing the toilet. She broke every agreement and promise she made with Options' staff to change her ways, insisting she didn't need our support. Usually she managed to avoid us by running away or locking us out. She begged us to let her be her own boss and to terminate her from Options. This was not, however, the quality of life of a person in control of her own life, yet for many months I resisted making a drastic move. What about autonomy and choice, what about Carol's wishes? She seemed so tormented by our involvement in her life. Finally, in spite of my guilt, I took possession of Carol's benefit checks and backed her into a corner. She very quickly and quietly went along with the rest of my demands.

Strangely, Carol seems very at ease and comfortable with our new arrangement. She has not uttered a single word of protest or dissatisfaction with my renewed involvement in her life. In fact, she seems more at peace with herself and her life than I've seen in several years. It's as if she is relieved that someone finally rescued her from the chaos that her life had become and that she was helpless to change. The guilt I feel now is for failing to end her misery sooner by working out a truce in Carol's private war.