Independent Living Research Utilization

Promoting Self-Direction and Consumer Control in Home-and Community-Based Service Systems

Third of Three Papers on
Unlocking the code of effective Systems Change

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I. Introduction

Over the past several years, staff members and partners of the Independent Living Research Utilization (ILRU) team have provided technical assistance, training, publications, and other support to the Real Choice Systems Change initiative of the Centers for Medicare & Medicaid Services. As we conducted this important work, we began to observe there were clear distinctions between those programs that achieved (or showed real promise for) enduring change and those programs that failed to realize their full potential. In 2004, after almost four years of working with Real Choice grantees, we took the step of looking much more closely at how to foster meaningful, sustainable changes in the social services systems that support people with disabilities of any age. We identified six outstanding projects that had received Real Choice Systems Change grants; each of these projects initiated significant and beneficial change in their respective states (Arkansas, Connecticut, New Hampshire, New York, Oklahoma, and West Virginia). The chosen projects were diverse in many respects, including

- the scale, scope, and character of the service systems in place,

- the people and needs that were the focus of the changes,

- the types of participants involved in the change process,

- the changes being pursued, and

- the history and duration of the change process.

We asked representatives of these projects to reflect on their experiences and share lessons they learned about systems change. We interviewed project staff and consumer leaders. We wanted to know whether there were common factors that are central to achieving people-friendly systems change.

In January 2005, ILRU continued its investigation by inviting representatives from the six projects and other key Real Choice Systems Change leaders to a colloquium to discuss key elements of meaningful and sustainable systems change.[2] The group spent 2 1/2 days in Houston in active dialogue focused on three topics:

- Key components of systems change

- Features of a high-quality community service system

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[2] Readers interested in the original three papers used as catalysts to stimulate dialogue at the colloquium may access them at http://www.ilru.org/html/projects/CMS/colloquiumindex.htm

- The promotion of self-direction and consumer control in service programs and systems

From our study of successful programs and the recommendations and guidance of the colloquium participants, we have developed three papers that address these central aspects of the creation of enduring change.

> The first paper in the series, *Key Components of Systems Change*, creates an overall framework for the discussion of systems change and serves as a summary of the concepts discussed in all three papers. In addition, it includes several specific recommendations that can be applied now by any grantee, state, or program to enhance prospects of achieving enduring change in home and community based services.

> The second paper in the series, *Features of High-Quality Community-Based Services*, identifies the features of high-quality integrated community services and the systems that support them. It serves as foundation work for additional exploration and discussion of what constitutes effective community services. The paper will undergo continuing development in discussions with representatives of projects and consumer leaders in states. The authors believe the paper, in its current form, will augment assessment of existing systems and planning of new or improved systems and, after refinement, it will become an even more useful tool for those involved in systems transformation.

> In this paper, the third in the series, *Promoting Self-Direction and Consumer Control in Home- and Community-Based Service Systems*, we examine what contemporary social service systems can do to promote consumer-directed services. We identify different features that make a service "self-directed," and we identify characteristics of successful consumer direction and self-determination. As with the second paper, in its present form, it serves as foundation work for additional dialogue and will also undergo continuing development in discussions with representatives of projects and consumer leaders in states.

II.   Self-Direction and Consumer Control in Service Delivery

People with disabilities, including older adults, seek to live their lives in the same fashion as people without disabilities. People with disabilities often report they are hampered in this quest not by their disabilities, but rather by artificial barriers created by the cultural environment in which they live; discrimination born of superstition, ignorance, and even paternal benevolence continues to impede progress toward a world in which equality is the norm.

Social service systems cannot eliminate all of the barriers that arise from society's stereotypes and cultural norms. However, they *can* provide service and support in a way that gives control to those receiving services, fostering greater independence and autonomy among service users. At the very least, systems should not create barriers that prevent individuals from participating in all aspects of family and civic life.

A. Distinguishing between "Consumer direction" and "Empowerment"

We first want to explain why we specifically chose the terms "self-directed," "consumer-directed," and "consumer control" to describe the types of systems advocated in this paper. Before our 2005 colloquium, we originally planned to title this paper *The Character of Personal Empowerment*. After further discussion, however, the colloquium work group concluded "empowerment" is distinctly different from consumer direction and is not necessarily fostered through consumer direction. Empowerment is a highly personal concept—what constitutes empowerment for one person may not for another. Self-direction, on the other hand, is a more concrete concept, and it is a valuable pursuit in and of itself. It improves the quality and effectiveness of services by giving the service recipient greater control over the services offered, the method of delivery, and the provider of the services—thereby increasing the likelihood that services truly meet the needs of those who receive them.

B. The Lack of Consumer direction in Many Current Service Systems

People with disabilities, including some interviewed during preparation of this paper, report human service systems often fail to foster personal control and autonomy. This may well be a reflection of concepts and sensibilities of our broader society. Many people with disabilities can clearly articulate how their experiences as service users have deprived them of personal control and autonomy. *"My life should not be about 15-minute increments of service,"* said one West Virginia resident. A woman in Connecticut said, *"I feel like a conduit through which the government passes money to professionals."* Having to plan your life around the availability of staff at the local home health agency virtually eliminates the flexibility other people enjoy. Admittedly, not everyone has these perceptions or experiences of restriction, but they are reported often enough that we must consider the implications of these perceptions.

There are many reasons that human service systems may not offer meaningful control and direction to the people who receive their services. These typically include, but are not limited to, social devaluation, poverty, stereotypes and stigma, professional sovereignty, assigned roles, prejudicial beliefs and attitudes, vested interests, fears, limitations, and institutional expedience. Sometimes the factors that hinder consumer direction in a particular system are difficult to unearth; much of what prevents control and autonomy is done unconsciously and there are often multiple factors at work. These factors are operative even though their workings may be obscure, denied, or disguised. Later in this paper, the

author's will describe several approaches for ensuring that service users do have true direction and control of services, but first it is appropriate to consider a common definition of consumer control and direction.

III. Defining Consumer Control and Direction

To simplify the definition of consumer control and direction, we can identify several attributes of direction and control that many human services leaders intend to promote and endorse. These include factors such as:

• Valued roles

• Person-centeredness and individualization

• Legal rights

• Flexibility, responsiveness, and enablement

• Enriched life opportunities

• Respect; absence of degradation and mistreatment

Actions that encourage these attributes support consumer direction and control, while actions that discourage these attributes reduce individual control.

A service may do well in promoting some of these attributes while failing to promote others. Consumer direction, therefore, is a relative concept that varies along a continuum ranging from little control for the user to full control. To evaluate how effectively a service system provides consumer-directed services, we must evaluate the system in terms of the levels of control it offers.

A. Levels of Consumer Direction and Control

To measure the control offered by a service system, we must begin by asking two key questions:

1. Is the person who is using the services actually able to make a significant difference, *through his or her own actions*, in the character of the services he or she is receiving?

2. More precisely, how many key decisions about the design and operation of the service are made by *the person who is using the service*, and how many are made *by others on behalf of the service user*?

A "key decision" is anything that substantially affects the nature of the service an individual receives. For example, service staff members account for as much as 85% of the total cost of services—to what degree, then, does the service user control who the service staff members are? By noticing who is making the actual

decisions about services, we can distinguish who is actually in control of the service and who is not.

We have created a continuum from low to high that can be used to describe the degree of consumer direction and control offered by a given system. We have adopted a simple six-level "empowerment" scale developed by Michael Kendrick; each level describes a greater degree of self-direction and control measured by the authoritative decision-making standard.

>*Level One:* At this level, service users make *no substantive decisions about their service.*

>*Level Two*: At this level, service users make no substantive decisions about their service, but they are routinely informed about the decisions others will be making on their behalf.

>*Level Three:* At this level, service users are routinely consulted about their service preferences by the actual decision-makers.

>*Level Four:* At this level, service users routinely make a *significant minority of the substantive decisions about their personal services.* (A significant minority, in statistical terms, might range from 25% to 45% of key decisions.)

>*Level Five:* At this level, service users routinely make a *significant majority of the substantive decisions* about their personal services.(A significant majority, in statistical terms, might range from 55% to 90% of key decisions.)

>*Level Six*: At this level, service users so routinely make the *vast majority of key decisions* that they consider themselves to be *fully in control of the services and supports* they receive.

Few service users have experienced service systems that rise above a level two or three. Even fewer have seen a level four or higher service, though these do exist and are relatively easy to establish and maintain. Again, it is important to emphasize the gap between rhetoric and reality in implementation of consumer direction. Common empowerment rhetoric used in association with service systems suggests users have much more authority and power than they often actually do. All too often, users are consulted about comparatively trivial issues, but authoritative decision-making power is reserved for people other than the service user.

This scale helps us to evaluate the actual relationship of service users to the substantive decision-making that affects their lives and services. It also gives us more concrete guidelines for developing models of service design that offer service users more control.

B. Scope of Direction and Control: Over What Does the Person Exercise Authority?

In addition to considering the level of control that service users exert over services, we must also consider the *scope* of control, and we must ask *over what specific elements of personal life and services that control is exercised. Common aspects of life that individuals may wish to determine for themselves* could include relationships, money, life goals, religion, priorities, lifestyle, appearance, health, life interests, obligations, risks, and home.

The same can be said about the degree and scope of control a person exercises in configuring his or her support services. A service user should normally have authority over the following elements of his or her service:

Goals	Values and vision
Priorities	Budget
Hiring, supervision, and dismissal of staff	Methods, practices, and processes
Intentional safeguards	Risk management
Service assumptions, theories, and models	Formal affiliations and contracts
Accountability and documentation	Quality
Personalization of supports	

This list might surprise some service users; most have experienced only systems that were designed *for* them, not *with* them. Yet while many professionally designed services can be effective and beneficial, the point of this discussion is to explore how much more beneficial and effective services can be when the users direct as much of the service as they wish.

Many service models can now be devised and governed solely by the service user or by the service user in partnership with service providers. These options require either that the service users (or their families and friends) have undisputed authority to make decisions about all crucial aspects of service design and direction, or that they share this authority with a formal service provider that offers personalized support.

While many individuals and families want to control all aspects of services, many others prefer not to take on a service management role. Greater attention should be focused on models in which the service user can control the support arrangement, but may choose to have others – such as existing service providers or competent, trusted individuals from the community – perform the more burdensome administrative tasks. (This model proved highly effective in the Cash & Counseling Demonstrations described in our first paper.)

Similar arrangements are possible in projects in which the service user or a family member governs the service at an individual level, as well as at the overall service or project level. Currently, consumer-governed or family-governed models are less common, but they are quite functional nonetheless. Regardless of which model is chosen, it is important to be clear about the aspects of services over which the service user has authority, because this helps reduce disputes and clarify responsibilities.

C. Support and Facilitation of Personal Control

For some service users to function as they wish, they sometimes may require additional support for some activities. Needing support is an ordinary human condition; most people are both dependent and interdependent on others. Truly responsive systems can allow for support and facilitation of decisions about the services provided and how they are provided.

Examples of common facilitative supports that might enable people to do well in consumer-directed contexts include:

Training	Information and guidance
Exposure to optimal role models and practices	Access to experienced peers
Consciousness raising related to consumer direction	Assistance with "start up"
Help with supervision and negotiation	Administrative and technical help
Assistance in planning safeguards	Assistance in ensuring quality
Support with decision-making	Problem and crisis solving

People with disabilities, including those who may require facilitative support, experience many of the same diverse demands experienced by almost all people. Most people ask for assistance, guidance, and support from others from time-to-time. Add to this the complexity of managing services and there may be occasions in which the person receiving services desires assistance. This doesn't mean that self-direction is unworkable. Rather, it means program developers and managers are challenged to implement flexible systems that provide people with what they need in order to be successful. This means planning for a range of supports in directing services. Offering support does not have to reduce the service user's independence.

There may be times when self-direction does not work perfectly. Users may become temporarily overwhelmed with managing services and supports. Systems can be designed to provide flexible supports and contingency solutions so that the need for the service user to step back temporarily does not result in abandonment of consumer direction for that user.

There are many ways to develop self-direction supports and implement them before they are needed. This is more likely to happen if all involved in designing the systems, including consumers and consumer direction advocates, are realistic about what individual service users need. Advocates and service providers must become more aware both of service users' strengths and their limitations. With effective personalized assistance, service users get only the support they need; the risk that they will be unable to succeed is greatly reduced.

IV. Summary of Recommendations to Create or Enhance Consumer Direction in Service Programs

These recommendations are taken directly from notes of the colloquium discussion group that focused its attention on consumer direction. They are presented here as a record of the group's discussion. The authors believe they also serve as a summary of important points to be addressed in fostering true consumer direction in service systems. The authors will explore many of these points in greater detail in future discussions with service users, providers and administrators. In Section V of this paper, the authors have extracted from these recommendations some key examples of actions that leaders can initiate immediately to foster change.

The recommendations are grouped into categories that address standards and measures; policy and system design; approaches for consumer leadership and involvement in decision making; and equalization of knowledge.

A. Implementation of Standards, Indicators and Measures of Consumer direction

- Establish clear standards and performance indicators at the federal, state, and local level for incorporating the consumer direction paradigm into service systems.

- Ensure that standards and indicators address consumer direction both at the "end user" level and at the program planning and implementation levels.

- Create and use measurement tools that reflect the consumer direction paradigm and are based on a clear set of consumer direction standards and indicators.

- Ensure that service users have leadership roles from the very outset of all policy development, program design, program implementation, and related research initiatives.

- Include "end users" in systems design and policy development through a variety of strategies, including managing boards, advisory bodies, leadership task forces, focus groups, surveying, structured interviewing, and continuous assessment of outcomes and satisfaction.

- Establish expectations in federal funding solicitations and policy for self-direction based on federal standards and indicators.

B. Policies and Systems Design Enhancements Related to Consumer direction

- Create and use feedback loops to support continuous learning cultures within organizations; ensure that consumer "end users" are key parts of the feedback mechanisms.

- Create corporate cultures of customer (consumer "end user") satisfaction and routinely measure end-user satisfaction.

- Establish quality management mechanisms using end-user outcomes and satisfaction as principal indicators.

- Establish transparent and objective processes involving consumers to address issues of health, safety, and risk management; work to prevent "protection mechanisms" from acting as a barrier to consumer choice and direction.

- Create broader definitions of services; involve those who receive services in the creation of those definitions so that the services are shaped to better meet needs of those who receive them.

- Address the fear of reprisal experienced by consumers, advocates, families, service workers and others by implementing policies and procedures that afford methods of informing leaders of problems and that provide for harsh punishment for any act of reprisal against persons who raise concerns.

- Make the existence of such policies and procedures widely known, especially to consumer "end users," advocates, families, community service providers, state workers, and others.

C. Approaches for Consumer Leadership and Involvement in Decision Making

- Create managing boards and advisory bodies that provide *authentic* leadership in service systems.

- Create recruiting and selection mechanisms to develop a renewable pool of consumer leaders who are representative of typical service users and who are willing and able to engage in leadership roles

- Improve accountability by establishing mechanisms to ensure that executives and managers receive and act on guidance from boards and advisory bodies.

- Ensure that executives frequently report to those bodies on their actions.

- Establish an ongoing program of "knowledge equalization" that supports informed decision making on the part of those leaders.

- Employ service users as consultants in policy review and in systems analysis as another means of securing end-user perspectives in systems design and enhancement.

- Provide for consultant fees, travel reimbursement, personal assistance services, child care, and other supports that facilitate involvement of consumer leaders.

D. Equalization of Knowledge

- Create materials for those who receive services to support informed decision making about services, delivery approaches, and strategies for navigating systems, etc.

- Create materials and other resources that support informed consumer leadership at the federal, state, and local level, ensuring those leaders have full knowledge of funding, legislation, policies, management systems, services, service systems, system constraints, and other matters about which they will be called to make decisions.

- Establish independent bodies, primarily of consumers, to create and review the materials and information that support informed choice by those who receive services and by consumer leaders.

V. Key Steps Leaders in Agencies and Organizations Can Take to Foster Consumer Direction

There are no silver bullets that will make self-direction an everyday experience for the users of present services. However, there are many strategies that, if combined and pursued with some determination, will make a measurable difference. The following are some steps that can be taken to create a foundation for consumer direction. They are described very briefly here, not as a comprehensive treatment of the subject, but rather as suggestions for getting practical results. These examples are drawn from the recommendations in Section IV above. Several also appeared in the initial paper presented to colloquium participants for their review.

A. Strategies to Prepare for Consumer Direction at the Organizational level

1. Make Consumer Direction a Central Goal
   Articulating a goal of consumer direction at the top level of agency management and throughout all levels is an ideal approach to advance consumer direction, although managers at even a single level of the agency can do much to advance such a goal. Systems not designed with people-

centered goals generally fail to promote consumer direction. Faithful and conscientious work toward a goal of consumer direction usually results in progress.

2. <u>Provide Opportunities for Service Users, Staff, Board, Funders, and Others to Learn More about Self-Directed Services</u>
Be intentional about the creation of "vision and people building" experiences to help all involved "stretch" their sense of the potential of consumer-directed services. Raising the bar can foster positive change. People respond to inspiring examples of what is possible – but they cannot implement visions that they have not yet had.

3. <u>Use Examples in a Positive Way to Foster Expansion of Consumer Direction</u>
As agencies advance consumer direction, there will be more and more examples of successes. Leaders can use these examples to show funders, legislators, and other stakeholders what might be possible with enhanced consumer direction.

B. Strategies for effective leadership in Consumer Directed-Systems

Implementing any new system presents challenges for leaders. Consumer-directed service systems are no exception. Indeed, consumer direction may bring some additional challenges, since agencies and service delivery organizations are called to create management approaches in which service users and advocates have leadership roles. Leadership development must take place within the traditional structure of the agency or organization and outside it as users are supported in assuming leadership roles.

1. <u>Select Managers and Service Leaders Who Are Committed to Enhancing Their Own Competencies in Consumer direction</u>
To help consumers achieve self-direction, managers and service leaders must not only be committed to the concept, they must also possess competencies that are consistent with consumer direction. Service leaders should know, practice, and impart them to all within the organization. Staff development activities should incorporate training that will help leaders and staff at all levels develop these competencies. Individuals who have honed these skills should be appointed to key leadership roles. Naturally, service users will have their own instincts about who the most committed service leaders might be, so users should be included in the selection and supervision process. Items 2 through 5 are examples of these competencies.

2. <u>Promote Collaborative Leadership Approaches</u>
Leaders capable of and willing to work in a collaborative framework, involving stakeholders within and outside their organizations, can do much to advance consumer direction. The complexity of managing any service system increases when those who are the recipients of services are involved in leadership. (There are also advantages for agencies in involving consumers, including having advocacy voices who can speak in support of the system

and the agencies operating it.) Working collaboratively and in teams requires different skills from traditional "top down" management approaches. Relinquishing paternalism in favor of welcoming the contributions of others is significantly more enabling. Agencies can select leaders with this competency and support leaders in acquiring it through training and adoption of team oriented management approaches throughout the agency.

3. Learn To Share Control and Authority
   One meaningful way to share control is to establish an advisory board or task force that includes a substantial number of service users and other advocates who have *authentic* power to influence policy, service delivery, and evaluation of services. Leaders can learn to share control by becoming more aware of how they monopolize control, power, and authority (albeit unconsciously and unintentionally).

4. Acquire a Level of Comfort with the Messiness of Participatory Processes
   Once we open the door to participation, we begin to share the public space with others. People do not usually fit easily into someone else's preferences and notions of how participation *ought* to unfold. Conversely, by relaxing and accepting a more open-ended approach to how participation might take place, we can allow others to shape the experience and to make their own unique contributions.

5. Restrain Vested Interests That Might Limit Service Users' Potentials
   When users of service have an authentic role in directing the systems that affect their lives, it is much more likely that the focus will remain on what is in the best interest of all concerned. In any service system, there are always opportunities and temptations for those involved to indulge their own vested interests, whether those interests are power, size, reputation, wealth, or any other largely self-serving aim. Service leaders must instead look for opportunities to defend, expand, and enrich the interests of people who are the recipients of the services offered.

C. Strategies for working with service users

Some service users may need training or other specific supports to fully realize consumer direction.

1. Properly Support People with Their Efforts to Have More Control
   Many people require training or targeted support in order to fully realize their self-direction potentials. Providing self-direction opportunities may not be enough to assure empowering self-direction outcomes. Systems should be designed from the outset to provide additional support in the form of training or continuing facilitation. For example, users could benefit from training on personal assistant supervision or training on how to complete and check time sheets so the person providing the service can be paid in a timely manner.

2. Avoid Structures and Practices That Undermine Personal Power of Service Users
   Leaders must be vigilant to avoid practices that are prescriptive, exclusive, and driven from the top down; they pre-empt otherwise feasible service user choices and prerogatives. Some aspects of current systems can take on a life of their own and inadvertently take personal power away from staff and service users alike. Leaders should create continuing dialogues with users, staff, and other stakeholders to prevent the drift toward prescriptive practices common in service systems. For example, risk management is one highly charged issue that especially benefits from straightforward, intentional discussion and decision-making. Service users and advocates may have significantly different views about what constitutes risk and the level of risk that is acceptable. Even when most other structures that support self-direction are in place, the presence of just one fearful professional who is not willing to allow the service user to take a risk can destroy the entire attempt at autonomy.

3. Make Efforts to Relieve People of Their Fears of Change, Uncertainty, and Reprisal
   Create mechanisms that diminish the potential for uncertainty as plans are laid for change. Involving stakeholders in all phases of planning and having clear, honest continuing discussions with stakeholders can help minimize fears and uncertainty about change. It is also important, in the initial design or improvement of a system, to create mechanisms that diminish the potential for reprisal. Service users report fears of retaliation for making complaints related to the services they receive. Advocates express similar concerns that they will experience a backlash from officials when they take a strong advocacy stand. One way to diminish reprisal and the fear of it is to create clear, emphatic policies prohibiting reprisal and then enforcing those policies. Fears of change, uncertainty, and reprisal can hold people and organizations back from their potential. The release of these fears can unleash positive energy, since that energy is no longer diverted to maintain people's mistrust, insecurity and anxieties.

4. Foster Ties to and Cooperation with Independent External Advocates
   Agencies must support the important role that independent advocacy can play. People will not consider themselves in control of their own lives if their voices are ignored or if they are cut off from powerful allies who might help them uphold their own vision and priorities. Independent advocates can be fearless in their ability to attend to contentious issues; they are excellent sources of challenge for complacent systems. Keeping service users silent and isolated from independent advocacy is not consistent with providing consumer-directed services. In addition, advocates can often play a supportive role with funders and others whose decisions have an impact on service systems.

5. <u>Welcome Thoughtful Dissidence as a Natural Part of Expressing Autonomy</u>
   When people feel free to express disagreement, this is usually a sign that they do not feel threatened or intimidated by conflict with people in roles of authority. Admittedly, when people are testing out their autonomy and ideas, they may not always express themselves with tact – but with practice, most people do become more diplomatic. Sometimes what they say is useful and productive, and it is important to attend more to *what* they are saying rather than *how* they are saying it.

VI. Conclusion

The rhetoric of consumer direction has been heard now for several decades, but putting authentic consumer direction into practice has proven challenging for leaders at federal, state, and local levels. Doing so requires a paradigm shift, a new way of thinking and new ways of acting at all levels of organizations. Leaders are called to share power, seek guidance, accept and grow from criticism, and abandon old, often paternalistic, ways of managing programs. Leaders are called to embrace continuous quality improvement, using what they learn from service users to drive innovation. They are called to find new ways of managing risk without encroaching on personal freedom. These are big changes that leaders and organizations can make with commitment and the right kinds of support. It is our hope that this paper will serve as one part of that support.

We have offered a beginning framework of recommendations and guidelines that leaders can use as they strive to realize true consumer control, embracing authentic, meaningful direction from those who are served by the programs they administer. As with the other papers in this series, the recommendations here were drawn from our review of programs that evidenced genuine consumer direction and from the guidance of the participants in the ILRU systems change colloquium. We intend this and the other papers to serve as catalysts for additional exploration and development of in depth guidance for those administering programs. Over time we will create other opportunities for those who participated in the colloquium, and others, to delve deeply into each of the recommendations in these papers, to test them, refine them, and improve them.

VII. Reading List

This list, which is common to all three systems change papers produced by ILRU, contains the two publications which were referenced in the second and third papers, but primarily is offered as a reading list for those wishing to read more about improving service systems to make them more responsive to people with disabilities, the users of those systems. The list draws from many fields, not just human services. Not all materials are still in print, but the reader should be able to locate all these references in most large libraries.

Badcock, C.R., *The Problem of Altruism*, Basil Blackwell, 1986

Bella, Robert N., Madsen, Richard, Sullivan, William M., Swidler, Ann, Tipton, Steven, M., *The Good Society*, Vintage, 1992

Bella, Robert N., Madsen, Richard, Sullivan, William M., Swidler, Ann, Tipton, Steven, M., *Habits of The Heart*, University of California Press, 1985

Ciulla, Joanne B., (Editor*), Ethics; The Heart of Leadership*, Praeger, 1998

Colby, Anne, Damon, William, *Some Do Care: Contemporary Lives of Moral Commitment*, The Free Press, 1992

Coles, Robert, *The Call of Service: A Witness to Idealism*, Houghton Mifflin, 1993

Collins, Pam, (editor), *Relationships and Everyday Lives*, CRU Publications, Brisbane, Australia

Driedger, Diane, *The Last Civil Rights Movement, Disabled Peoples International*, St. Martin's Press, 1989

Easterbrook, Gregg, *The Progress Paradox; How Life Gets Better While People Feel Worse*, Random House, 2004

Eddelman, Murray, *The Symbolic Uses of Politics*, University of Illinois Press, 1985

Fratangelo, Pat, Olney, Marjorie, Lehr, Sue, *One Person at a Time*, Training Resource Network, Inc., 2001

Frieden, L., Richards, L., Cole, J., & Bailey, D., *ILRU Source Book: A Technical Assistance Manual on Independent Living*. Houston, Texas: Independent Living Research Utilization, 1979

Galper, Jeffry H., *The Politics of Social Services*, Prentice Hall International, 1975

Gilman, Sander I., *Disease and Representation, Images of Illness from Madness to AIDS*, Cornell University Press, 1988

Gladwell, Malcolm, *The Tipping Point; How Little Things Can Make a Big Difference*, Back Bay, 2002

Goffman, Erving, *Relations in Public*, Harper and Row, 1971

Goffman, Erving, *Frame Analysis*, Harper and Row, 1974

Gottschalk, Simon S., *Communities and Alternatives; An Exploration of the Limits of Planning*, John Wiley And Sons, 1975

Gray, Barry, Jackson, Robin, (editors), *Advocacy and Learning Disability*, Jessica Kingley Publishers, 2002

Hillman, James, *Kinds of Power; A Guide to Its Intelligent Uses*, Doubleday, 1995

Hoopes, James, *False Prophets; The Gurus Who Created Modern Management and Why Their Ideas Are Bad for Business*, Perseus Books, 2003

Hoos, Ida R., *Systems Analysis in Public Policy; A Critique*, University of California Press, 1972

Ignatieff, Michael, *The Rights Revolution*, House of Anansi Press Limited, 2000

Kallen, Evelyn, *Label Me Human; Minority Rights for Stigmatized Canadians*, University of Toronto Press, 1989

Kendrick, M., Levels of Empowerment, *Planet Advocacy*, Issue Number 7, March 2004, pp 6-7

Klees, Janet, *We Come Bearing Gifts, The Story of the Deohaeko Support Network*, Copywell, North York, Ontario

Kuhn, Thomas S., *The Structure of Scientific Revolutions*, 2nd Edition, 1970

Kouzes, James M., Posner, Barry Z., *Credibility*, Jossey Bass, 1993

Kouzes, James M., Posner, Barry Z., *The Leadership Challenge, Third Edition*, Jossey Bass, 2002

Lasch, Christopher, *The Revolt of the Elites and the Betrayal of Democracy*, W.W. Norton And Co., 1995

Leiss, William, The Limits To Satisfaction: An Essay on the Problems of Needs and Commodities, University of Toronto Press, 1976

Loeb, Paul, R., *Soul of a Citizen*, St Martins Griffin, 1999

Loeb, Paul, R., *The Impossible Will Take a Little While*, Basic Books, 2004

Melnyk, George, *The Search for Community; From Utopia to a Cooperative Society*, University of Toronto Press, 1985

Minow, Martha, *Making All the Difference; Inclusion, Exclusion and American Law*, Cornell University Press, 1990

Morgan, Gareth, *Images of Organization; The Executive Edition*, Sage, 1998

Neugeboren, Jay, *Transforming Madness; New Lives for People Living with Mental Illness*, William Morrow And Company, 1998

Oliner, Samuel P., Oliner, Pearl, M., *The Altruistic Personality*, The Free Press, 1988

Porta, Donatella Della, Diani, Mario, *Social Movements; An Introduction*, Blackwell Publishers 1999

Palmer, John L., Smeeding, Timothy, Torrey, Barbara B., *The Vulnerable*, The Urban Institute Press, 1988

Piven, Francis Fox, Cloward, Richard A., *Poor People's Movements; Why They Succeed, How They Fail*, Vintage Books, 1977

Putnam, Robert D., *Bowling Alone*, Simon and Schuster, 2000

Race, David, (editor), *Leadership and Change in Human Services, Selected Readings of Wolf Wolfensberger*, Routledge, 2003

Reinders, Hans S., *The Future of the Disabled in Liberal Society; An Ethical Analysis*, University of Notre Dame press, 2000

Resnick, Herman, Patti, Rino J., (Editors), *Change from Within*, Temple University Press, 1980

Rost, Joseph C., *Leadership for the Twenty-First Century*, Praeger, 1993

Rosenberg, Charles E., *The Care of Strangers; The Rise of America's Hospital System*, Basic Books, 1987

Saddhatissa, Hammalawa, *Buddhist Ethics*, Wisdom Publications, 1997

Sharpe, Virginia A., Faden, Alan I., *Medical Harm; Historical, Conceptual and Ethical Dimensions of Iatrogenic Illness*, Cambridge University Press, 1998

Thrall, Bill, McNicoll, Bruce, McElrath, Ken, Blanchard, Ken, *The Ascent of a Leader; How Ordinary Relationships Develop Extraordinary Character and Influence*, Jossey Bass, 1999

Toch, Hans, *The Social Psychology of Social Movements*, Bobbs-Merrill, 1965

Tronto, Joan C., *Moral Boundaries; A Political Argument for an Ethic of Care*, Routledge, 1993

Turnbull, H.R., Turnbull, Ann P., *Parents Speak Out; Then and Now, second edition*, Charles E. Merrill Publishing, 1985

Volkan, Vamik D., *The Need to Have Enemies and Allies*, Jason Aronson Inc., 1988

Wharf, Brian, *Communities and Social Policy in Canada*, Maclellan and Stewart, 1992

Wilson, James Q., *The Moral Sense*, The Free Press, 1993

Wolfe, Alan, *Whose Keeper? Social Science and Moral Obligation*, University Of California Press, 1989

Wolfensberger, Wolf, *The Principle of Normalization in Human Services*, National Institute on Mental Retardation, 1972

Wolfensberger, Wolf, and Glenn, L., *Program Analysis of Service Systems: A Method for the Quantitative Evaluation of Human Services, 2nd Edition*, National Institute on Mental Retardation, 1973

Wright, Chris, *The Sufficient Community; Putting People First*, Green Books, Devon, 1997