"…to interact with non-disabled persons to the fullest extent possible."
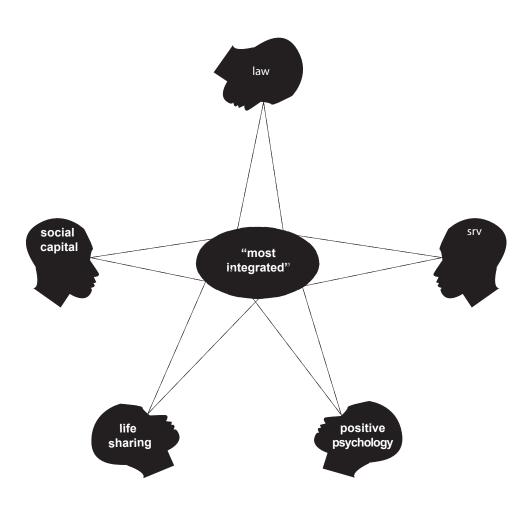
Perspectives On "Most Integrated" Services for People with Developmental Disabilities

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These notes are **not intended and should not be used as a source of advice on how to meet legal or administrative requirements**. They are simply a resource for discussing the sorts of assistance that offer people with developmental disabilities the best chances for social integration. Such discussions are a necessary part of planning and providing services among those who take seriously the criterion of "most integrated".

Thanks to Marcie Brost for framing the question that led to this publication and to Connie Lyle O'Brien, Anne Escrader, Jim Gardner, Mike Green, Ray Lemay, Jack Pealer, David Race, and Alan Tyne for reviewing and commenting on an earlier version. Ray Lemay kindly shared his writing on SRV and social integration. Participants in a retreat for people involved in Maine's community building initiative informed the SRV section.

US law offers people with developmental disabilities a safeguard in the form of a requirement that services offer the "most integrated" way to meet each person's needs. These notes offer a way to think about what "most integrated" can mean. They are based on the experience of people with developmental disabilities who, with the support of committed allies, live as contributing members of their communities, and thereby experience regular and positive interactions with their non-disabled fellow citizens.
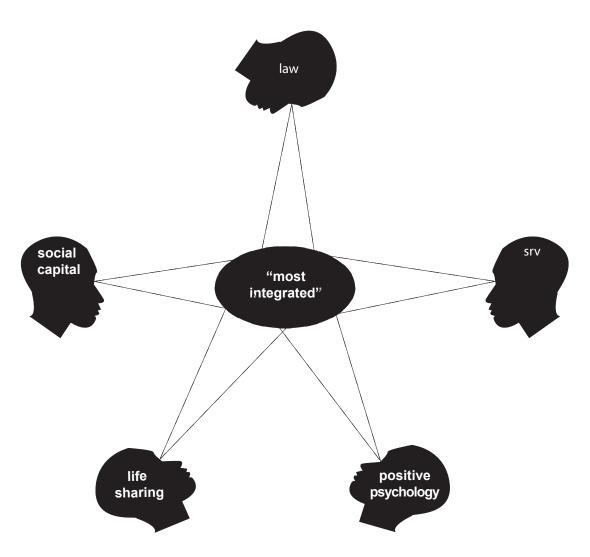
Providing supports that "enable individuals with disabilities to interact with non-disabled individuals to the fullest extent possible"* is a matter of skillfully weaving a fabric of relationships that cross exclusionary boundaries separating disabled and non-disabled people. The art of assisting people with developmental disabilities to make and maintain satisfying relationships with people outside the human service world has advanced far enough to support three conclusions:

- Mutually rewarding relationships between people with developmental disabilities and non-disabled people are possible, regardless of the type or extent of a person's impairment or the person's history.

- The more assistance a person receives, the more that person's relationships with non-disabled people depend on the way assistance is provided. When necessary supports are individualized and offered by skillful assistants who highly value relationships, people are more likely to have more diverse social networks. The design of services and the culture that shapes the attitude of assistants are the predictors of a person's interactions with non-disabled people that are most open to influence by service planners and managers.

- Many people with developmental disabilities continue to lack connections beyond their relationships with their families and other people in the human service settings they attend. This reflects a history of discrimination against people with developmental disabilities which is expressed in multiple barriers to social integration. Though good services can help people to overcome these barriers, it usually takes conscious, sustained work by people and their supporters to make good relationships and keep them alive.

These notes contrast a compliance approach to social integration with a learning approach. Then they consider the meaning of "most integrated" from five points of view and use these perspectives to define "most integrated" in a way that offers some ideas for increasing the chances that people will have good, diverse social networks. The five perspectives on "most integrated" are these:

*The definition of "most integrated" adopted by the US Supreme Court in deciding *Olmstead v L.C.*

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- A **legal** perspective that can be read from the US Supreme Court's decision in *Olmstead v L.C.*
- A perspective drawn from **social role valorization**, a theory which has influenced service practices along with its predecessor, the principle of normalization.
- A perspective from **positive psychology**.
- A perspective drawn from those who practice **life sharing** by creating intentional relationships between people with developmental disabilities and non-disabled people.
- A perspective from research and policy discussions on forming **social capital**.

law

social capital

"most integrated"

srv

life sharing

positive psychology

Continuing learning rather than legal compliance

"Most integrated" services for people with developmental disabilities and their intended outcome, "enabl[ing] individuals with disabilities to inter-act with non-disabled persons to the fullest extent possible," are best understood as means to personally and socially worthwhile ends. Inter-action – a rather cold and technical sounding term for a warm and often conflicted and confusing human reality– takes three forms. It indicates the participation in social networks, membership in associations, and mutuality of friendship associated with health, happiness, resilience, and opportunity for individuals (Seligman, 2002), with civic, economic success for communities (Putnam, 2000), and good quality services for people with developmental disabilities (Gardner and Carran, 2005; Wolfensberger, 1998).

Participation, membership, and friendship are the ends to keep in view when working to assist people with developmental disabilities to live a satisfying life in their community. The key questions are:

- Who can this person call on and who calls on this person for informa-tion, assistance, and influence and what opportunities does the per-son have to further extend his or her **personal network**?
- With whom does this person pursue shared interests and common agendas and what opportunities does this person have to deepen engagement or increase **memberships** in community associations?
- With whom does this person share the bonds of **friendship** and what opportunities does this person have to honor existing friendships or pursue new ones?

These are dynamic questions in anyone's life, They are especially difficult questions in the lives of people who have been separated from ordinary social opportunities for long periods by human service prac-tices that congregate people with disabilities under professional control. They are the kind of questions that open up a field for learning through purposeful, collaborative action, not questions that have a right or wrong answer.

Suspend the condition of positive engagement with non-disabled people other than family and staff, and the quality of life for many peo-ple with developmental disabilities looks pretty good, often even within institutional walls. Many people have friends among the staff and clients in their service groups in their residential program, day program, and recreation program; belong to one or more developmental disability groups (often associated with an organization that provides services); and (usually to a lesser extent) network with other people with devel-

opmental disabilities outside their immediate service groups. They may also have some casual "say hi" relationships with non-disabled people incidental to where they shop or browse.

Introduce the condition that relationships cross the boundaries of family and service, and the need for deep learning becomes clear. From this vantage point, a terrible inertia separates most people with developmental disabilities from adding satisfying ties and connections with their fellow citizens to their current network of relationships. Familiar routines, comfortable if sometimes frantically busy for staff and often comfortable if frequently less busy for their clients, shape lives lived at a distance from other citizens. Mini-vans shuttle group home residents to and from day-programs and recreation programs and, as long as the price of fuel permits, on outings to malls and fast-food outlets and public events. Small groups of people with disabilities move among other citizens under staff tutelage as spectators, window-shoppers, and small-time consumers (Walker, 1999). In this social world, bounded and structured by professionally administered services, people may have to pay the price of isolation and loneliness for the pride and freedom that comes from living and working on one's own. Occasionally, some groups present their wider community with a contribution –sport, art, drama, or charity– whose often impressive and even exuberant performance somehow both impresses and maintains a personal distance between developmentally disabled producer and non-disabled patron and whose quality is framed by the developmental disability indicator, "Special" or even "Very Special".

The pride and pleasure that people with developmental disabilities often take in these "Special" activities is a vivid reminder that separation does not necessarily mean dejection. There is pain as well as missed opportunity in being relegated to the social margins, rejected as something less-than and other-than fully human. But, because they are alive, resilient human beings, most of the riders on a locality's crisscrossing human service mini-vans make do and make lives satisfying to themselves, especially if the staff who oversee them are warm and decent people with the means to offer reasonable living conditions. They make friends and enemies, enjoy good times, offer and receive consolation, fall in and out of love, make the best of their talents, and find meaning in the company of those among whom they are placed. Like the goldfish that are said to match their growth to fit the size of their tanks, most people with developmental disabilities manage the limits imposed by their social environment with aplomb.

Learning where the limits of "most integrated" lie requires that people with developmental disabilities work together with their allies to expand their networks, memberships, and friendships. On the part of people with developmental disabilities, undertaking this kind of learning takes confidence and courage: confidence that they have something to give and something to get from new relationships; courage to risk initial discomfort and possible rejection.

Allies in this kind of learning need to embrace the uncertainty and discomfort that comes from an urgent sense that people with developmental disabilities deserve staff's best efforts to assist them to discover the possibilities in new relationships, and that these efforts are likely to call for changes in settled service routines, practices, and policies. Failure may not follow from the behavior of the person or the community but from everyday things in the service world that prove unmanageable like an inflexible staff roster or a residential agency transportation policy.

The conviction that a person deserves a better chance at new relationships than current circumstances allow creates organizational motivation to learn. It also sets up a distraction in the form of pressure to escape tension by boxing people with developmental disabilities into a self-justifying story that rationalizes current social isolation or deprivation of opportunities to contribute to civic life. These stories come in three varieties: blame for the person; blame for the community; and blame for the service system. Five storylines outline common ways to avoid responsibility for learning. Each works by denying that it is simply a story: it poses as a common sense, rational account of settled facts that realistically describe the way things are and must continue to be.

One. The **person can't** meet the presumed conditions of participation or friendship because he or she is in some way too impaired: too limited in communication, too dangerous and scary; too vulnerable; too cognitively impaired; too poor; too immature; too dependent on others for help with eating or toileting; too weird in appearance or pre-occupations.

Two. The **person chooses not to** involve himself or herself in any relationships or activities outside those currently available within the boundaries of specialized services. One version of this story suggests that to encourage engagement and relationships is to impose alien values on a person who chooses social disengagement as a preferred lifestyle. Other versions carry the assumption that people with disabilities are best suited to be with "their own kind" (understood as other people with disabilities) for one or more of three reasons: a) because they cannot be expected to meet non-disabled people's standards and

their shortfall would be painful to them; or b) because they prefer the company of others with similar abilities and experiences; or c) because people with disabilities share a culture that offers them superior opportunities to those available in the ordinary community –participation in which culture is denied by staff pre-occupation with imposing connections to non-disabled people.

Three. The **service system cannot** do what it might take. The person's limitations mean that to pursue any relationship or membership outside their service group would require more staff assistance than is affordable or fair. Individualized supports are too expensive. Group management and transportation are the only cost effective ways to proceed. Legal requirements for client confidentiality prohibit staff making introductions or supporting people to get acquainted. It is risky or isolating for staff to accompany and assist people in community settings.

Four. The **community is rejecting** or unready or predatory or dangerous in contrast to the safety, acceptance, and kindness that is exclusively, or at least much more predictably, available in special settings. Attempts to build relationships outside the boundaries of service settings will almost certainly have unpleasant and harmful results. At least, service providers must carefully screen and supervise relationships in order to protect service organizations against liability claims and people against injury.

Five. Nowadays, non-disabled people are too occupied in the daily round of getting and spending to have the energy and time for memberships and friendships for much of anyone outside their family circle. Social networks and local associations, and even perhaps face-to-face friendships with people who begin as strangers, are **romantic and nostalgic** notions. They simply no longer exist in the real world, or do not exist in an accessible form, or exist locally only in very limited or restricted supply, or exist only through internet connections.

Each of these storylines include plausible elements. Some people do require accommodation in order to participate. Some people do have a history of sometimes doing dangerous or scary things. Staff values, attitudes and priorities do influence the people who count on them for assistance, and it is possible for even the most sensitive staff to assume that what matters to them matters to the person they assist. Some people have decided that the hassles of belonging outweigh the possible benefits. Some kinds of assistance are beyond the budget. Trust is a widespread concern and a number of people in any community are patronizing, some are rejecting, and a few are exploitative or dangerous.

Our society does seem to be shifting in unpredictable ways around the forms that association and friendship, and family take. There are many barriers to inclusion.

These barriers only define the story of social integration when people who could act in positive ways become timid, draw back inside the relatively comfortable borders of the human service world, and apply themselves to making the conditions of exclusion more pleasant. Only people actively working for positive change can demonstrate failure. The success of many people with developmental disabilities in forming mutually satisfying relationships with their non-disabled fellow citizens makes it plain that working for social integration is not like defying gravity or implementing cold fusion. All it takes is willingness to embrace good reasons to find ways to walk through the walls that keep people with developmental disabilities and their fellow citizens apart.
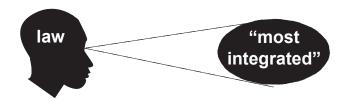
The discovery of ways through walls begins in the good relationships that people already have: with family members, with other people with disabilities, and with service staff. One aspect of these good relationships is acceptance. As Taylor and Bogdan (1989) put it,

> *Accepting relationships are not based on a denial of the disability or difference, but rather on the absence of impugning the disabled person's moral character because of the disability.*

Accepting relationships include shared positive experiences which give rise to an appreciation of what there is to enjoy in a person's company and what the person can contribute to our common life. This appreciation can form the basis for a plan for learning through action how to broaden a person's networks, memberships, and friendships to include greater engagement with non-disabled people. In a sense, social integration is no more than letting a wider circle of citizens know what those close to a person know: that whatever differences may be, there are good things to come from being with this person. (See O'Brien and Mount (2005) for a process that assists support staff to move from their appreciation of a person to increasing a person's participation in community life.) This is not to say that everyone enjoys good relationships with family or staff –sadly, some people do seem entangled in close relationships that produce only accounts of deficiency and deviance. When this is true, the first step toward "most integrated" is clearly to realign existing relationships.

Five perspectives on "most integrated" provide good reasons and practical guidance for seeking next steps into a wider social world.[*]

* Each of these perspectives include far more than will fit within the scope of this brief paper. I have borrowed only a few relevant ideas. Anyone who wants a real understanding of social integration will study the key works referenced.

A legal perspective

"Most integrated" is by no means a new standard. Before it became a legal standard, advocates and professionals debated social integration as a criterion for good quality services. By 1969, when the President's Committee on Mental Retardation published *Changing Patterns in Residential Services* (Kugel and Wolfensberger, 1969), the criticism of institutions as unnecessarily isolating and the call for as much interaction as possible between people with developmental disabilities and their non-disabled fellow citizens was an established theme in the controversy over the future of institutions.

In the US, controversy over the role of institutions soon came to court. Concern about the unnecessary segregation of people on the basis of disability figures in the briefs and opinions generated in response to many complaints about institutional conditions. The decisions and consent decrees that settled these cases have powerfully shaped community services, both directly and through their influence on the regulations and the administrative culture that implement Medicaid funding.

Nearly 40 years after it began, the controversy over institutionalization remains unsettled.[*] With this unresolved controversy goes an ambiguous definition of "most integrated." Lack of agreement about the need for public institutions keeps them open in all but ten states; all but four states house substantial numbers of people with developmental disabilities in facilities with more than 16 residents; and every state continues to pay for nursing home placement of people with developmental disabilities (Prouty, Smith, & Lakin, 2005). Clearly, there is a way of judging "most integrated" that includes being placed –regardless of personal choice– to live with a large number of others under professional control outside the usual places and patterns of ordinary community life and perhaps at considerable distance from family members. The logic that allows this can be read in an influential US Supreme Court's decision.

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[*] The issue does not remain unsettled for lack of convinced advocates on each side of the question. Some organizations advocate vigorously to keep institutions open. (For example, The Voice of the Retarded, whose positions can be examined at www.vor.net). On the other side, in substantially larger numbers, are advocates for the complete replacement of long term institutions by community services. This position is well expressed in *The Community Imperative* –a statement that calls for community services for everyone, regardless of the extent of disability– which has been endorsed by 648 US organizations representing people with developmental disabilities, family members, and professionals (thechp.syr.edu/community_imperative.htm). Many studies establish the feasibility and effectiveness of community services (for example, Staincliffe and Lakin, 2004). In between these vigorous advocates lies an un-mobilized mass of citizens who find more than enough to do to in simply living their lives and whose continuing disorganization on the issue leaves it unresolved.

Justice Ginsburg, writing for the US Supreme Court in *Olmstead v L.C.*, summarizes the three qualifications that legally square the "most integrated" standard with holding a person long-term in an institution.

> *…we confront the question whether the proscription of discrimination may require placement of persons with mental disabilities in community settings rather than in institutions. The answer, we hold, is a qualified yes. Such action is in order when the State's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities.*

527 U.S. 581 (1999)

The *Olmstead* decision draws on the US Attorney General's Regulations implementing Title II of the American's with Disabilities Act for its understanding of what constitutes illegal discrimination, and it is by affirming this regulation that the Court makes "most integrated setting appropriate to the needs of qualified individuals with disabilities" the qualified standard for testing the appropriateness of institutional placement. It is also from this source that the Court takes its definition of "most integrated" as

28 CFR pt. 35 (1998)

> *a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.*

This decision has influenced statements of federal and state policy. Many states have published plans, motivated by the idea that a plan for reasonable progress toward the development of community alternatives forms a key part of an adequate response to *Olmstead*. By Executive Order, President Bush called for concerted action:

> *The Federal Government must assist States and localities to implement swiftly the Olmstead decision, so as to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life.*

Executive Order: Community-based Alternatives for Individuals with Disabilities, 19 June 2001.

The practical effects of these initiatives on institutionalized people have not as yet been overwhelming, as summarized in the title of this statistical note (Lakin, Prouty, Polister, and Coucouvanis, 2004)

> *States' initial response to the President's New Freedom Initiative: Slowest rates of deinstitutionalization in 30 Years*

In my reading, the Court's logic for determining whether a placement is discriminatory rests on these two assumptions, among others. First, it assumes that the most important distinction lies between institutional and community settings. This logic has a judge ask, "Is institutionalization justified by this person's assessed needs, or does it constitute discrimination because professionally assessed needs could be met through an available or soon to be available community placement?" Second, it assumes that "need" can be defined in a way that is adequate to this judgement. The Court thinks that institutional treatment professionals can make this determination by predicting the effects of different alternative settings in a way that points accurately to one placement or another as enabling an individual to interact with non-disabled people to the fullest extent possible. A particular picture of service systems is necessary to make these assumptions reasonable. In this picture, services form a continuum of placements, where each placement matches a different sort or level of need, and each need makes possible a given level of integration and requires a corresponding level of restrictiveness for its appropriate treatment. (See Taylor, 2001 and Taylor, 1988 for a thorough criticism of the still influential picture of services summarized below.) These assumptions and this picture save from absurdity the argument that "the institution is the least restrictive, most integrated placement appropriate to this person's needs".

Institution	Specialized Facility	Nursing Home	Group Home	Foster Home	Apartment Program

More restrictive ———————————————————————————— Less restrictive
Less integrated ———————————————————————————— More integrated
More intensive ———————————————————————————— Less intensive

This logic may underwrite the best balance of contending political and legal interests that it is currently possible for the Court to draw. However, widespread experience refutes all of it.

It is possible to establish living conditions that restrict and isolate people with developmental disabilities in every sort of community setting, regardless of its size or location and regardless of the level of assistance people require. Community settings offer a greater potential for interaction with non-disabled fellow citizens than institutions can, but actualizing this potential requires thoughtful, individualized action. The potential for this action can be powerfully constrained by the design of community services and the practices of those responsible for managing and monitoring the organizations that provide them.

It is possible to provide sufficiently intense and relevant support to allow people with every level of need for assistance and every type of developmental disability to grow up with families, attend typical schools, and live in their own homes. For most people it is also possible to support successful employment in ordinary community settings. These typical roles and settings offer the best odds of social integration, though they do not assure it. Given the appropriate deployment of resources, there is no professional response to developmental disability that cannot be adequately provided in an individualized manner in a community setting.

The most effective way to understand a person's needs is to discover the individualized assistance a person needs to function successfully in typical activities in particular community settings that have meaning for him or her (Thompson, 2004). This requires specific knowledge of a person's capacities to respond to the demands of particular community settings of interest to the person and cannot be reliably generalized from the person's functioning in an institutional setting or, for that matter, from the interests and competencies a person demonstrates in group based community services that separate people from valued social roles.

The faulty logic applied by the court unnecessarily subordinates relationships to professionally defined "treatment". Instead of valuing a good and diverse network of social relationships as the most desirable context for any successful professional intervention that might decrease the effect of a person's impairments on the life they wish to lead, it positions professional interactions as superior. It suggests, falsely, that there are treatments for the impairments associated with developmental disability which are effective without regard for social context and relationships. This turns common sense on its head while it perpetuates a dangerous myth: that developmental disability of itself could legitimately require professionally administered quarantine. This myth drove the expansion of institutions in the period of eugenic alarm, to the great detriment of those caught in them (Trent, 1994).

The state of Wisconsin safeguards people who are protectively placed through annual reviews by probate judges, assisted by guardians *ad litem*, to assure that services are "least restrictive" and "most integrated". Ironically, striving to legally justify service arrangements as "most integrated" can block the learning necessary to deliver good answers to the central question, "Does this service arrangement offer this person the best possible opportunity to experience satisfying relationships with non-disabled people?" Annual trips to court will not yield opportunities if

concern for continual improvement in capacity to support diverse relationships is not alive everyday. The tactical question –"How can we persuade the judge to approve or continue this placement?"– can hide what is important by replacing day-by-day attention to human questions about social relationships with a once-a-year formality certifying that current arrangements support the highest level of interaction with non-disabled citizens that is possible for this person.
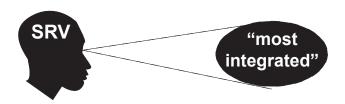
Lack of critical thinking about the importance of individualized support from assistants who value interaction with non-disabled people can lead those responsible for organizing and providing services from judicial approval of a placement to complacency. "Most integrated" becomes whatever happens in the way of relationships after a person is placed in a setting that is judged to meet the criterion. A superficial understanding of "choice" reinforces this complacency when a person who lacks opportunity, encouragement, and relevant assistance to reach out toward new involvements is said to "choose not to participate". It is a short step to defending isolation with the justification that encouraging new relationships would be an illegitimate imposition of staff values on the isolated person. A superficial understanding of providing competent assistance reinforces this complacency when a person 's behavioral difficulties or physical impairments are taken as a blanket justification for the conclusion that the person's disability renders them incapable of good relationships with non-disabled people.

While legal proceedings draw attention to "most integrated" as a standard, the legal perspective alone cannot sustain the kind of learning that is necessary to meet it for two reasons. First, the legal perspective assigns responsibility for defining the conditions that are most integrated to professionals responsible for the person's "treatment" and to those with authority over plans and budgets. This definition of "most integrated" rests on judgements of what is possible in places and among non-disabled people that the judging professionals may not even know. No science validates a model for such predictions that rises above self-justifying superstition. Second, the legal perspective has developed as a way to settle conflicts over whether people should be housed in an institution or not. Beyond presenting the "most integrated" standard, a legal view can offer little detailed guidance about how to proceed to meet the plain sense of its wording: that people interact with their non-disabled fellow citizens. This is because it necessarily looks at placement in service settings rather than at actualizing participation in real community places. If the professionals and administrative decision makers on whose assess-

ments and plans judges depend do not continually apply themselves to discovering better ways to assist good relationships, the test posed by "most integrated" will be routinely passed without much strain.

Indicating the limits of the legal perspective isn't the same as advocating a stronger role for the courts and their officers. It will be a happy day when legal judgements affirm that there is no justification in developmental disability for institutionalization and, further, that there is an affirmative right to individualized and self-directed supports. That day waits for a shift of legislative will and a wider public and professional consensus, but its coming depends in important ways on the willingness of people with developmental disabilities and their allies to stretch the boundaries of everyday life by seeking and prospering in new and diverse relationships with non-disabled fellow citizens.

There is plenty of room for disagreement with the Court's deference to "the state's treatment professionals" in defining "most integrated", not least because it suggests that they and their bosses enjoy a near angelic freedom from conflict of interest. But there is wisdom in recognizing the potential for legal authority to overreach its competence and usurp the civic and organizational space that people need to occupy in order to overcome a long history of social exclusion. In at least one situation, attorneys frustrated with progress toward community participation have tried to use court authority to require regular objective measurements that demonstrate progress toward integration. This intervention backfires as it shifts energy and attention toward documenting compliance with external demands and away from creating a climate in which people freely commit themselves to learning how to build good relationships.

To make progress on meeting the challenge of offering "most integrated" services, people have to decide to reach for a deeper understanding of "most integrated" because they are personally persuaded that it is the right thing to do. The legal standard can be an element in coming to this decision; it can never be sufficient. The key to the deeper understanding that underwrites the required learning can be found in reflection on the purpose of "most integrated" services, which is to enable interaction with non-disabled people to the fullest extent possible.

Social Role Valorization

Social Role Valorization (SRV) (Wolfensberger, 1998a) and its predecessor theory, the principle of Normalization, provide a comprehensive and controversial theory of social change aimed first at minimizing the harm that human services do to people with developmental disabilities and to the social fabric and second at achieving the best possible results from organized efforts to serve people with developmental disabilities (Flynn and Lemay, 1999). An evaluation instrument operationalizes each of these theories –the principle of normalization in *PASS* (Wolfensberger and Glenn, 1973 and SRV in *PASSING* (Wolfensberger and Thomas, 1983).

SRV helps people who want to push the limits of "most integrated" by providing a way to talk about what social integration means and why it is important that allows learners to analyze the strengths and weaknesses of their efforts and the threats and opportunities in the environment that contain their work. (See Reidy and Sullivan (2000) for a good example of an evaluation of the state of social integration in a service region.)

The first helpful distinction that SRV makes separates **physical integration** –presence in ordinary settings, activities, and contexts, where non-disabled people are also present– from **social integration** –a person's valued participation in voluntary relationships with non-disabled people in ordinary activities in typical community settings. In SRV terms, full realization of "most integrated" means "personal social integration and valued social participation" where the relationship is mutually chosen by the people involved.

This definition makes it possible to tell the difference between good things that can become confused in ways that lead people to think that "most integrated" has been accomplished when it has not. Please note in the examples that follow that the comparison establishes a distinction between good things. The comparative word is "different from", not "better than" or "worse than".* The pleasures of friendship with another person who uses the same services that you do are not, because of the fact of shared status as service users, greater or lesser than those of a friendship with a non-disabled person who has nothing to do with services. The possible positive effects of this difference are on the range

*Some other SRV teachers would disagree with this understanding because they identify substantial advantages to socially devalued people in having relationships with people and places of high social value. They would object to my softening the comparison.

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of experiences and opportunities that become available to everyone involved, and on the level of connectedness, appreciation of difference, and mutual understanding in community and society, and on the way a person with a developmental disability is seen and valued.

Example. Sharing time in a human service setting, being with, enjoying, offering and gaining strength, support and skills from other people who receive and provide assistance is good. It is not social integration because it does not happen in a community setting and it does not include direct and mutually voluntary involvement non-disabled community members.

Example. Doing preferred or necessary community activities (shopping, going to a movie or concert, going to the doctor) in company with staff and service recipients who like you and enjoy being with you is good. It is not social integration, because it does not include direct involvement with non-disabled community members outside of commercial or professional transactions.

Example. The residents of a group home regularly attend Sunday church services with a staff member. What else would you need to know to decide whether or not this is social integration as well as physical integration?

This distinction makes a difference because experience in evaluating human service programs, summarized in the graph, shows how difficult it is to consistently support social integration. On average, human service programs achieve 60% of the possible score for physical integration, but only 19% of the possible score for social integration. While physical integration is desirable for many reasons, including being a precondition for social integration, it does not assure social integration.

The notion that what is most integrated is voluntary is worth reflection. As Wolfensberger says,

> we see **valued** participation as something that can only occur on a **voluntary** basis. After all, one cannot force people to value others, their presence, or their participation. In contrast, [another understanding] is based on a rights (primarily legal rights) notion that prefers valued presence but will enforce an involuntary, devalued presence. (1998b)

This increases the challenge in creating "most integrated" supports in at least two ways.

One. The sense of accountability that prevails in many human service systems puts great store on predicting and controlling results. Being as-

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100%

Physical
Integration
60%

Acceptable

Social
Integration
19%

0%

Average achievement of 1259 human service programs on measures of physical and social integration (Flynn, Guirguis, Wolfensberger, & Cocks, 1999)

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sured that what is necessary will be provided according to plan is good. But social integration is different. It often takes thoughtful effort to set the conditions for relationships to emerge, but real relationships happen (or not) based on the choices and actions of the people engaged in them. A service can be accountable for providing the kinds of assistance that can be managed –such as assisting a person who needs help to get dressed and ready on time to meet the person who is giving her a ride to church, or helping a person prepare dinner to host a friend. But a friendship or a membership belongs to the people in it and is unmanageable by staff, even though staff hold a responsibility for the person's well-being that is assigned by the system that finances and monitors their work.

Two. People need to choose to make and maintain their friendships, memberships, and network connections. People's level of interest in making such choices reflects the quality of their supports more than their temperament (most shy people enjoy the roles and relationships they have every bit as much as those who are more extroverted do). If assistants have confidence that the person has something to offer, and if they have earned the person's trust by listening carefully to the person and following through on what they hear, they will be able to encourage the person to take the risks involved in reaching out. If those who support a person are themselves only complying with an external order to "integrate people", the chances that people with developmental disabilities will do the work involved in social integration go down.

SRV raises awareness of the ways that many common service practices interact to influence the level of social integration a person experiences. In particular, it draws attentions to the importance of the social roles a person plays and to the many ways a human service affects those roles. A person has far better chances for mutually satisfying relationships in a service club if he plays an active and valued part in the group than if he is seen and treated as a pitiful incompetent who is just along for the ride. When human services structure their living conditions, people's ability to fill satisfying and valued roles depends on how consciously, consistently, skillfully, and powerfully service workers orchestrate available resources to assure that they are seen and treated in positive ways (social image enhancement) and that they have active support to perform capably (competence enhancement).

A human service enhances image and competence through meticulous attention to the ways that its practices influence where people are,

who people are with, what people are doing, and how people are seen, thought about, and talked about. This means attending both to major service design decisions –so that people live, work, learn, and play in valued community settings– as well as to the details of interaction between people and their assistants –such as people's appearance or the ways assistants talk with and about them.

Lemay (in press) explores the implications of SRV for social integration and suggests several rules of thumb for people who want to move toward a more integrated world. Some of these are paraphrased here.

	Socially Valued Role	
	Image enhancement	**Competence enhancement**
Where people are		
Who people are with		
What people are doing		
How people are seen & interpreted		

- Focus on one person, one setting, and one role at a time, especially when people have a history of social exclusion.
- Fit the role to the person, considering individual competencies, affinities and interests and the demands and developmental possibilities of a role that is likely to be attractive to a person.
- Look at the whole setting around the role of interest; identify the people and interactions that will increase the chances of satisfaction and success; and enlist those people in the effort.
- Don't let the desire for a primary role such as "best friend" overshadow the important of secondary roles such as volunteer usher for the community theatre group. Establishing capable performance in a secondary role is usually more manageable than landing a primary role in a single jump and secondary roles can lead on to primary ones.
- Smaller settings that have fewer people to do necessary work can offer good opportunities for the person's involvements to expand.
- Involve family and friends in identifying and supporting new roles and settings, and in supporting the person to succeed there.
- Expect roles to change and develop, and adjust supports accordingly.
- Build on success by assisting the person to add new roles and settings based on their experience in the initial roles.

SRV and its related teachings also provide an account of why it is so difficult and slow to build more diverse and inclusive networks, associations, and friendships. Its reading of history and sociology show long standing patterns of social devaluation of developmentally disabled people. Knowledge of the mythologies that led social reformers to build

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segregated institutions and services, and the common pattern of personal wounds that are their legacy, builds commitment to the hard work of social integration.

There is more at stake in this work than just individual satisfaction. Greater social integration will decrease the numbers of non-disabled citizens who think death preferable to living with developmental disability as peole encounter one another's ordinariness. The awful, widespread, and mostly unconscious web of devaluation and social distancing that ensnares so many people makes sense of the key recommendation of Reidy and Sullivan's study (2000) of social integration: identify, encourage, and train family members, people with developmental disabilities, and staff to be champions for social integration.

Can this level of attention to theory help? Consider the experience of DDRC, a large service providing organization in Calgary, Alberta. SRV has been one of the guiding ideas in ten years of organizational development (Ramsey, 2005). Begining in 1993, DDRC closed its nine group homes and four congregate day programs and replaced them with more individualized services. Person-centered planning approaches that focused on honoring people's choices and helping people to attain what they desired steered this change process.

A careful look at the result of these major and generally successful efforts through the lens of SRV revealed a new set of problems that resulted from success at individualizing supports. Choice had become a sort of sacred cow, and many people understood choice simply as looking for what a person would find familiar and fun to do. Expectations that people would find it desirable to reach for new possibilities were low, and so many people's social worlds remained small and limited to familiar networks of people served by the agency and its staff.
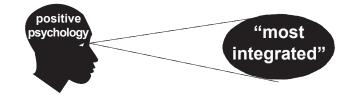
Reflection on these results stimulated revision of the person-centered planning process to incorporate a more explicit focus on community roles and relationships, a greater investment in widespread SRV training, and multiple investments in building community connecting skills. A renewed focus on encouraging work, volunteer activity, and then, a bit later on intentional support for friendships, has resulted in substantial improvements, reflected in the changes summarized this table.

	2002	2005
People employed	35%	68%
Average wage per hour	$5.17	$7.56
People with volunteer roles in community settings (sometimes in addition to paid employment)	32%	48%
People who pursue all activities during service hours in an inclusive manner	35%	90%
At least one friend in the community where reciprocal visits occur regularly (does not include family or friends among staff or other people with disabilities)	13%	57%

Positive Psychology

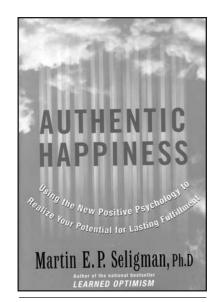Positive psychology is a growing body of research arising from the idea that psychology should be as concerned with what is right with people as with what is wrong with them. It explores the conditions under which people develop their capacity to enjoy positive emotions and exercise their strengths and virtues. The researchers involved work to discover measures and methods that improve people's chances to experience lasting happiness (Seligman, 2002; Seligman and Csikszentmihalyi , 2000; Seligman, Parks and Steen, 2004) They aim to understand what enables individuals and communities to thrive.

Unlike SRV, positive psychology is not directly concerned with people with developmental disabilities or with social integration.* It contributes to a better understanding of "most integrated" by providing a way to think about the consequences of different ways that any person, developmentally disabled or not, uses their signature strengths. It also enriches the discussion of "most integrated" by drawing connections between the ways people use their signature strengths, their happiness, and the well being of their communities.

Asked what they wish for their sons and daughters, many parents answer, "Happiness." Many staff who assist people with developmental disabilities answer the same. This raises a further question, "What are the ways to happiness?"

Positive psychology identifies three paths to greater happiness. On the first path, people seek to experience pleasurable sensations and emotions. They cultivate gratitude and forgiveness in order to increase enjoyment of their memories of the past. They learn to attend to and savor what is positive in the present moment. They build hope and optimism about their future. It is this path of feeling good that many people identify most easily with happiness. When people are fortunate in traveling this path, they can be said to be living the **pleasant life**.

Seeking the pleasant life focuses many efforts to make life good for people with developmental disabilities, and these efforts have paid off. Most people with developmental disabilities are warm enough and decently fed. Most are surrounded by furnishings and possessions that they enjoy. Some garden or ride horses (often in the name of therapy). There are sports and entertainments and recreations and occasional shopping sprees. Wishes for once-in-a-lifetime experiences like sky

This book provides a very good overview. For links to this growing field, go to www.positivepsychology.org/

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*Researchers interested in developmental disabilities are beginning to draw on positive psychology, for example see Dykens (2005).

dives or white water trips sometimes come true despite many hurdles to overcome. Provision for holidays is a justifiable expenditure for many. Special needs trusts provide amenities unaffordable with public funds. Many staff enjoy providing their clients with treats and surprises. Motivational speakers with disabilities inspire a growing number of people with developmental disabilities to esteem themselves and grasp their future with optimism.

For people who need assistance, these important occasions of good feeling take thoughtfulness and extra work by staff and family members. There is every reason to appreciate these efforts and their results, especially considering how much greater the chance for a pleasant life has become since the dark time of the pre-medicaid institution. But there is no reason to stop with the pleasant life; positive psychology identifies two more paths to happiness.

The two additional paths to well being represent ways that a person uses his or her **signature strengths** (Peterson and Seligman, 2004). Strengths build when a person has opportunities to choose to use them and learn to improve them. Exercising a strength is valued for itself, regardless of whether or not it has a desired result, but it usually produces a sense of fulfillment in the doer and observers often feel admiration, uplift, and maybe even envy. Strengths are rooted in, and express, six virtues that positive psychologists believe are valued across cultures. They name these six virtues wisdom, courage, humanity, justice, temperance, and transcendence. They have developed ways

Wisdom & Knowledge
Curiosity
Love of learning
Judgement
Ingenuity
Social intelligence
Perspective

Courage
Valor
Perseverance
Integrity

Transcendence
Appreciation of beauty
Gratitude
Hope
Spirituality
Forgiveness
Humor
Zest

Humanity & Love
Kindness
Loving

Temperance
Self-control
Prudence
Humility

Justice
Citizenship
Fairness
Leadership

to measure an individual profile of twenty-four signature strengths. The diagram identifies the twenty four strengths and their associated virtues.

It gratifies people to fully engage their signature strengths in activity, and this defines the second path to happiness.[*] Different people find gratification in different pursuits: having a great conversation, meditating, playing football, piecing a quilt, playing a piece of music, learning from observing nature, hunting, sticking with a work team all the way through the resolution of a conflict. Gratifications absorb people. They may lose track of time and most everything else outside the flow of the gratifying activity itself: an hour may seem like five minutes. There may be short cuts or passive ways to pleasures (for example, eating ice cream or getting a massage), but there are no shortcuts to gratification. People engaged in gratifying action, which draws on and builds up signature strengths, may not report much feeling at all while they are involved in the activity. Indeed the activity may involve frustration and pain –think of running a marathon– but the overall experiences brings a satisfaction that is deeper and more lasting than the pleasures are. Call this route to happiness the **engaged life**.

Like the engaged life, the third path to happiness also attracts and develops a person's signature strengths, as the person commits these strengths to serve something larger than self. People on this route to well-being deploy strengths in order to belong to and contribute something they experience as beyond their narrow self-interests. They might name what they serve family, community, country, knowledge, justice, goodness, or God. People with developmental disabilities have benefited greatly from this kind of service, especially from mothers whose development and vigorous exercise of their strengths has opened up opportunities from local life to national politics (Lyle O'Brien and O'Brien, 1999). Call this way to happiness the **meaningful life**.

The idea that services should support people to "get a life" has become popular. Positive psychology offers a way to reflect on what kind of life it is that service workers aspire to assist people to get. Historically, institutional services offered people little beyond the conditions for survival. More recently, developmental disability services have done much better at providing people with a pleasant life. An even better future lies in the direction of active partnership between people with developmental disabilities, their allies, and their assistants. This partnership will make life better if it is based on the expectation of engaged and meaningful lives that flow beyond the boundaries of the service world into the many areas of community life that draw people's interests and build people's signature strengths.

[*] To understand signature strengths better, take the test and get a profile of yours at www.authentichappiness.org
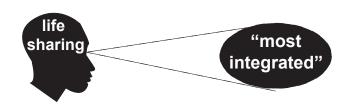
Positive psychology suggests some ways that these partnerships can proceed:

- Most people develop signature strengths from appreciation and teaching and challenge from others who see those signature strengths. Put the discovery and development of signature strengths at the core of the organization's work.
- Be sure that the time spent in individual planning results in deeper understanding of people's signature strengths and clearer ideas for increasing opportunities for engagement and meaning.
- When services control people's schedules, make sure that each person has time each day and each week for engagement on activities that draw on and develop signature strengths.
- Put ways to deal with the effects of people's impairments in learning, movement, communication, health, or self-control in the context of living an engaged and meaningful life. This demands both competence and imagination from staff with professional skills and authority.
- Presume competence. Hold tight to high expectations that all people have signature strengths and the capacity to find gratification and meaning in exercising them. Break the spell that allows the belief people with developmental disabilities are limited to passive reception of other's efforts to make their lives pleasant. This spell can entangle people with developmental disabilities themselves as well as family members, staff, and community members. As a matter of civility, everyone should take some interest in making the lives of the people around them as pleasant as possible, but this is not a one-way stream with people with developmental disabilities on the receiving end; neither is it the only path to happiness that people can travel together.
- Encourage people to reach out and find role models, teachers, and mentors to match their signature strengths. This will almost certainly involve assisting people to expand their networks and memberships. It takes at least a village to encounter sufficient diversity of gifts to match all twenty-four strengths.
- Make it a principle of management to support and challenge staff to develop their own signature strengths in the context of their work. This is especially important for those staff who spend the most time with people with developmental disabilities.

It is along the paths to discovering, using, and developing signature strengths that people are most likely to meet companions and become involved with those parts of their communities that are most important to them. "Most integrated" lives will not only be pleasant lives, but engaged lives and meaningful lives.

Life Sharing

Life sharing refers to a variety of different ways that people live together in intentional communities that include people with developmental disabilitie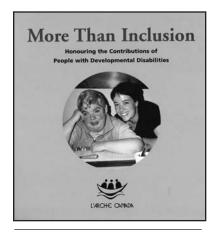s and people without disabilities in mutual relationships that aspire to reach beyond the staff-client roles that are typical of many human service settings. These efforts began with purposeful efforts to invite disabled and non-disabled people to share home life together. Each draws on its own distinctive spiritual source and each has its own tradition of understanding and responding to disability that grows with participant's continuing reflection on life together. Some, like many Camphill communities, gather a number of households and places of occupation into a small village. Others, like most l'Arche communities, consist of one or more small households and sometimes workshops which are typically dispersed throughout a locality. Though these communities may seem conservative in social values, they are consciously counter-cultural in their commitment to live in a way that provides a true alternative to the competitiveness and materialism expressed in the larger society overall and particularly in the social devaluation of people with developmental disabilities.

Camphill, founded in Scotland in 1939, and l'Arche, founded in France in 1964, have spread throughout much of the world. These larger and more organized traditions of living together have inspired many other efforts. Some of these are shared households and some are organizations that support families to thrive in the presence of developmental disability. Many of the people who have spread the practice of creating circles of support with people with developmental disabilities draw strength and inspiration from life sharing traditions, especially those of l'Arche.

Though their spiritual sources, understandings of disability, and traditions differ, both Camphill and l'Arche share the conviction that people with developmental disabilities have a vital role to play in the world. This role does not depend on their talents and accomplishments –though both movements honor and encourage the cultivation of every member's gifts– but on the relationships that they can bring into being with and among people who recognize their full and equal humanity despite powerful and devaluing cultural messages to the contrary.

In l'Arche's terms, these mutual relationships create a school of the heart. In this school, non-disabled community members can be students of teachers with developmental disabilities and developmentally disabled community members are well positioned to learn from assistants without

Download this book from www.larchecanada.org/Resources/

developmental disabilities as trusting relationships grow among them.[*] L'Arche's identity statement says, among other things,

> *People with developmental disabilities often possess qualities of welcome, wonderment, spontaneity, and directness. They are able to touch hearts and to call others to unity through their simplicity and vulnerability. In this way they are a living reminder to the wider world of the essential values of the heart without which knowledge, power and action lose their meaning and purpose* (Charter of the Communities of L'Arche, 1993).

The founder of l'Arche, Jean Vanier, summarizes its practice this way

> *L'Arche seeks to create communities of love, acceptance, and celebration for people who have been traumatized by stigma, rejection, and loneliness, in order to reawaken desire, hope, energy, and dreams.*

The conviction that people with developmental disabilities have important things to give through their different individual ways of being with others does not mean that Vanier and his associates think that they live among angels. If it is real, life together brings people into contact with brokenness, anguish, violence, and hurt in one's self and in others. And many people with developmental disabilities are tormented by a history of rejection and belittlement. It is in sharing what comes up over time around the simplest routines and rhythms of life that people find their ways to strengthen each other's hearts and help each other grow.

Of course, life sharing is no panacea. The efforts are small in number compared to the vast empire of segregation managed by the nursing home industry. Some people with developmental disabilities who have tried living in this sort of intentional community don't like it and others are ready to move on after a time. So also with many people without developmental disabilities. And, like any setting that brings people together around strong beliefs, life sharing places hold the potential to turn in on themselves and shun the world outside. It is the fact that developmentally disabled members of many of these communities have made connections and friendships with non-disabled people beyond their households that makes a life sharing perspective on "most integrated" interesting.[**]

L'Arche demonstrates that some people with developmental disabilities need a very strong foundation at home if their friendships, memberships, and networks are to stretch to include non-developmentally disabled people. This foundation of mutual relationship and secure space and time has to be woven and re-woven among those who live together.

*To discover some of what men of considerable intellectual achievement have learned from sharing life with people with developmental disabilities, read Jean Vanier's CBC Massey lectures (1999), *Becoming human*. Toronto: Anansi; Henri Nouwen (1990) T*he road to Daybreak.* New York :Image, and Henri Nouwen (1997) *Adam: God's Beloved*. New York: Orbis.

**What follows focuses on the experience of l'Arche Canada, portrayed by Beth Porter (2005), supplemented by an account of the pedagogy of l'Arche by Anne Escrader (2001).

The threads come together around making a fruitful ritual of everyday routines: bathing, dressing, preparing meals, clearing up, doing house-work, raking leaves. The tasks could come from a checklist for any home help service, but two qualities convert these tasks into a secure foundation for new relationships. The first quality is the mutual respect and attention that the people involved bring to their shared perfor-mance of ordinary tasks. Appreciation of the other person's reality and dignity, as revealed in the smallest matters and moments, can slowly relax the power of stigma, rejection, and loneliness to trap people inside themselves. The second quality that distinguishes relationship weaving from efficient and impersonal service delivery is people seizing occasions to waste time with one another. This essential hanging-out time expands when people have support to resist the temptation to let the television dominate spare moments.

Ritual also figures in honoring small and large transition points. Daily marking the main meal and perhaps group prayer or reflection as com-mon rites and waking and bed times as personalized ceremonies offers some people the security to launch expanding relationships. Celebrat-ing anniversaries and birthdays and accomplishments, frequently invit-ing dinner guests, holding pot-lucks and throwing parties that gather in all sorts of people provides an abundance of opportunities for relation-ships to spark and develop. Small and large rituals also give people a framework for connection by offering chances for the performance of one of the many roles of celebrating, hosting, or entertaining.

Taking trips and making pilgrimages together renew contacts, expand connections, and build confidence. People with developmental disabili-ties develop awareness of people, places, and social issues beyond their usual horizon. This awareness provides new topics for conversa-tion, and a variety of calls for shared action.

Marking occasions together weaves a stronger fabric as members get married, have children, move on to other places, deal with major illness, and die. Sharing these milestones in people's lives creates stories that remind people of who they have been to each other and to initiate newcomers into the flow of life together.

Experience shows that some non-disabled people find the dignity of people striving to live simply and hospitably together attractive in itself. Dinner or party invitations become prized. Regular encounters with people on occasions that offer models of respectful interaction some-times lead to the discovery of common ground across big differences in achievement, status, and income.

In this context of regard for mutuality in the finest details of everyday life, some people gain the confidence to move out of isolation into roles and connections that carry them deeper into and then beyond their intentional community, adding new friendships and memberships to those that continue to offer security and strength.
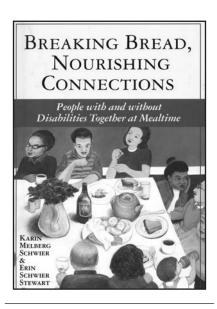
L'Arche's experience underlines the importance of investing in significant amounts of regularly scheduled time for assistants (non-disabled community members) to reflect on their lives and relation-ships. Deep listening to one another allows assistants to pull together the threads of their own learning, most of which begins without words in the flow of everyday life. Stories of personal transformation –both observed in other intentional community members and experienced in one's self– heighten moral imagination about what it means to belong with others. Piecing together valid accounts of the gifts of the people with whom assistants share life deepens appreciation of each per-son and may point the way to new opportunities for connection and contribution. Having a variety of resources to help make sense of the cultural and social forces that shape the exclusion and denigration of people with developmental disabilities strengthens determination to resist these dark powers and to support others to resist them.

While the particular spiritual wellsprings from which l'Arche draws may not be palatable to everyone, adopting the habits of reflection that shape l'Arche at its best will strengthen any organization commit-ted to serving people with developmental disabilities.
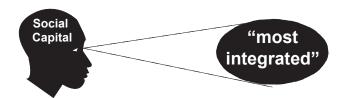
L'Arche's experience in assisting people to expand their friendships, memberships, and networks suggests some useful questions for any organization that wants to learn how to make "most integrated" a reality.

- How do we assure that the staff who assist people are working thoughtfully on building mutual relationships based on an apprecia-tion for the inherent dignity and the gifts of each person?
- How do we encourage and assist people to host people from out-side their usual circles for meals and parties?
- Do we expect staff to be transformed in positive ways through their relationships with people with developmental disabilities? How do we support them in the reflection necessary to integrate that learn-ing?
- How do we talk about people's gifts, and do we have ways that lead directly to practical encouragement of those gifts in settings that include new people?

- How much thinking have we done about the kinds of contributions people with developmental disabilities can bring to the lives of other citizens who are concerned with matters of social justice, spirituality, and right living? How much has this thinking included consideration of people with profound disabilities or difficult behavior?
- Do we have a clear understanding of the individual conditions that work best to support each person to recruit new people into his or her life? How do we make sure that these conditions are met when people have the opportunity to connect with new people?
- How do we shape the rhythms and rituals of each person's life to provide a secure foundation for reaching out to new people?

This book (Melberg Schwier & Schwier Stewart, 2005) is a wonderful source of ideas about mealtimes as occasions fr nourishing and extending relationships. Includes lots of practical ideas for people who have difficulties with eating and swallowing.
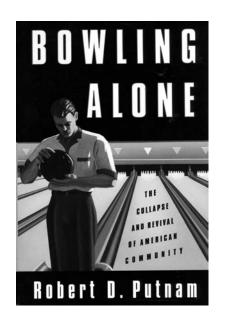
Social Capital

"most integrated"

For nearly ten years the formation of social capital has been an important topic of debate among people concerned about civic life. The basic proposition is that important social benefits flow from strong and diverse social networks. Communities differ in the extent of their available social capital in ways that have significant, measurable effects on well being. Social networks grow from and build up exchanges of trust, information, and cooperation which have positive impacts on a community's overall economic and cultural success, and its citizen's levels of education, health, and safety. The value of all of a community's social networks and the inclinations that arise among members of these networks to do things with each other is identified as "social capital". The richer the connections among people, the richer the community. (Putnam, 2002)

Social capital grows or shrinks depending on people's choices. When people understand and emphasize the centrality of relationships in their efforts to achieve their goals, social capital grows. This happens through the accumulation of large decisions –like the choice to form an alliance of local employers in order to create job access for people with developmental disabilities or the choice to become a volunteer firefighter– and small ones –like the choice to turn off the television and go out to a block club meeting or forgo a fast food stop in favor of the spaghetti supper at church. That we reach out to one another builds social capital; toward whom we reach determines the shape our community's networks take. When we reach toward others we see as "like us" we create **bonding social capita**l. When we reach toward people we see as different, and find a new basis for continuing connection with them, we build **bridging social capital.** Bonding social capital grows when the parents of children with autism gather for mutual support. Bridging social capital grows when some of these parents get active in the politics of providing affordable, accessible housing by joining in coalition with people who may never have met a person with autism but care about better housing for other reasons.

There is (controversial) evidence that usual ways of forming social capital are less effective than they have been in the past, especially among the World War II generation, which has had very high levels of civic engagement. Membership in most service clubs and many associations is declining; direct political participation is declining; and, to pick up on the book's title, more people than ever go bowling, but many fewer people belong to bowling teams and self-organized leagues. If

www.bettertogether.org/

citizens don't discover and invent new ways of connecting socially that fit a rapidly changing society, our communities will grow poorer in every sense of the word. Given the growing diversity of the population, inventions that support the creation of bridging social capital are especially important.

This civic challenge intersects with significant opportunities for quality improvement in organizations that provide services to people with developmental disabilities.

Since 1993, The Council on Quality and Leadership (CQL), an international organization that supports organizational learning to improve service quality and accredits services to people with disabilities, has developed, applied, analyzed and refined measures of personal outcomes in the lives of people who receive services. The table on the next page summarizes the extent to which these twenty-five valued outcomes are present in the lives of people served by many different organizations that participated in the accreditation review process using the *Personal Outcome Measures* (The Council, 2005).

CQL's most recent analysis of outcomes, (Gardner and Carran, 2005) leads it to redefine service quality in terms of the impact that a service organization has on social capital. Among the findings of the Council's analysis are these:

- Organizations have greater success in facilitating outcomes that depend on the internal processes that they manage and less success in assisting people to attain outcomes that depend on connecting with people, settings, and roles in the community outside their boundaries.

- People labeled severely or profoundly mentally retarded have significantly fewer personal outcomes than people with mild or moderate mental retardation. People with severe or profound mental retardation have the best chance of good outcomes in individualized services provided by small organizations (where small means that the whole organization serves <100 people).

- There is no evidence that associates greater choice with less safety and less freedom from abuse and neglect. More choice does not have to mean less safety, and more choice is a powerful predictor of the presence of all of the other personal outcomes.

Percent of Personal Outcomes Present	
People have time, space,& opportunity for privacy	89%
People are satisfied with services	86%
People are safe	84%
People are satisfied with personal life situations	83%
People choose their daily routine	83%
People are free from abuse & neglect	81%
People experience continuity & security	81%
People decide when to share personal information	77%
People use their environments	76%
People have the best possible health	75%
People interact with other members of the community	71%
People have intimate relationships	70%
People are respected	69%
People realize personal goals	66%
People are connected to natural support networks	66%
People participate in the life of the community	65%
People choose services	55%
People have friends	51%
People exercise rights	47%
People are treated fairly	47%
People live in integrated environments	46%
People perform different social roles	44%
People choose personal goals	43%
People choose where & with whom they live	43%
People choose where they work	34%

Based on measurements gathers by trained reviewers during accreditation of 552 organizations, involving 3,630 different people. Each outcome is personally defined and described by the person or a key informant.

- Health and wellness outcomes are good overall. These outcomes are no worse in more individualized settings than in specialized facilities, regardless of the level of people's disability. However, attainment of other personal outcomes is substantially greater in more individualized services, no matter what the level of a person's disability.
- The best predictor of personal safety and freedom from abuse and neglect is having intimate relationships and having friends (most of these relationships are within the service group or with family).

In summary, the greatest opportunities to improve quality for the developmental disabilities field as a whole lie in discovering ways to cross the boundaries of services and connect with valued roles (such as a job or having one's own home) and community resources. The need for this learning is greatest when the focus is on people who need most assistance. Many organizations face the further challenge of moving from services that deal with people in groups to the individualized supports that are associated with better results on all of the more challenging personal outcomes.

CQL traces a five step history that outlines the transformation of the relationship among people with developmental disabilities, service providing organizations, and community (The Council, 2005). This is an adapted version of that history:

I. Organizations focus on housing, occupying, and supervising people up to twenty-four hours a day, seven days a week. Good management results in safe, clean facilities where staff assure that people observe prescribed routines and treatments and document the ways that they follow procedures and schedules.

II. The focus shifts to consumer (and often family) satisfaction through processes managed within the boundaries of the organization. Good management results in services that offer people more choices from a more varied menu of activities.

III. The focus widens to include additional human services the person is eligible for in his or her community. The organization becomes a player on the human service scene, joining others to influence disability issues through trade associations and coalitions. Good management extends the menu of available services by increasing people's access to such resources as senior centers, mental health services, and vocational rehabilitation and protects human service budgets when it can't expand them.

IV. Focus sharpens to assist consumers to make some connections in the community that match their individual interests. The resident of a group home may join the church choir, perhaps with the help of a staff member with the job title, Community Connector. Good management creates the episodes of flexible and individualized assistance that people need to move into occasional community roles.

V. Focus widens and sharpens again as the whole organization commits itself to forming bridging social capital at every level of it's activity. On the person level, people with developmental disabilities get assistance to build personal networks and memberships. On the program level, staff go about their tasks by extending their networks and collaborations. For example, job development engages staff in joining and building networks that include local employers, workers, unions, and economic and human resource development efforts. The organization as a whole positions itself as an active contributor to efforts to strengthen the community. Good management creates the conditions for people with disabilities and staff to exercise leadership and make good investments of the organization's resources in generating and supporting initiatives that engage and strengthen community networks.

To meet the challenge of improving quality, service organizations and workers need to learn how to build trust, reciprocity, information flows, and collaborative actions that bridge between disability networks and the myriad networks that make up the larger community. The good news from research on social capital is that these efforts will also benefit the larger community by building up bridging social capital.

Talk about social capital will be just talk until people with developmental disabilities build bridges by taking up active roles in a wider and wider variety of networks. Some people need specific assistance with making these connections, and some organizations understand a commitment to "most integrated" services as requiring significant investment in learning how to provide it. *Sharing Community* (Mills and Messinger, 2005) records the lessons and strategies from one such effort, which has been happening at Options in Community Living for more than ten years. The book issues twenty specific "Community Builder's Calls to Action" and provides examples, illustrations, and guidance for responding to each of them. (Following Options' usage, the staff person who does this work can be called a Community Builder.)

An accessible, practical guide. Order from www.optionsmadison.com

Of course, not everyone needs assistance from a Community Builder. Many people with developmental disabilities need very little beyond the freedom of movement offered by individualized assistance. With this freedom they pursue their own interests and grow their own networks, memberships, and friendships. And, once most people with developmental disabilities make contact, they are as capable of recruiting people into relationship with them as most non-disabled people are, as long as the staff on whom they count for practical help value their activities and relationships enough to support success. But some people get stuck just at the point of looking around to discover new possibilities for connection or reaching out to try them. This is the point at which someone who functions as a Community Builder can assist.

Sharing Community's account of the lessons one organization has learned about assisting people to make connections outside the boundaries of their service world highlights the importance of working through networks to extend networks. When they are effective, Community Builders create social capital.

The Community Builder's work proceeds on trust. Information about what the person with a developmental disability cares about only flows when a person with a developmental disability trusts that the Community Builder can be a reliable guide. Trust in the Community Builder can be important in tipping the personal balance from fear of moving outside familiar routine toward desire to try something new.

Locating possible connections depends on the Community Builder thoughtfully growing a network of trust that permeates the community. A Community Builders access to large and diverse networks opens many paths to explore. It allows connection to opportunities that might match a person's interests, or a new contact with someone in a further network who might be willing to arrange a link. The Community Builder's own exchanges with members of diverse networks builds up a sort of a fund of social capital that the Community Builder can invest in accrediting the person with a developmental disability: "Gary and I worked together on a project; if this person is OK with Gary, he's OK with me."

Being part of a wide and diverse network increases the Community Builder's confidence that possibilities for connection exist, no matter what a person's interest might be. An example: *Sharing Community* tells the story of locating the Tarantula Appreciation Society. This confidence that community has abundant opportunities for the pursuit of diverse interests allows the Community Builder to welcome whatever a person identifies as important as a starting point for a search. It means never
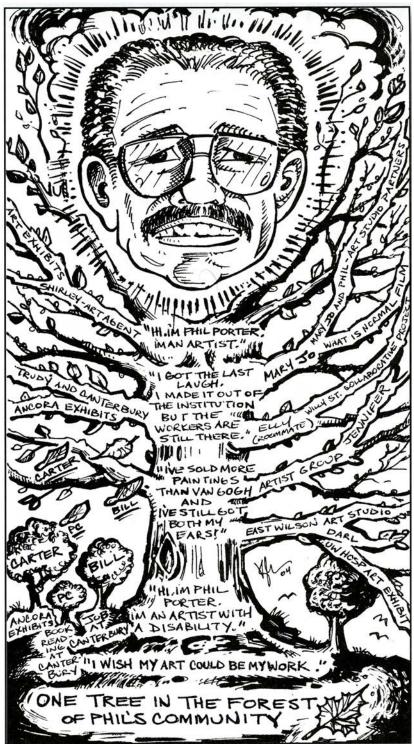
having to discount as "un-realistic" the possibilities in any dream a person might find a way to share.

Success in building social capital encourages success, as well as modesty about what can be guaranteed. The resiliency of people in social networks becomes clear. Every connection does not work out perfectly or turn into friendship or endure forever. Connections often grow when interested people show up and join in, despite distractions, hiccups, and occasional disasters. Many people will do what they think they can do in order to accommodate a person's unusual attributes or needs for accommodation. A little effort by the Community Builder to help people find a different way to understand the person or engage people in problem solving can enlarge what people think they can do by quite a lot. Troubles, failures, disappointments, and discoveries that what seemed like it would be interesting doesn't turn out that way are all opportunities to build greater trust between people and their allies, including the Community Builder, as together they commiserate, figure out what lessons can be learned, and decide what to try next.

Over time, a Community Builder gets more and more attuned to the music of connection. Even small hints in conversation open up possibilities for participating with new and different people. Postings on the coffee shop wall or the supermarket window become interesting as pointers to possible matches. Bits of conversation overheard on the bus may stimulate the Community Builder to introduce herself and ask to know more. The Community Builders catalog of local human interests and activities grows, and each activity in that mental catalog has a face beside it that stimulates the imagination of new and interesting links.

The work of bringing people together becomes more satisfying as it becomes clear that one thing has a way of leading on to another. The cartoon on the next page shows Phil's journey from a wish, that art might be his work, to a reality, a successful career as an artist. Each branch shows the growth of Phil's network, and with that growth, the shift in his self identification from "I want to be an artist." to "I'm an artist with a disability." to "I'm an artist." (This does not mean that Phil no longer identifies with other people with developmental disabilities –this tree only depicts his art work life. He remains as concerned as ever with disability issues like freeing other people with developmental disabilities from institutions.)

Phil is a talented artist and an interesting person to meet and to know. It is also true that he continues to count on the Community Builder he

ART EXHIBITS

SHIRLEY - ART AGENT

"HI. IM PHIL PORTER. IM AN ARTIST."

TRUDY AND CANTERBURY

ANCORA EXHIBITS

"I GOT THE LAST LAUGH. I MADE IT OUT OF THE INSTITUTION BUT THE WORKERS ARE STILL THERE." ELLY (ROOMMATE)

MARY JO — MARY JO AND PHIL - ART STUDIO PARTNERS

WHAT IS NORMAL FILM

WILLY ST. COLLABORATIVE PROJECT

CARTER

"IVE SOLD MORE PAINTINGS THAN VAN GOGH AND IVE STILL GOT BOTH MY EARS!"

ARTIST GROUP

JENNIFER

BILL

PC

CARTER

BILL

PC

EAST WILSON ART STUDIO

DARL

UW HOSP. ART EXHIBIT

ANCORA EXHIBITS

BOOK READING AT CANTERBURY

JOB AT CANTERBURY

"HI. IM PHIL PORTER. IM AN ARTIST WITH A DISABILITY."

"I WISH MY ART COULD BE MY WORK."

ONE TREE IN THE FOREST OF PHIL'S COMMUNITY

From *Sharing Community*, page 63. © Atwood Publishing, 2005 reproduced with permission.

has known for years as one key re-source person in keeping his tree of art world connections healthy and growing, just as he continues to rely on supported living staff for the individualized assistance he needs to hold together his life in his own home. Community building is seldom a quick-fix and it isn't neces-sarily a short-term relationship where the Community Builder simply makes a contact and moves on. For one thing, connections are sticky. Community Build-ers themselves become weakly tied to the networks through which they move (see Gladwell, 1999). For another, even very able people need continuing assistance to keep growing their networks to match the expansion of their gifts.

By assisting in planting many different sorts of trees of connection in more and more of the many combinations of soil and shade that every community offers, the Community Builder comes to see the meaning in the work of weaving new connections. With regular opportunities for reflection and renewal, the lessons are reinforced: building social capital by creating occasions for people to discover interests and that bridge the apparent differences enriches flows of information, opens up new opportunities, and allows people greater power to act on what mat-ters to them. The knowledge that small acts of bringing people together, artfully done, can accumulate over months and years to make many lives better makes the abstract idea of social capital real.

The work of social integration

Social integration is not a treatment that professionals can administer to clients. Neither is it a product that human service staff can deliver to consumers. Social integration is a form of work that people with developmental disabilities and the non-disabled people in their networks, associations, and friendships can only do with each other. It is work in the sense that any relationship is work: people have to reach out to engage others, act in ways that satisfy each other's expectations, and maintain trust with one another. It is also work in a particular sense, because it bridges a social boundary that can generate anxiety and awkwardness on both sides. The difficulty of this work is compounded when accommodating relationships outside the administrative boundaries of the service world tests the survival strategies of the human services that people with developmental disabilities count on for assistance.

The work of social integration can be difficult, and life within the borders of the service world can be pleasant, so it is easy to dilute the challenge of "most integrated" to a standard that can be satisfied by living in on an ordinary street and saying "hi" to the server at the coffee shop. Indeed, thousands of inmates of nursing homes, institutions, and similar facilities wait for the service system to attain even this level of accomplishment. Moving beyond it requires the choice to learn new ways.

Experience suggests that more people with developmental disabilities are willing to take on the work of social integration when the family members and service workers in their lives strongly support them. This support begins with appreciation of the person's worth and contributions, recognition of the person's signature strengths, hope for the valued roles a person can play, willingness to accommodate the changes in routines and assistance strategies required to increase the person's participation, and openness to learn from what emerges as the person's networks, memberships, and friendships grow.

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