Reflecting on Social Roles
Identifying Opportunities to Support Personal Freedom & Social Integration
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John O'Brien
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Thanks

To Marcie Brost, Peter Leidy, the DD staffs of Outagamie, Shawano, and Winnebago Counties in Wisconsin, and the people and families who tested this review tool with them.
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Compliance or Commitment

Current service reforms aim to restructure patterns of funding and service to align public resources toward two related outcomes for people with developmental disabilities: people with developmental disabilities have as much personal freedom as possible; and, people with developmental disabilities have as many opportunities as possible to interact in positive ways with other citizens without developmental disabilities. Achieving this means re-investing public funds currently allocated to settings that do not offer the least restrictive, most integrated way to meet individual needs in services and supports with a better chance of supporting personal freedom and social integration.

Growing demand for deep change offers the stakeholders* in local services to people with developmental disabilities a choice between two paths: compliance or commitment.

The path of compliance leads local people to react to the call for restructuring as one more in a list of external demands. They focus attention on working efficiently within existing patterns of service to meet the requirements imposed by the many rules and regulations that surround them. On the compliance path there is a strong emphasis on the difficulty or impossibility of adequately meeting individual needs outside of restrictive and separated service settings. There is vigilant attention to reasons to minimize change. There may well be a demand for additional funding—perhaps in substantial amounts—to offer incentives for highly specialized facilities or very high staff ratios. There may well be an argument for “out of area placement”, based on a judgment that the expertise necessary to meet individual need is only available if people are congregated on the basis of what is wrong with them. On the path of compliance, restructuring is primarily a matter of re-location in conformity with a minimally disruptive interpretation of the “least restrictive, most integrated” standard.

There are good reasons to choose the path of compliance. Both federal and state budgets for supports to people with developmental dis-abilities are overstretched and future allocations are uncertain. Local systems are overcommitted and face continuing and competing demands. Lack of community capacity, makes it difficult to individualize supports. And, in some places, group based services have been satisfactory to local people and there is limited experience in tailoring supports to people. Despite these good reasons to be satisfied with compliance, some people have committed to a long term process of developing capacity to support personal freedom and social integration.

The path of commitment, sketched in the diagram below, leads local people to actively look for occasions to improve the quality of available services and supports by offering transformed opportunities to people who have been disadvantaged by institutionalization, and sometimes by local failure to discover and deliver adequate community services. This commitment motivates them to search for knowledge resources before they look for fiscal resources. Framing budgets within limited resources will begin from a deeper knowledge of each person in light of the aims of maximizing personal freedom and opportunities for positive interactions with other citizens, and an updated account of the person’s needs based on new understandings of disability and new ways to assist. Recognition of the central importance of individualized supports obsoletes the search for specialized facilities and leads instead to seeking ways to bring capable, committed, well supported assistants into people’s lives. Assuring adequate supports might require higher than historically typical rates for some people, but higher levels of investment go hand-in-hand with greater possibilities for improving quality of life.

*Stakeholders - refers to the people who are affected by service reform including people with disabilities and family members, judges and legal advocates, political decision makers, system managers, service coordinators, and service providers.
The path of commitment begins when people decide to adopt a new way of measuring the adequacy of the service system’s efforts. This way of understanding quality allows people to develop individualized courses of action that give people with developmental disabilities better opportunities for personal freedom and social integration.

Pursuing the path of commitment calls on people to do three difficult but rewarding things. It asks people to set high expectations and then to engage in honest and thoughtful self-evaluation and then to implement new kinds of services. Higher expectations, thoughtful assessment of practice, and development of better supports can’t be imposed from outside. People need to embrace them as the right thing to do.

Reflecting on Social Roles is one means to honest self-appraisal. It offers a way to identify capacities that, once developed, will expand a community’s ability to offer individualized supports that promote personal freedom and integration. The inventory asks for judgments about the likelihood that a person will perform valued roles in community life, allows identification of service constraints on people performing these roles, and grounds the choice of goals for capacity development in what is desirable for the people the local system serves.

Social Roles
The concept of social role provides a way to name people’s interdependencies. Roles identify the ways that people belong to each other, participate in exchanges with each other, and expect reciprocal responsibility from each other. They identify the contexts in which people learn skills and perform skillfully and the areas of life where people can experience satisfaction and earn status.

The focus on community roles in Reflecting on Social Roles can help self-appraisal for four reasons.

- Identifying the social roles a person is likely to perform in community settings, with necessary support, provides a clear, positive measure of social integration, a measure which is strongly related to the exercise of personal freedom. People who experience social integration participate in community life in a variety of ways that promote positive recognition and interaction with other citizens. This positive engagement can be summarized by naming the roles that a person performs in different sectors of community life.
- It sets very high expectations. Studies of service practice show that performance of a variety of social roles in community settings correlates strongly with measures of other valued outcomes (especially measures related to choice, health, and safety), but that it is among the most difficult outcomes for human services to attain (Gardner and Carran, 2005; Flynn and Aubury, 1999; Lemay, 2005).
- Improvement in capacity to support the performance of a variety of social roles in ways that create satisfying interactions with and positive recognition by other citizens without developmental disabilities is difficult, but possible. This improvement calls for a significant increase in the individualization of supports and a focus on the human service provider as a bridging organization. (Council on Quality and Leadership, 2005; Gardner and Carran, 2005; Ramsey, 2005)
- It links to a substantial body of theory that provides helpful, if sometimes controversial, ways to understand human service practice (Flynn and Lemay, 1999; Wolfensberger, 1998).

References
How To Use the Inventory

The purpose of *Reflecting on Social Roles* is to encourage thoughtful discussion of the meaning of “least restrictive and most integrated” as criteria for service adequacy. It does not intend to offer a reliable and valid measure of social integration, only to prompt careful and creative thinking.

You will use this scale to summarize your best prediction of the extent to which a person will be performing valued social roles one-year from now in ways that promote positive recognition by and interaction with citizens other than human service clients or staff.

*Reflecting on Social Roles* asks you to make judgements based on what you know now about the person who is the focus of your inventory, the current capacity of your community and service providers, and existing plans for improvement. If time allows, gathering additional information from the person and the person’s allies, from providers, and from others who know the local situation would be desirable, but make a best-for-now judgment even if you have only a little information. If you know very little about the person, this may mean judging based on usual practice in your community. If most people with developmental disabilities hold jobs with community employers, it may be reasonable to assume a high (though maybe not the highest) likelihood that this person will too.

*Reflecting on Social Roles* identifies eight sectors of community life. This prompts attention to the variety of individual interests and the variety of community settings and roles. It would be a remarkable person that would fill valued roles in all eight sectors: most of us will be more engaged in some sectors than in others and have a varied profile. If there seems to be overlap among sectors—a gymnast has a job at a gym as well as participating on a team—just make the most accurate account of the situation you can.

Define “social roles” in common sense ways. The list of roles at the head of each page is simply for illustration. Add to it according to your experience of your community.

Review the “Considerations” section before assigning your rating. The more of the “Considerations” are true, the more confidence you can have in assigning a high rating. The fewer “Considerations” apply the more cautious you should be about assigning a high rating.

Lower ratings are not judgements that reflect negatively on the person or those who work in the current system. They are an honest appraisal of the capacity of the current system to promote social integration and personal freedom. The struggle for social integration is a long term effort in which the human service field as a whole has made real but slow progress. An honest account of current reality is essential to moving forward; denial of the distance we need to travel feeds illusions that will block progress.

Remember that social integration means performing social roles under conditions that have a real chance of promoting positive recognition by and positive personal interaction with other citizens who are not human service staff or clients. This distinction recognizes that a person could play a valued role in a setting that makes interaction with other citizens outside the human services very unlikely: a person could be a singer who only performs for others at her day center, a great cook who never invites anyone for dinner, or a capable worker in a sheltered workshop. These roles might be satisfying, challenging, and capably performed, but they would not directly promote social integration. Performing positive roles inside the boundaries of human service settings would probably be reflected in a rating of 3 or below because of “limits to recognition by or interaction with citizens outside human services.” Likewise, the situation of a person who is in a potentially positive role in a community setting but lacks the support to perform it capably would probably be described by a rating of level 3 or below.

The “Constraints” check list is the most important link to determining priorities for local capacity development. These are not excuses for limiting efforts to expand personal freedom and deepen social integration, they are possible areas in which hard, creative work is likely to pay off in greater local capacity.
Home & Neighborhood

_Around the house_: Tenant or home-owner • Host, cook, house cleaner, handy-person, gardener, decorator, collector, hobbyist, etc.

_In the neighborhood_: Good neighbor, regular customer, shopper, neighborhood watch member, participant in neighborhood clean-up or other improvement projects, etc.

A person with valued roles at home plays an active part in the work of the household, perhaps with assistance or through partial participation strategies.

A person with valued roles in the neighborhood is recognized and recognizes others as belonging and participates in neighborhood life in ways that make sense to the person and the person’s neighbors.

**Considerations (check as many as are true)**

- The neighborhood is safe and convenient for the person.
- The lease or mortgage belongs to the person.
- The person or the person’s allies* selected the place the person lives from real alternatives.
- The person or the person’s allies selected the person’s housemates.
- The person or the person’s allies selected the staff who assist the person.
- The person shares his or her home with people who are not human service clients, as housemates, live-in staff, live-in companions, foster family providers, etc.
- Furnishings and decorations reflect the person.
- The person or the person’s allies participated in fixing-up, furnishing, decorating.
- The person or the person’s allies set the menus, schedules, and household routines as equal participants with housemates.

*“Allies” are family members or friends who know and care about the person and are personally committed to discover and represent the person’s interests and preferences when the person cannot represent her or himself or when the person needs active support to represent her or himself.

**Constraints (check as many as apply)**

- We don’t yet know the person well enough to identify his or her interests and capacities in this sector of community life.
- The person says “no” to developing opportunities in this sector of community life.
- The person’s guardian says “no” to developing opportunities in this sector.
- Some other authority says “no” to developing opportunities in this sector.
- Developing opportunities in this sector involves too much risk.
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- We don’t yet know how to assist the person to develop the knowledge, skills, and habits necessary to pursue an interest in this sector of community life.
- We don’t yet know how to assist the person to manage behaviors that compete with engagement in this sector of community life.

**Other constraints:**

_Thinking about what you know about this person, current community and provider capacities, and existing plans for improvement, use this scale to record your best estimate of the chances that the person will be performing valued social roles in this sector of community life one year from now._

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Family & Friends
Wife, husband, son, daughter, brother, sister, grandson, granddaughter, uncle, aunt, cousin • Girlfriend, boyfriend, fiance, significant other • Friend, soulmate, kindred spirit, pal, confidant, buddy

A person with valued family roles is typically expected and expects to maintain contact with other family members, to participate when possible in family events and rituals, and to call on and be called on by other family members for emotional and practical support.

A friend typically expects to initiate and respond to invitations to share time and to exchange with the other person.

Considerations (check as many as are true)

___ The person lives near at least some family members.
___ Immediate family members are actively involved in the person’s life.
___ Extended family members are actively involved in the person’s life.
___ The person participates in family events (holiday observances, vacations, etc.)
___ Family members are investors in the person’s life (offering regular periods of assistance, providing funds through a special needs trust, investing in a home).
___ The person spends regular, individual time with friends.
___ The person hosts family or friends for dinners, parties, or celebrations with assistance as necessary.
___ The person’s network of friends includes some people who are not also clients or staff of human service agencies that serve the person.
___ The person has a circle of support that is organized and actively promotes his or her wellbeing.

Constraints (check as many as apply)

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Other constraints:

Thinking ahead about what you know about this person, current community and provider capacities, and existing plans for improvement, use this scale to record your best estimate of the chances that the person will be performing valued social roles in this sector of community life one year from now.

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Work

Work roles are usually named by a job title: for example, receptionist, produce clerk, baker, nurse’s aide, machine operator

- Co-worker
- Union member
- Owner
- Intern
- Trainee, apprentice
- Trainer
- Supervisor
- Employer

A person with a valued work role performs a task in exchange for a wage or, as an owner, invests his or her resources in the expectation of a return. Most work roles also include the opportunity and the expectation that the worker will interact productively with other people: e.g. customers, co-workers, supervisors.

Considerations (check as many as are true)

____ The person’s job matches the person’s interests and abilities.
____ The person’s job challenges the person to develop his or her knowledge and skills.
____ The person works in an ordinary community business.
____ The person earns the same wages and receives the same benefits as non-disabled workers doing the same tasks do.
____ The person’s job calls for on the job interaction with other people, including people who are not also clients or staff of human service agencies.
____ The person’s job offers opportunities for social contact outside of work (shared breaks and meals, training events, company celebrations, company sports teams or leagues etc.) that include people who are not also clients or staff of human service agencies.
____ The person’s job offers the chance for career advancement.
____ The person’s co-workers or supervisors play an active part in design and implementation of any accommodations or adaptations necessary to insure that the person performs successfully.

Constraints (check as many as apply)

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Other constraints:

Thinking about what you know about this person, current community and provider capacities, and existing plans for improvement, use this scale to record your best estimate of the chances that the person will be performing valued social roles in this sector of community life one year from now.

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Learning
Student, learner • Teacher, instructor, trainer, mentor, tutor, guide • Enthusiast, independent scholar

A person with a valued learning role engages in study for a purpose. Study may be formal or informal and the purpose may be personal pleasure, exploration, social contact, or advancement toward some goal that is meaningful to the person such as a qualification, certificate, degree, or license.

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Other constraints:

**Considerations (check as many as are true)**

- Learning activities reflect the person’s interests.
- Learning activities offer a clear path to a goal that the person has chosen as meaningful to him or her.
- Learning activities involve the person with others, including people who are not also clients or staff of human service agencies.
- Teachers and fellow students play an active part in design and implementation of any accommodations necessary to insure that the person performs successfully.
- The person is a teacher, instructor, trainer, mentor, guide, or tutor.

**Thinking ahead about what you know about this person, current community and provider capacities, and existing plans for improvement, use this scale to record your best estimate of the chances that the person will be performing valued social roles in this sector of community life one year from now.**

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Spiritual & Religious
Member, parishioner • Deacon, elder, trustee, bar (bas) mitzvah, confirmand, usher, choir member, reader, server, greeter, religious education student, religious education teacher, committee member, small group member.

A person with valued spiritual and religious roles is recognized as a member and often participates in some additional service, study, or social activities related to their membership.

Considerations (check as many as are true)

[] The person is enrolled in the congregation as a full member.

[] The person participates in spiritual and religious activities that involve him or her with others including people who are not also clients or staff of human service agencies.

[] Other members play an active part in design and implementation of any accommodations necessary to insure that the person participates fully.

Constraints (check as many as apply)

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Community Association
Member, office holder, committee or task group member • Voter, tax payer, public office holder • Volunteer

There is a very wide variety of community associations. They may be formal or informal. They may exist for political purposes; for service; for the promotion of a cause; for the protection of members’ interests; for celebration of a person, place, or thing important to members; for mutual support; or for enjoyment. A person with valued roles in a community association will be recognized by other members as one of them and will usually contribute in some way to the association’s activities.

Considerations (check as many as are true)

___ The person is recognized by other members as being a full member. If there are tokens of membership (membership cards, pins, formal or informal articles of clothing, etc.), the person has them.

___ The person participates in the work of the association beyond simply belonging, perhaps by doing tasks like mailing or setting up meeting space, perhaps as a committee or work group member, perhaps as an office holder.

___ The association provides opportunities for face-to-face interaction with other members (vs “send a check and get mailings” organizations or “internet only” groups).

___ The association includes people who are not also clients or staff of human service agencies.

___ Other association members play an active part in design and implementation of any accommodations necessary to insure that the person participates successfully.

Constraints (check as many as apply)

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Sports & Fitness
Athlete, player, competitor, champion • Sport specific roles: halfback, pitcher, striker, center • Coach, manager, trainer, referee, scorekeeper • Cheerleader • Fan, booster

People may play valued roles as participants in athletic or fitness activities, as workers who make events possible, and as fans and spectators.

Considerations (check as many as true)

___ The person is active either as a player or an active fan (not just a TV spectator).

___ If there is equipment or paraphernalia associated with being an active participant or devoted fan, the person has at least some of it.

___ Through sports and fitness, the person interacts with people who are not also clients or staff of human service agencies.

___ Other involved people play an active part in design and implementation of any accommodations necessary to insure that the person participates successfully.

Constraints (check as many as apply)

___ We don’t yet know the person well enough to identify his or her interests and capacities in this sector of community life.

___ The person says “no” to developing opportunities in this sector of community life.

___ The person’s guardian says “no” to developing opportunities in this sector.

___ Some other authority says “no” to developing opportunities in this sector.

___ Developing opportunities in this sector involves too much risk.

___ We lack a service provider committed to supporting engagement in this sector.

___ We lack sufficient staff time to develop opportunities or provide the continuing assistance the person would need to sustain involvement in this sector.

___ We can’t arrange or provide the transportation the person needs to sustain involvement in this sector of community life.

___ The person can’t afford the costs of involvement in this sector of community life (equipment, dues and fees, admission, etc.).

___ We can’t yet identify any opportunities in this locality for the person to pursue an interest in this sector of community life.

___ We don’t yet know how to negotiate the access and accommodations the person needs to pursue an interest in this sector of community life.

___ We don’t yet know how to assist the person to develop the knowledge, skills, and habits necessary to pursue an interest in this sector of community life.

___ We don’t yet know how to assist the person to manage behaviors that compete with engagement in this sector of community life.

Other constraints:

Thinking about what you know about this person, current community and provider capacities, and existing plans for improvement, use this scale to record your best estimate of the chances that the person will be performing valued social roles in this sector of community life one year from now.

<table>
<thead>
<tr>
<th>Rating</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>It is highly unlikely that the person will perform any social roles in this sector of community life in ways that will promote positive recognition by or interaction with other citizens outside human services.</td>
</tr>
<tr>
<td>2</td>
<td>The person will probably perform some social role in this sector of community life, but with important limits to recognition by or interaction with citizens outside human services.</td>
</tr>
<tr>
<td>3</td>
<td>The person will perform valued social roles in this sector of community life that will promote positive recognition by and satisfying interaction with other citizens outside human services.</td>
</tr>
<tr>
<td>4</td>
<td>Highly confident that the person will perform valued social roles in this sector of community life that will promote positive recognition by and satisfying interaction with other citizens outside human services.</td>
</tr>
<tr>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

1 2 3 4 5
**Creative Expression**

Artist, actor, chorus member, musician, singer, composer, dancer, weaver, quilter, poet, writer • Coach, teacher, director, choreographer, conductor, stage crew member • Producer, promoter, agent, publicist • Patron, subscriber, book discussion member, collector, connoisseur, critic

People may play valued roles as creators, as workers who make arts events possible, and as viewers, listeners, and readers.

**Constraints (check as many as apply)**

- We don’t yet know the person well enough to identify his or her interests and capacities in this sector of community life.
- The person says “no” to developing opportunities in this sector of community life.
- The person’s guardian says “no” to developing opportunities in this sector.
- Some other authority says “no” to developing opportunities in this sector.
- Developing opportunities in this sector involves too much risk.
- We lack a service provider committed to supporting engagement in this sector.
- We lack sufficient staff time to develop opportunities or provide the continuing assistance the person would need to sustain involvement in this sector.
- We can’t arrange or provide the transportation the person needs to sustain involvement in this sector of community life.
- The person can’t afford the costs of involvement in this sector of community life (equipment, dues and fees, admission, etc.).
- We can’t yet identify any opportunities in this locality for the person to pursue an interest in this sector of community life.
- We don’t yet know how to negotiate the access and accommodations the person needs to pursue an interest in this sector of community life.
- We don’t yet know how to assist the person to develop the knowledge, skills, and habits necessary to pursue an interest in this sector of community life.
- We don’t yet know how to assist the person to manage behaviors that compete with engagement in this sector of community life.

**Considerations (check as many as are true)**

- The person expresses him or herself creatively.
- The person owns or controls materials, tools, and equipment relevant to her or his creative pursuits.
- The person has opportunities to improve his or her skills and knowledge and the choice to make use of them.
- Through creative expression, the person interacts with people who are not also clients or staff of human service agencies.
- Other involved people play an active part in design and implementation of any accommodations necessary to insure that the person participates successfully.

**Thinking ahead about what you know about this person, current community and provider capacities, and existing plans for improvement, use this scale to record your best estimate of the chances that the person will be performing valued social roles in this sector of community life one year from now.**

<table>
<thead>
<tr>
<th>1</th>
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<td></td>
</tr>
</tbody>
</table>
Profile
Complete this profile to summarize your predictions about the valued roles the person will be performing one year from now. Shade in sections up through the level you have selected for each sector of community life.
Review the “Constraints” on this person performing valued roles in each sector of community life.

Be thoughtful about identified constraints that involve choice or judgements about interest.

• Is it possible that a person or a guardian is saying “no” because they have never seen anyone they can identify with succeed in a valued role in this sector of community life?

• Is it possible that a person in authority is saying “no” because he or she has not been actively engaged in planning and problem solving with the person?

• Is it possible that a provider is saying “no” because staff or managers lack knowledge or skills that would give them confidence to try a different way?

Be thoughtful about the judgement that something that might be desirable involves an unreasonable risk to the person or to others.

• Is it possible that the judgement that something is too risky is based on an isolated or long ago event and that updating the person’s history would be important?

• Is it possible that people’s interpretation of relevant laws, rules or requirements need updating?

• Is it possible that investment in staff knowledge and skills combined with an expanded problem-solving effort would result in new estimates of the balance between risk and benefit to the person?

• Is it possible that thinking about this person is biased by a myth about people with disabilities (for example, “They can’t learn.” or “They only want to be with their own kind.” or “They have the minds of children.”)?

Thinking About the Person

What does this review tell you about the person’s interests, capacities, and gifts?

What else do you want to learn about the person?

Brainstorm a list of actions that you think would either allow this person to occupy valued social roles even more fully, or take up a valued social role in a way that increases the chances of positive interaction with people outside the human service system, or safeguard the person in continuing to fill a valued social role. At this point, don’t leave anything off the list because you can’t think of where the necessary permission, connection, money, time, or knowledge could come from.

Transfer the most promising ideas from your list into the box on the next page that best matches your judgement about the potential benefit and likely difficulty.
Possible Action With the Person

After you have placed all of the promising ideas in the box that best identifies how much positive impact they might have and how hard they are likely to be to implement, put stars next to the three possibilities you think are most worth investment.
Thinking About the System

Review the Considerations and Constraints, asking “What does this review tell me about our system for planning, coordinating, delivering, and evaluating services and supports?” Record the main points here.

Brainstorm a list of possibilities for improvement in the whole system’s ability and willingness to support people to fill valued social roles. At this point, don’t leave anything off the list because you can’t think of where the necessary money, time, or knowledge could come from.

Which capacities is it most important to develop if your goal is to create the most possible opportunities for people to perform valued roles?

Transfer the most promising ideas on your list to the matrix on the next page.
After you have placed all of the promising ideas in the box that best identifies how much positive impact they might have and how hard they are likely to be to implement, put stars next to the three possibilities you think are most worth investment.