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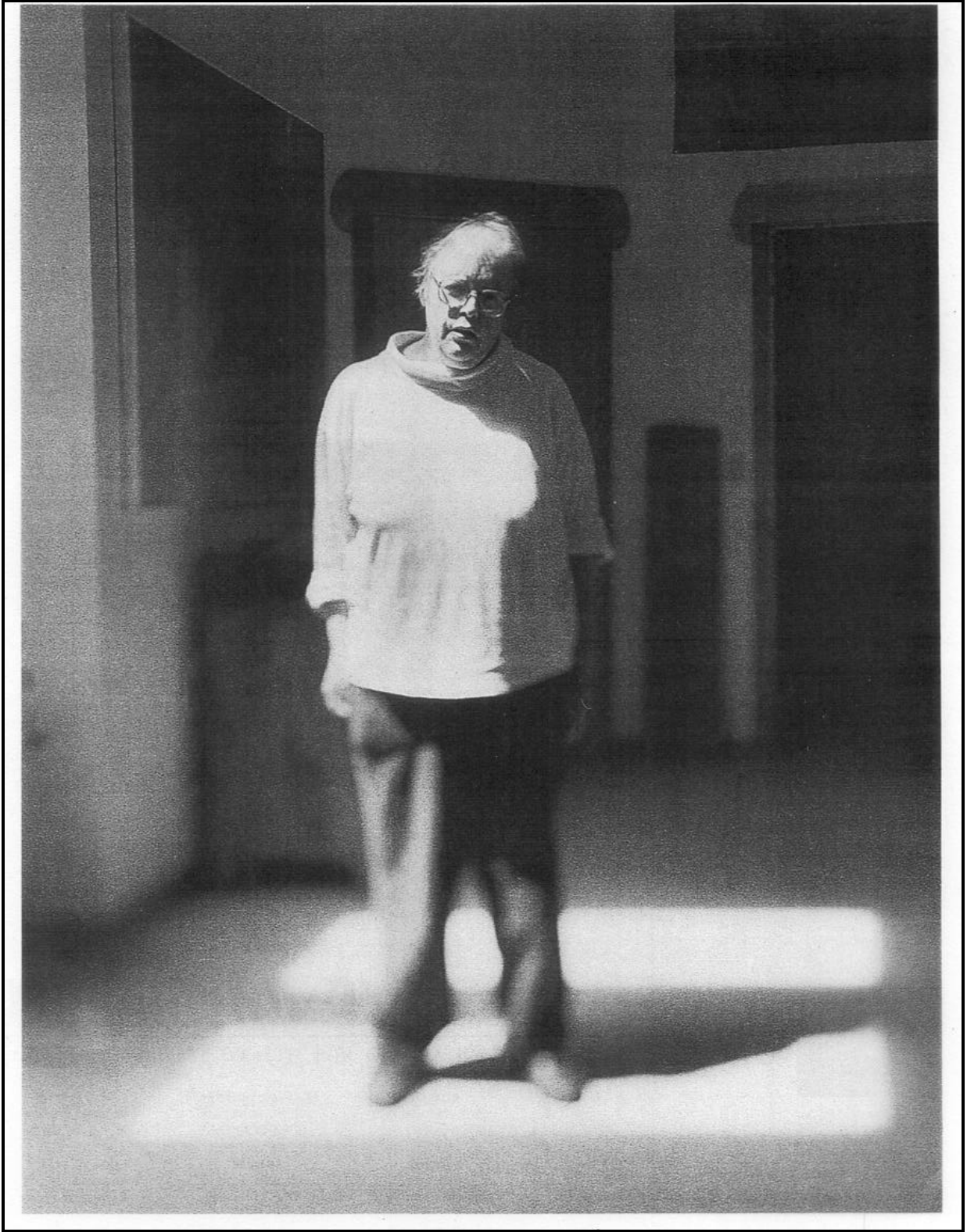# Loneliness
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Implications and Recommendations For Policy Makers

Compiled and presented by
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National Association. of
Developmental Disabilities Directors
2003 Annual Meeting

Karen Edna Wallstein, Camphill Village U.S.A., Copake, NY, Photograph by Matthew Swarts,
New York Times Magazine, September 10, 2000

Credit where credit is due

Social policy is not my forte. My brain is quickly overwhelmed by decisions that might affect hundreds or thousands of people. If it involves moving money around from one funding stream to another, or balancing a multi-million dollar budget, count me out. I have worked in the field for 25 years and I still don't understand Medicaid.

What I do know is that policies implemented on the state or federal level can make a positive difference in people's day-to-day lives. Everywhere there are examples of people getting services that they need because, among other things, someone figured out how to influence policy in DC or a state capitol. I have the luck of knowing some very smart people who do know how this works. They generously offered their time and insight to help better inform this discussion:

Steve Eidleman, Executive Director, The Arc of the United States, Silver Springs, Maryland. **Mary Lee Fay**, Administrator, Office of Home and Community Supports, Seniors and People with Disabilities, Salem, Oregon. **Dennis Gray**, Upper Valley Services, Moretown, Vermont. **Charles Hopkins**, Special Assistant to the Director, Division of Mental Health, Developmental Disabilities, and Addictive Diseases, Atlanta, Georgia. **Chas Mosely**, Director of Special Projects, National Association of State Developmental Disabilities Directors, Alexandria, Virginia. **John O'Brien**, Responsive Associates, Lithonia, Georgia. **Linda Rolfe**, Director, Division of Developmental Disabilities, Olympia, Washington. **Nancy Thaler**, Centers for Medicare and Medicaid Services, Baltimore, Maryland. **Al Vechionne**, The Francis Foundation, Moretown, Vermont.

About the title…

I thought, for the longest time, that I had invented the phrase used in the title of this report — *Loneliness is the Only Real Disability* — and then someone said they heard it from Judith Snow first. I asked Judith if she had coined it and she said, "I wish I had." Years later, someone else told me that Beth Mount said it first and I wrote to Beth to see if it was true. She wrote back, "Use it and don't worry about making it mine--so much of what we all say and do has been borrowed from our network...don't worry about crediting me with that which we all know, the power of relationships to heal and make whole. " Looks to me like Beth deserves the nod.

The obvious may not be so obvious.

- Many people who experience our services are profoundly lonely. Much of their suffering results from isolation <u>not</u> disability.

- The ultimate success of a service system depends upon its ability to help people to maintain and develop positive, "enduring, freely chosen" relationships. (O'Brien, 1987).

- When people are connected to a social network, they are generally happier, healthier, and better able to adjust to life's ups and downs.

- The benefits of our therapies and interventions cannot be sustained in the absence of meaningful relationships. Relationships are a necessary pre-condition to long-term success.

- People who most need relationships are often relationship resistant. Many are experiencing Post Traumatic Stress Disorder as a result of betrayal and abuse. Our high turnover rates are re-traumatizing these individuals and it is unethical not to act.

- There is a big difference between coverage and relationships. We keep giving people coverage (and programs and interventions) when they desperately need to be in relationship.

- Caring *about* someone is not the same thing as taking care *of* someone. You can't make people care about one another but the good news is that happens all the time.

- People should not have to "earn" the right to be with friends or family.

- Difficult behaviors are often an individual's only way of creating engagement. We must ask, "Who would the person be if he or she did not exhibit difficult behaviors?"

- Social policy is, at best, a blunt instrument. We can promote things that enhance an individual's chances of forming and maintaining relationships (e.g., we can support families to raise their children at home; we can support the inclusion of children with disabilities in their neighborhood schools; we can help people to find real jobs for real wages in the real world; we can support home-ownership; we can fund self-directed supports), but the reality is that the tools for the job require a great deal of precision (e.g., someone needs to know each person in a meaningful sense, understand what works and what doesn't work, provide support over time).

- Sadly, most of what we pay for erodes the potential for people to maintain or develop meaningful relationships (e.g., treatment centers for children; "special" classrooms; sheltered workshops; group homes; budgets that are allotted to groups of people rather than individuals).

- Our growing reliance on Medicaid has only heightened the chances that we will lose track of the importance of relationships because of increased paperwork requirements and the financial incentive to promote medical or habilitation "therapies."

- It probably goes without saying that there are a number of things beyond our control.   What's needed now, more than ever, is the courage to work for things we can't reasonably expect to happen for all the people in our service system.

- The people most likely to find the courage to stand up for relationships are the ones who understand the importance of relationships in their own lives.

To be vulnerable is not to be in jeopardy.
To be vulnerable and isolated is the matrix of disaster.

- Willard Gaylin, M.D.

"What I believe…"
Margaret Wheatley (2002)

*People are the solution to the problems that confront us. Technology
is not the solution, although it can help. We are the solution --
we as generous, open-hearted people who want to use our
creativity and caring on behalf of other human beings and all life.*

*Relationships are all there is. Everything in the universe only
exists because it is in relationship to everything else. Nothing exists in
isolation. We have to stop pretending we are individuals
who can go it alone.*

*We humans want to be together. We only isolate ourselves when we're
hurt by others, but alone is not our natural state. Today, we live in an
unnatural state -- separating ourselves rather than being together.*

*We become hopeful when somebody tells the truth. I don't know
why this is, but I experience it often.*

*Truly connecting with another human gives us joy. The
circumstances that create this connection don't matter. Even
those who work side by side in the worst natural disaster or crisis recall
that experience as memorable. They are surprised to feel joy in the
midst of tragedy, but they always do.*

*We have to slow down. Nothing will change for the better until we do.
We need time to think, to learn, to get to know each other. We are
losing these great human capacities in the speed-up of
modern life, and it is killing us.*

*The cure for despair is not hope. It is discovering what we want to do
about something we care about.*

Relationships make all the difference in the world

Old questions...

- For years, the human services profession has been pre-occupied by three questions (Lyle-O'Brien, O'Brien, and Mount , 1998):

  - *What's wrong with you?*
  - *How do we fix you?*
  - *What do we do with you if we can't fix you?*

New questions....

- The field is now moving toward a much more promising set of questions (Lyle-O'Brien, O'Brien, and Mount, 1998):

  - *How can we help the person to discover and move towards a more desirable future?*
  - *How can we offer needed assistance in a way that promotes valued experiences for the person?*
  - *How can we offer needed assistance in ways that support and promote community competence?*

Important questions still…

- I like these questions posed by Mary Romer (Romer, 2002). They strike me as fundamental to anyone's success:

  - *Are enough people engaged in the person's life?*
  - *Are there people who are imbued with the belief and hope for a brighter, better future for the person?*
  - *If not, how might such people be found or how might that sense of hope be instilled in those committed to walking with the person?*

The NASDDDS Strategic Plan

In the Fall of 2001, the National Association of State Developmental Disabilities Directors (NASDDD) released a strategic plan to assist member organizations in "building person-centered systems of services and supports for people with developmental disabilities." On November 13, 2003, the NASDDDS asked me to comment on the five goals of the strategic plan. Below are my comments.

Goal One:
Strengthening System-wide Quality Assurance
and Improvement Capabilities

Observations:

- Our current system emphasizes "detached, objective" professionals. What keeps people safe is the presence of people who care deeply, have a commitment to the person over time, and who understand the role of attachment in well-being. While there is no 100% guarantee that a person will be free from harm or exploitation, the odds improve dramatically when a person is surrounded by good, stable, and <u>informed</u> relationships (O'Brien and Lyle-O'Brien, 1993).

- Paid professionals do not stay long. A goal of our service system should be to help people to develop "enduring, freely chosen relationships" (O'Brien, 1987).

- Our quality assurance systems rely on coercion. More often than not, the only thing that is achieved by regulations is that providers engage in activities which "limit legal liability and provide 'feasible deniability.'" Instead of actively pursuing quality, providers "are encouraged to avoid confronting problems" (Sundram, 1993, p. 2).

Recommendations:

- Encourage citizen involvement in the monitoring of our services.

- Encourage planning processes which involve a person's family and friends such person-centered planning.

- Consumer-directed supports such as micro-boards, which make clear, at the outset, that people who *know* the person and are critical to a successful outcome.

- A simplification of the rules governing such organizations, along with rate structures that compete with congregate models of care.

Goal Two:
Building the Community Infra-Structure Needed to Under-Gird a System of Individualized Supports

Observations:

- Human beings are complex. *Knowing* someone in a deep and meaningful sense is a strategic resource.

- Many of the failures of the current system result from <u>not knowing</u> the individuals we serve <u>in a meaningful sense</u>. We don't know people's stories and we don't even notice that we don't know them.

- Our system reinforces a disregard for individualized supports in obvious and not-so-obvious ways. An example of a not-so-obvious way is how we sometimes move people to community without regard for the relationships they have formed with other people living in the institution. It is not to argue for continued institutional care as a "choice" (no one had the "choice" to live there in the first place so why would choice be an issue now?). It is simply to point out that advocating for a system of

"individualized" supports requires an alignment between the things we say we believe in and everyday practice.

Recommendations:

- Case management or support brokerage, if they are to succeed, must be predicated on the belief that every person supported by our system holds a story. It is critical to each person's well-being that this story is understood by those who provide support.

- Case managers/support brokers, if working within an organization, should know that the people who best provide support to individuals may not necessarily do paperwork well. It is a reasonable accommodation to support the "right" people to get the paperwork done in a way that has integrity.

- Smaller case loads are a necessity, particularly for people with the greatest support needs. Case managers with fewer people to think about can help with a variety of direct care duties including job development and job training.

- When people move from congregate settings, careful attention should be paid to the relationships that exist between people in those settings. Whenever possible, we should support people who want to continue to live together to move together into community settings, or, at the very least, to maintain contact.

Goal Three:
Building Community Capacity to Support People
with Multiple and Complex Support Needs

Observations:

- Understanding someone takes time. Understanding someone who has multiple and complex support needs usually takes longer. People with multiple or complex support needs are best

What matters most to people's safety

….is the extent and quality of their relationships. People are safer the more others care enough about their safety and well being to keep a close eye on their situation, to stand up to difficult situations with them, to act imaginatively in response to their vulnerabilities, to negotiate on their behalf with others who control important opportunities, and to struggle with them over situations in which they are contributing to their own problems. Many people with developmental disabilities are more vulnerable exactly because they lack opportunities and assistance to make and keep good relationships. But most current policies and practices ignore these vital relationship issues, and most service dollars are spent on congregating people with developmental disabilities in settings which segregate them. By suggesting that people could be kept safe and well in settings where strangers can drop in to check on quality of life, current approaches to safety fundamentally misdirect attention away from people's most important safeguard, the safeguard that most service settings are most likely to discourage or disrupt.

- O'Brien and Lyle-O'Brien (1993)
Assistance with Integrity

supported in intimate settings by people who know them well.

- Sound clinical support will always be needed. But relationships are the foundation upon which all medicine must rest.

- The match is everything. When the "right" people show up in a person's life, most of what he or she needs will happen. Ninety percent of what works is finding the right people and making sure they stay awhile.

- Our system, says Al Vechionne, "routinely relies on young professionals to determine who should support who. When it doesn't work, they assert overly-simplistic motivations for behavior — like attention-seeking — because they do not understand attachment issues and how arousal might play a central role in someone's difficulty."

- Many of the people with multiple and complex support needs are experiencing Post Traumatic Stress Disorder. One of the worst things you can do to a person who is experiencing PTSD is to surround him/her with the wrong people, and/or the 'right' people who leave because of a lack of support.

- People in direct support roles often have little or no idea about PTSD and its implications. Information needs to be provided in a manner that is understandable and practical.. And the people need to meet on a <u>regular </u>basis to discuss attachment and its implications (as opposed to program issues).

- The costs of <u>failing</u> to support people with multiple and complex support needs are often understated. In addition to the human costs of someone not realizing their potential, we tend to overstate the costs to our service system when care givers experience a sense of failure.

- Inattention to finding and keeping the "right" people also results in other costs, such as the need to train and retrain new

A person's needs are best met by people whose needs are met.

-Jean Clark

staff, frequent hospitalizations for an individual in crisis, injuries to staff, etc.

Recommendations:

- As Al Vechionne says, the first goal of a system should be to "lavishly recruit." When we find the 'right' people, we should try to make them "feel guilty about the deal."

- We should insist that support plans for people in crisis address questions of a person's relationships. A guiding question: "How can we help the person to broaden and expand his or her relationships?"

- Our crisis management plans should emphasize the importance of relationships. Those who provide back-up in crisis should, whenever possible, have an on-going relationship with the person. Those who agree to provide back-up should actually show up.

- Move away from congregate models of care, especially for people with the most complex support needs. People with the most complex support needs need the most intimate supports.
- Dispel the myths that supporting people in intimate settings with people who stay a long time is too costly. Make news of what it really costs to isolate people in congregate settings.

- Determine if there are incentives in the system for hospitalizing people in crisis. Replace these incentives with incentives that encourage providers to support people locally.

- Provide support to care providers regarding Post Traumatic Stress Disorder.

- Create regular opportunities for people to meet and share ideas regarding best practice. Be sure they meet often. Create incentives for them to share what they are learning with others.

Goal Four:
Developing a Skilled Workforce.

Observations:

- The vast majority of people providing support are good and caring people, who, if given the right support, will do the right thing.

- Money is one reason why we can't attract or keep good people. But a central reason is that we are asking people to do unnatural things in unnatural settings. Another reason is that we keep distracting, demoralizing, and confusing them with unnecessary paperwork.

- As if that wasn't enough, the people most directly supporting a person often have little or no input into the decision-making process.

- We frequently overlook the needs of caregivers. To paraphrase Jean Clark, "A person's needs are best met by people whose needs are met."

Recommendations:

- Emphasize the importance of relationships in all training efforts.

- Use bulletins, public speaking engagements, and other means of communication to emphasize the importance of relationships.

- Lead by example. Share stories of your own relationships with individuals and families supported by the system.

Hopkins Law #3:
There is an inverse relationship between how much the state will pay and the level at which consumers and families value the service.

- Charles Hopkins

- Work directly with direct support workers to determine if there are barriers to their work imposed by federal, state or local policies/rules/regulations. Work to remove those barriers whenever possible. For example, create forums to discuss 'dual-relationship' policies that inhibit community building.

- It is a mistake to assume that people in direct care roles know how to problem-solve. Encourage providers to teach problem-solving skills that involve people in decisions affecting their work lives. The more that decision-making is (generally), the better.

- Al Vechionne: "Lavishly recruit. And then, when you find the 'right' people, do everything you can do to make them "feel guilty about the deal."

Goal Five:
Develop responsive financial systems and strategies.

Observations:

- Not everything that people need can, or should be, provided by our support system.

- Our historical emphasis on clinical and therapeutic services has created an unhealthy dependency on "therapy" and services. People need supports that promote ordinary, everyday

lives, so, it is generally a good idea to fund ordinary, every day supports.

- The people who are getting the most ripped off are the people who are getting services and supports that they don't need or want.

- It is difficult, at times, to keep the person at the center of our consideration when addressing issues of reimbursement and job security for their caregivers. They are not mutually incompatible goals, despite the difficulties that may arise. For example, knowing that an individual's need for support may decrease over time, it is reasonable to expect costs to decrease as well. But keeping the "right" people involved requires us to eliminate as many disincentives as possible. Do we really want to cut back on the "right" person's involvement with a person because things are going well?

Recommendations

- Whenever possible, people should be able to direct their own services and supports. When they need help making decisions, our system should encourage them to get the advice they need from people who *know* them best.

- A goal for the system should be to make things as simple as possible for people who are willing to involve ordinary citizens in the oversight of individualized budgets. The rates of reimbursement for these supports should be competitive with the rates of reimbursement for congregate models of care.

- One of the best ways to make sure everything is on the up and up is to involve citizens who can understand a check book and who make a commitment to staying *involved.*

- Incentives for saving money from an individualized budget. People should not be punished for developing natural supports or finding ways to cut costs.

I can't bear to tell our story to one more case manager. The story has become flat because I have told it to so many professionals.

- Sister of a man who uses services in Virginia

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Available at dimagine.com

The Importance of Belonging
This handout is designed to help people to develop strategies for supporting the development of "enduring, freely chosen " relationships.

Supporting A Person with Post Traumatic Stress Disorder (PTSD)
Many people who experience disabilities have experienced trauma during their lives. *Supporting A Person With Post Traumatic Stress Disorder* describes the effects of trauma and offers strategies for helping a person to heal.

Toolbox for Change: Reclaiming Purpose, Joy, and Commitment in the Helping Profession
Many professionals in the helping profession are worn out and discouraged. *Toolbox for Change* is a collection of tools for getting the work done and reclaiming purpose, joy and commitment at the same time.

Also—Check out Links and Other Resources for additional information regarding Building Relationships and Post Traumatic Stress Disorder

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