

Emerging Safeguarding and Advocacy Issues Related to Self-Direction/Self-Determination

Listed below are a number of points that emerged from discussions at the study session hosted by OPA on June 9, 2005. I have attempted to organize them under several broad topic headings, and to identify particular issues we need to learn more about. As always, we welcome thoughts and suggestions. - Jim McGaughey, OPA Executive Director

Understanding the Nature and Potential of Self-Direction:

- Self-Direction (Self-Determination) is sometimes discussed as if it were a totally new, all-or-nothing alternative model for personal support - one that represents a complete and still somewhat unproven departure from traditional human service programs. It might be more useful, however, to see the concept not as a radically new alternative human services model, but rather as a still-evolving mechanism that seeks to improve the fit between responsible administration of public resources and the needs, goals and potential contributions of individuals who need assistance. But self-direction is more than an evolving administrative mechanism. It also implies, and, in fact requires that our understanding of the social and cultural realities confronting people with disabilities, and our ability to respectfully listen to and work with individuals and families must also evolve. Because human beings have different visions, interests, connections, cultural identities, skills, needs, and life experiences, and because peoples' situations are subject to change over time, fulfilling the promise of self-direction/self-determination requires both flexible administrative mechanisms and a deeper level of understanding and commitment from advocates, administrators, providers and policymakers than previous progressive endeavors. The more clearly these realities are articulated and understood, the more likely they will be well implemented and supported. *We need to learn more about the range of administrative mechanisms, formal and informal structures, and practical options for implementation that might be useful to people in a variety of circumstances. We also need to keep thinking and learning about what works and helps, and, when something falls short of expectations, we need to try to understand why.*
- Although the liberating potential of self-directed supports holds wide appeal, for some people, the boundary separating "self-determination-land" from more traditional forms of service delivery looms as a worrisome discontinuity. This may be especially true for people who have been receiving supports through more typical provider arrangements, and who have not experienced opportunities to practice autonomy and make informed choices. For many people, the prospect of moving to a situation where one is pretty much on his or her own provokes understandable anxiety, especially when there is no clear alternative path to safety if things fall apart. *As we learn more about structuring, managing and safeguarding self-directed support systems, we also need to learn about how to help people acquire the competencies needed to utilize self-directed supports. Part of this involves respecting the experiences of participants; much also depends on finding ways that people can understand and connect to authentic sources of security in*

their lives. We also need to develop strategies that allow sensible transitioning between traditional service forms and self-directed ones.

- As the concept of self-directed supports gains currency in Connecticut, funders, regulators, policy makers, advocates, providers and prospective participants can learn a great deal from people who have been attempting to implement self-directed strategies both in Connecticut and elsewhere. People “on the ground” can most reliably report on the impact of particular policies and practices, and can often suggest improvements. Listening to the experience of people engaged in similar efforts in other locations can also help avoid pitfalls and spur innovation. Careful listening, and really hearing what people are saying is also essential for assisting with individual supports. It takes time to develop trusting relationships and responsive systems, but listening is where it all starts. *Structuring periodic opportunities for planners to listen to participants, to invite and listen to innovative thinkers, and to sponsor critical assessments of overall progress will stimulate thinking and increase the likelihood that systems will evolve in positive directions. We should encourage training and administrative practices that stress the value of listening, both as an important skill and as an index of the respect that ought to underlie all support efforts.*
- Peoples’ needs may change or be more fully revealed over time, sometimes even over relatively short periods of time. Systems for planning, monitoring and funding should be alert to changing individual needs, and be flexible enough to allow timely responses. *We need to learn more about how to reconcile changes in an individual’s needs with system-wide planning and resource reallocation processes.*
- Notwithstanding the increased personal freedom and autonomy inherent in self-directed supports, individual growth and satisfaction may still be constrained by underlying social and economic realities such as limited availability of public transportation, poverty, underemployment, high costs for housing, pervasive abuse of substances, living patterns that stress independence but contribute to social isolation, and fragmentation in health care delivery. It is important to recognize these infrastructure limitations in order to keep individual and systems planning grounded in reality, and to develop collective strategies to address them. Indeed, as greater reliance is placed on generic community systems, human service agencies need to devote increased attention and resources to ensuring that those community services are accessible and relevant to the particular people who they are charged with supporting. This may mean developing “bridges” with community organizations, ensuring effective outreach, sharing clinical competencies and fulfilling other consulting roles. *We need to find ways to systematically capture information about the social and economic realities that limit opportunities for participation and contribution, and include that information in service planning and advocacy strategies. Service systems should see their roles as both empowering individuals to pursue their goals, and assisting communities to competently include those individuals.*

Maximizing Positive Outcomes While Addressing Foreseeable Risks

- Self-directed supports directly expose participants to both opportunities and risks, including risks to health, safety and general welfare that have hitherto been filtered and managed by systems with established norms. It is axiomatic that such risks cannot be entirely eliminated: bad things can and sometimes do happen even in well conceived and responsibly operated conventional services. However this reality justifies neither indifference nor over-reaction. Rather, it requires the exercise of informed judgment, prudent planning, and much more extensive dialogue and consensus-building regarding how risks are to be balanced with principles of respect for personal autonomy, choice, and privacy. *To protect the promise of self-directed supports, we need to pursue this dialogue pro-actively, rather than waiting to respond defensively to criticism. We should try to avoid “policy making by headlines”, working instead to increase the sophistication with which we exercise judgment in response to the dilemmas self-direction presents. It is particularly important to include consumer constituencies in discussions about those dilemmas, as the risks that actually concern them may be different from those assumed.*
- Although respect for individual choices and goals is an essential value, uncritically accepting low expectations or marginal situations in the name of choice forfeits potentially fulfilling opportunities and contributes to vulnerability. This can occur when choices are attributed to a person based on superficial perceptions of his or her motivations and interests. (E.G. “He really likes to eat cookies and lie on the couch watching TV. It is his choice not to do anything else...”) “Individual” planning processes can also contribute to this misunderstanding. While dutifully nodding in the direction of “vision”, “goals” and “personal preferences”, when the person they focus on is seen primarily in terms of his or her present circumstances, these planning processes can become blueprints for more of the same. However, genuine efforts to affirmatively promote positive long term vision can enhance a person’s potential for belonging, contribution, personal growth, meaningful relationships, health, self-respect and respect from others, all the while diminishing vulnerability and the potential for victimization. *We need to learn more about helping people to think “outside of the box”, and about the connection between positive vision, proactive planning and personal security. This will prove as challenging for individuals with disabilities and families as for human service veterans; we have all been habituated to think of possibilities in terms of typical “client” roles.*
- While most of the energy and resources tied to self-directed supports should go toward maximizing positive outcomes, some energy and resources need to be directed toward minimizing the likelihood of negative ones. This is not to say there is an inherent dichotomy between implementation strategies that move toward empowering, fulfilling directions and those concerned with limiting risk and providing for interventions and safety nets. Indeed, the two would seem to work best when seen as integral parts of the same whole. Reasonable strategies to reduce or address individual vulnerability to harm might include: 1) consumer education about personal safety, rights and when and how to

access remedial mechanisms; 2) conscious cultivation of relationships with trustworthy individuals; 3) formation of small, local, consumer-controlled collectives to enhance mutual welfare, manage personnel transactions, and provide for pooled back-up supports. Systems-level strategies for screening, recruiting, training and retaining responsible support staff should also prove useful. Some back-up “failsafe” planning might also be done at both the individual and the systems level to ensure that sudden loss of allocated resources or key supports does not result in collapse of a person’s situation. *We need learn more about these (and other) ideas.*

Retooling Connecticut’s investigation, protective services and advocacy mechanisms

- Connecticut’s current mechanisms for investigating and addressing abuse and neglect of persons with disabilities were established at a time when service systems were characterized largely by institutional and structured, regulated community residential programs. In fact, Connecticut is one of the few states in the U.S. that has no agency or official program charged with responsibility for investigating and initiating protective interventions for all adults with disabilities. (In Connecticut, only allegations concerning children, elders, people living in long term care facilities and adults with mental retardation are subject to investigation and protective remediation). Amongst currently existing investigation/protective services programs, the primary focus is on protecting against intentional physical harm, inhumane treatment and significant carelessness. Human service workers are mandated to report suspected abuse and neglect and to cooperate in investigations. Unlike these workers, however, neighbors, family members, acquaintances, and other individuals hired directly by people with disabilities may be under no legally enforceable obligation to report suspected abuse or neglect or to cooperate with abuse/neglect investigations. Similarly, requirements for frequent documentation of events, clinical evaluations and interdisciplinary team decision making disappear or significantly diminish in self-directed scenarios. While contributing to the liberating potential of self-determination, the diminishing availability of these traditional accountability mechanisms implies a need to develop new ways of triggering inquiries into suspected problems and of eliciting useful information in response to particular concerns. In addition, although situations involving financial exploitation have surfaced in traditional programs, the transfer of both resources and increased spending authority to individual, self-directing service recipients invites considerably more of this activity. *While arguably relevant to the circumstances of a quarter century ago, the definitions, reporting requirements, fact-finding authority and remedial schemes established in current law may well need to be retooled as service systems transform their roles and expand their investments in self-directed support approaches. Investigation and protective intervention programs need to be re-examined to ensure that they will be: 1) responsive to the emerging needs of people and families who are directing their own supports, perhaps placing greater emphasis on problems of exploitation and intimidation/manipulation; 2) discerning about and respectful of individual judgments; 3) competent to operate in community contexts (not just community-based human service environments); and, 4) conscious of the need for long-term, respectful resolutions for problems, as opposed to being focused on ameliorating immediate crises.*

- Proponents of the view that personal advocacy functions to “get (or force) the system to do its job” will need to re-think their approach: As self-direction expands, many tasks traditionally seen as “the job” of service systems will devolve to consumers, families, and, perhaps, small, informal collective organizations. To an increasing degree both the opportunities and frustrations people encounter will arise within local communities. While individual advocacy will no doubt continue to operate as a significant safeguard, it is foreseeable that finding solutions to particular problems will necessarily involve orchestrating or participating in multi-party negotiations, will require considerable creativity and call for different skill-sets, bases of knowledge and networks than has historically been the case. *Programs that train and support individuals engaged in personal advocacy (e.g. parents, peer advocates, para-professional advocates, etc.) will need to re-examine curricula, mechanisms for consultative support, and fundamental assumptions and paradigms.*
- Peer advocacy can be an important way to disseminate information, answer questions and assist prospective participants with the development of individual supports. Service systems can certainly contribute to such endeavors, but the expansion of self-directed supports affords advocacy organizations (e.g. groups formed independently to foster self-advocacy, protection of rights, consumer empowerment and social/political change) a great opportunity to spread awareness, inform others about options and places to turn for help, and to contribute to reconciliation of policy dilemmas at the systems levels. *Advocacy organizations need to learn more about the roles they can play in assisting participants and prospective participants in considering and implementing self-directed supports, and about how best to influence the development of oversight and safeguarding mechanisms.*