

# Cultivating Thinking Hearts

*Letters From The Lifesharing Safeguards Project*

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CAMP HILL VILLAGE KIMBERTON HILLS

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The Safeguards Project was funded through a contract from the Pennsylvania Developmental Disabilities Planning Council (Contract # 677581074). The opinions expressed are those of the writers and do not necessarily represent the official position of the Council.

Additional support for John O'Brien's work on the preparation of this document came through a subcontract from The Center on Human Policy, Syracuse University for the Research & Training Center on Community Living. The Research & Training Center on Community living is supported through a cooperative agreement (Number H133B80048) between the National Institute on Disability & Rehabilitation Research (NIDRR) and the University of Minnesota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDRR.

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## Foreword

The Pennsylvania Developmental Disabilities Planning Council undertook the “Safeguards Project” conducted by Camphill Village, Kimberton Hills in late 1988. Throughout the 1980’s the Council demonstrated its deep interest in nurturing a variety of natural supports to re-build community. We promoted and funded many relationship building projects among people with and without developmental disabilities in non-institutional settings. Among these were Citizen Advocacy Programs, Citizen Participation Projects, Permanency Planning and Family Support Services, Cooperative Housing and Shared Homes, which now has come to be called Lifesharing. At the same time we also acknowledged that regardless of the setting people with developmental disabilities are vulnerable and that abuse is potential even in the less formalized arrangements of lifesharing households. We knew we had to link our community building efforts with a concomitant examination of what it takes to keep people safe.

Thus we sought to support, and possibly broaden, the concept of ensuring safeguards for people with developmental disabilities beyond the conventional mechanisms of licensure, inspection, regulation or accreditation. We suspected that the ‘safeguards’ employed in settings typical to all human beings, such as what families do, were probably those that applied to lifesharing households. While we thought that the peer review model used by Citizen Advocacy Programs might be instructive, we also knew that any effort to ensure safeguards around lifesharers entailed being conscious and planful about how people live together. The Lifesharing Safeguards Project was brought to being and the ‘findings thus far’ are contained here.

Through the work of the Safeguards Project the Council found that lifesharing among people with and without disabilities may look like many different things, and is done for many different reasons, but it is a phenomenon becoming conscious of itself. Thus, it is observable as a social form. The Project revealed to us that effective safeguards for lifesharers require a rich mix of concepts: continuously seeking a deep understanding of each person’s place in the world; being a part of and fully experiencing the risks and rewards of ordinary life; choosing one’s own path but with the advice, counsel and influence of those who care about you; owning one’s self; being active in a supportive network; being open to questioning; inviting ‘outsiders’ to observe and ask you about your relationships particularly from the perspective of handicapped people; recognizing that diversity itself is a safeguard.

This booklet of letters and essays offers lifesharers the opportunity to grow, to be more

responsible and accountable to each other and to outsiders concerned with their households and communities. For example, in the essays titled “A Conceptual Map of Safeguards for Lifesharing Households” and “About Visits and Visiting” we see that the health of shared living settings can be assessed in ways that are meaningful to lifesharers, done by ordinary people, unobtrusive and non-adversarial. The Safeguards Project has taught us that the more insulated a setting is, the more vulnerable are the people in it. The more conscious lifesharers are about asking for a ‘visit’, the more likely is their genuine health. While it is possible to put into place formal protection for vulnerable people, the Safeguards Project found that we still only have human mechanisms on which to rely for discerning the real well being of people.

The Council invites a full array of readers to this booklet because we believe that the insights contained here are valuable to people, whatever their circumstances. Parents, the ‘first lifesharers’, will benefit as will people associated with intentional lifesharing communities around the world. People who provide professional services to persons with developmental disabilities will have food for thought as will their regulators and licensors. Teachers and students will profit from consideration of these issues and policy makers will gain a context for their work. We recognize that some readers may be uncomfortable with some of what is said here. But on the whole, we believe that *Cultivating Thinking Hearts* as a social analysis raising critical issues is a document that challenges all of us to think about what are true safeguards. The Safeguards Project leads us to conclude that if true safeguards are in place, thinking hearts probably have been cultivated.

Along with Helen Zipperlen and John O’Brien, the Council, too, invites your feedback and response to this work. It is, after all, a “correspondence.” We invite an open dialogue among all of us concerned with safeguards because we are confident that it will continue to contribute to the work of community building.

—Joe Leonard, Chairperson

The Pennsylvania Developmental Disabilities Planning Council

September, 1993

## To the reader

Dear Reader,

Since we began our purposeful exploration of lifesharing and its safeguards in the fall of 1988, we have visited, interviewed, retreated, conferenced, read, corresponded, debated and conversed, in person and by telephone, with hundreds of people who are linked in one way or another to a world wide network of people concerned with consciously building community. Many of these people are particularly involved with developmental disability, either because that is an event in their life or in the life of someone they care about. Others have never considered the role and contribution of people with developmental disabilities to their life work. [For a chronicle of our work, see page 101.]

We have found it exciting, stimulating, and occasionally creatively frustrating to be in contact with people who have questions, convictions, or criticisms about our work. When we are with others –one other or a large group– who share our quest, lifesharing comes alive and understanding shifts, grows, and deepens between us. What has been hard, and mostly merely frustrating, is to find written words to communicate even a bit of what we have learned. We have covered hundreds of small and large scraps of paper with diagrams, outlines, phrases, paragraphs, and short essays. But none of the words on paper came alive as much as even the briefest moment of shared concern with another person.

Finally we decided on the little book you are holding. Even though our times make letters much less common than telephone calls, we knew that letters from involved people brought alive the sense of lifesharing and we knew that we had learned from writing to a real person in response to a letter or a conversation. We have written original letters for this book and have not reproduced actual project correspondence. We have written to “composite people” rather than to particular individuals. The letters reflect actual events as a context for exploring the four key themes in our work to date:

- Conscious, long term effort to build up healthy community is the only safeguard for all of us, including those among us who are most apparently vulnerable because of their disability. This is paradoxical and difficult work because so much of our human and natural world is deeply wounded.

- The single most important task for those concerned with security and development is to invite and support more and more people into lifesharing relationships of all kinds and to learn how to assist people to be more capable lifesharers.
- To do this work we must find ways to feel and see and act integrally, as individuals, but particularly as life sharing groups. We must purposely cultivate thinking hearts with one another.
- One art in the cultivation of thinking hearts is the ability to act to create wholes from the apparently broken bits served up to us by our individual and collective histories. This art is similar across scale, whether practiced on behalf of a single person, as when a personally concerned circle helps a person piece together a sense of vision for her future, or of a group, as when invited visitors help a lifesharing group review their situations and frame their current challenges, or of a polity, as when citizens gather to search for better understanding of the contradictions of current policy and practice and wiser next steps. At root, it is the art of inviting diverse and often polarized others into honest and productive dialogue in the context of shared everyday life.

The letters can be read in any order, but they have been arranged to lead you from the edges of conscious lifesharing, into the midst of it, and then on to reflections on the question of safeguards. The first three letters introduce lifesharing to three people who are wondering how lifesharing relates to their differing interests of the moment. The next seven letters touch the concerns of people in the midst of lifesharing. The final two letters explicitly discuss the implications of our work to people who want to make wise decisions about making and keeping people safe.

We have linked some of the materials we wrote during the project to several of the letters. You will find comments on the materials in the related letter. A few of the people who read an earlier draft of this book suggested reading the essay which begins on page 78 first, as a context for the letters. You might find their approach helpful.

Along the way we have accumulated much gratitude to people who have made our learning possible through their hospitality and hard work on matters of common concern. We introduce you to some of these friends beginning on page 93. This is as much a letter of thanks as a directory.

Our deep appreciation to...

...the people and the Board of Directors of Camphill Village Kimberton Hills for receiving the Developmental Disabilities Planning Council (DDPC) grant for the Safeguards project, and for patiently absorbing the extra work involved.

...the members of the Pennsylvania Developmental Disabilities Planning Council who supported and strengthened our work with their comments and questions, especially Joe



Leonard, Ken Mumma, Mark Friedman, and Ed Cohle.

...the staff of DDPC, especially Rosemary Barrett and Don Hahn, who made working with government a sheer delight and to David B. Schwartz, sower of many seeds.

...many friends in the Office of Mental Retardation of Pennsylvania's Department of Public Welfare, especially Nancy Thaler, Steve Eidelman, Mel Knowlton, Dana Olsen, and Don Frey, for sharing their perspectives on the safeguards dilemma, encouraging our research, and providing many hospitable occasions for fellowship and discussion.

...Donna Sturgis, a colleague from the outset. Donna's wise insights in human situations contributed to every step of our work, and her orderly management of our office and finances gave it a responsible base.

To our minds, the best possible response you could make to this book would be to want to join in our continuing conversation. You can call or write us at the address inside the front cover.

We look forward to hearing from you,

Helen Zipperlen & John O'Brien



## To a younger parent

Dear Marie,

Thank you for your thoughtful letter. You and Joe do indeed face crucial decisions about Jim's future and I'm happy that our conversation at the retreat helped you to put those decisions in perspective. I learned at least as much as you did from our exchange and I'm glad you have asked me to try and capture some of the main points of our conversation in writing.

Jim's graduation from high school makes a natural time to think carefully about his future, and your own. It's sobering to realize again how much Jim relies on you to make wise decisions about his life. As much as his learning has surpassed everyone's predictions, and as assertive as you have encouraged him to be in making his own choices, he still trusts you to decide what menu of options he will choose from. Once Jim is someplace, he is resourceful at making the most of it: his gift for treating strangers like friends, his pleasure at doing a good job, his sense of fun, and his willingness to struggle to figure things out are lifelong resources for him. But it's up to you and Joe to decide where Jim's someplace will be: he may from time to time announce that he is leaving home, but both you and he know that he's not going anywhere without your active and continuing support. In the first place, your love for him is so clear-sighted that you know that his future is deeply interwoven with your own. In the second place, even if you simply wanted to "place" him somewhere, you would have to advocate vigorously and wait long for the overburdened human service system to produce any place at all for him to live.

All three of you are willing to work hard for what you think best. But, in an important way, making plans about Jim's future comes down to a question of where you decide to place your trust and invest your best creative effort.

As you struggle together with this question, remember that it is fundamentally a question about Jim's identity and his place in the world. You spoke with deep feeling about the many ways that Jim has positively influenced some of the people he has met; so we are confident you won't discount Jim's importance to the world. And you spoke with such excitement about the difference it makes when Jim is with people who see him as, and expect him to be, his own person that we are confident that you will continue to seek out people who recognize Jim's wholeness and integrity.

In all of this, there is no way to avoid Jim's vulnerability. The consequences of his difficulties in learning are important: he will probably always need thoughtful help with his daily

planning, with making sense of new situations, and with developing new skills. Without capable people who take due regard of his disability, Jim's days would be very hard indeed. And it would be very easy for others to take advantage of his difficulties with numbers and concepts. But his gifts expose him as well: his desire to be friendly makes it easy for people to lead him and his trust in others leaves him open not just to the pain of disappointment but to outright exploitation or abuse.

It is frightening, but necessary, to think about how dangerous the world could be to Jim. No newscast goes by without vivid reminders of senseless violence; more and more people are talking about abuse –emotional, sexual, and physical– within families and among acquaintances; and the prevalence of corruption and schemes to dupe the credulous are a media staple. We all swim in a sea of messages about dangers that justify wariness if not outright distrust, but we all have to be thoughtful about the consequences of the ways we choose to strengthen ourselves. As most police officers remind us, watchful, involved neighbors reduce the opportunities for crime more than arming and isolating ourselves does.

We see at least three paths open to your family: strengthen the role of the government in Jim's life; let Jim go and hope that he will find enough of what some people call 'natural support' to make his way; or work consciously to extend the life you and Joe and Jim share to include other people who will take an active part in building up a healthy community in company with Jim. Let's think about each path in turn.

It may seem odd to call the first path 'strengthening the role of government in Jim's life.' But it seems to us that is the most powerful long term effect of successful advocacy for an increasingly well funded and well regulated system of coordinated professional services. Insistence that children with developmental disabilities were unjustly deprived of rightful opportunities for schooling led to a declared entitlement to special education. Exposure of the neglect and abuse of people with developmental disabilities in institutions drove up public expenditure and powered the implementation of most of our current community services for adults. Along with the benefits of increased government involvement have come costs.

- The systems created to insure rights and proper services have become increasingly complex and have themselves become a barrier to flexible, common sense responses to changing situations. More and more, innovators have to find ways to work around their own systems.
- There is a pervasive attitude of suspicion toward people who want to live and work with people with developmental disabilities: without increasing sophisticated surveillance and increasingly powerful sanctions, people will do wrong. This climate has a chilling effect on the kind of personal, inventive relationships Jim needs to make his unique contribution to our world.

- Perhaps most problematically, Jim's life becomes a government project. Professionally qualified outsiders determine the appropriateness of Jim's life plan, his goals, his objectives, and his progress. He becomes the subject of judgments about whether service providers are spending his time in the most cost beneficial use of tax money.

Many concerned people think that stronger government sanctions to enforce people's rights and better means of outside inspection are the only ways to assure safety for vulnerable people. But whatever the case may be about people with developmental disabilities as a class, what about Jim? There are people who appreciate his gifts and wish him well; he has important personal and social resources. Will life in a government managed environment enable him to make the most of these resources to be his own person?

Some people concerned about the negative effects of strengthening government involvement are now pointing to a second path, and a few people are trying to walk it. They believe that neighbors, classmates, co-workers, and other fellow citizens have much to offer Jim in the way of what they summarize as 'natural support.' Some even think that this natural support would be sufficient to provide all or almost all of the assistance Jim needs. As many explorers of this path understand it, this is a path of letting go for parents and professionals. If parents and professionals get out of the way, a person will find the support needed to get on with their lives, perhaps with short term involvement from a person who works as a facilitator of natural support. This path holds some promise. You know from Jim's past few years in school that many non-disabled students were willing to be involved with Jim and to assist him in more ways than you had believed possible; and his boss and his co-workers at the hardware store have enjoyed including him and being of help to him. Much of this has challenged you and Jim's special education teacher to deal constructively with your anxieties and move back to create the space for relationships to form. But hopeful as all this is, it is a long way from providing Jim with all the support he needs to become his own person.

- As welcome and as wonderful as these involvements have been for Jim, they fall far short of providing him with the amount of assistance he actually needs. He still relies on you and Joe for most of the human and material foundation that gives coherence to his days. It takes continuing effort to maintain and extend Jim's network of support. So far, it has been possible to step back from many activities, but not from continually attending to the relationships themselves.
- A number of people like being with Jim and treat him well. Surprisingly few people condescend to Jim as they accept him and assist him, but many people treat him as somehow diminished –'less fortunate.' Hardly anyone yet seems to have even caught a glimpse of Jim himself. You notice genuine concern from others, particularly from the young women Jim knows, but this concern has not yet translated to a recognition of Jim as a spiritual equal, involved as much as anyone else in a quest to discover his place in the world.

- Everyday life seems make long term, mutually supportive relationships anything but natural. Most of us are busy and tired from dealing with the increasing complexities of survival. Many people seem driven into hoarding time and materials by a sense of threatening scarcity. Some people seem too ready to promote their individualistic interests at the expense of anyone willing to get involved. A frightening few are violently anti-social. It is pretty to think that Jim would naturally attract the support he requires, but even in our country –far from the horrors of ethnic cleansing and enforced starvation and economic collapse– there seem to be many real barriers to decent civic relationships.

There is far too much promise along the natural supports path to abandon it, but far too many problems to trust it entirely.

The third path –building conscious community– is the path that excites and challenges me the most. This path begins where Jim is now: at the heart of a real and imperfect family who share their lives and their struggles to know and love one another in a way that enables each to contribute to a more just and complete world. These struggles have led you to work –and occasionally to fight– for Jim to have the opportunities and the assistance he needs to be included in many of the everyday experiences that would have been his without question if he were not developmentally disabled. These struggles have led you to encourage Jim –and occasionally to fight with him– to increase his abilities to be a responsible, thinking, interesting person.

The next steps along this path call for social invention. Somehow you and your friends must discover ways to expand the life that you share as a family to include more people. Jim will continue to enjoy and benefit from people who do activities with him, but Jim will only be his own person when more people consciously and deliberately share his life. This means all of you making the most of your individual gifts to find practical ways to...

...invite people into Jim's life and yours. People are not just joining Jim's life, even if they are attracted by him and spend most of their time with him, they are joining your expanding family life. Making the real and enduring boundaries around your family a bit more permeable is like forming your family itself: each individual has to keep discovering their own boundaries as they touch the others. This means that invitations must be given and accepted with deep respect for individual freedom.

...respect each member as their own person. Expect honesty, mutual challenge, responsibility to commitments, and fidelity from everyone.

...support one another to grow clearer about what joins you: each person is somehow a part of each other person's realization of themselves as their own person; time, accident, and conflict and reconciliation will make what joins you increasingly available for conscious reflection.

...act civically. Lifesharing is not just for the security of the individual but for the building

up of a more just community. One necessary aspect of civic action is working for a proper relationship between government and people with disabilities. Government has a proper role in assuring that Jim has adequate income to meet his needs for assistance; it should not be the owner of his life or the overseer of those who share their lives with him. Establishing the right relationship between Jim and the government will be a complex and time consuming issue. There are many other issues of vital importance to all lifesharers' safety and well being: insuring that the community has good, available housing and that citizens have access to good work and decent health care; working to heal the environment; working to overcome the social legacy of racism, classism, and nationalism.

...discover and call on the gifts, talents, and needs of each person who chooses to share their life. If it seems likely that Jim –and you and Joe– would benefit if he met others who would like to live with him for a time: listen for people who might find benefit in doing that and ask for help from the wider group (and their social networks) to make it happen.

...reach out and make active links with others who share your commitment to lifesharing.

This path is a difficult and painful one.

- It does not allow the illusion of certainty. Issues of who to trust and how much remain close to the surface. There will be problems, there could well be accidents and maybe even disasters.
- It requires substantial effort and maybe the sacrifice of other worthwhile pursuits.
- It doesn't offer a solution for everyone. You and Joe will very likely be reminded –perhaps by resentful people– that many people with developmental disabilities lack the social resources that Jim has. You may find yourselves wrestling with the question of whether what you are doing is fair.

These difficulties, which we believe are simply hidden and not resolved by the other paths we know about, are both the stimulus and the reason for consciousness in building community.

This has been a long letter, but ours was a long conversation. I'm confident that we will meet you again and again as we work together but in different places in company with people with disabilities.

My very best wishes,





## To an older parent

Dear Mr. Smith,

Thank you for your letter. I am really sorry to hear of Mrs. Smith's illness.

Naturally you have two worries, for your wife, and for your daughter, Sara, who has, for her forty years, depended almost entirely on her mother's daily care. Unfortunately, there are a great many families who, like yourselves, have cared for a son or daughter with disabilities at home, often without making any provisions for their own ageing or illness. You, like many fathers, probably expected to be the first to need care, which your wife would be able to give you. This unexpected event finds you unprepared, and you turn to me with questions about Sara's immediate and further future.

I must tell you that your letter touched a chord in me, and I have been awake since long before dawn thinking about your quietly heroic lives, wondering how to acknowledge the great debt society owes to people like you. Forty years ago! No doubt when Sara was born, you were confronted with an embarrassed doctor, advising you that her disability would prevent her from having a normal life, that her presence would destroy your family, that you should put her in the institution and forget the whole episode. She would be a ward of the State and appropriately cared for, while you should devote yourselves to other children and raising a normal family. Perhaps you went to visit one of those institutions of the '50's: "cottages" for eighty children each; wards for forty in one great space, with hardly room to walk between the beds; active kids who gave trouble tied to their bedframe; others, unable to walk, lay endlessly in their cots... Perhaps you explored a private "school," with fewer kids, beautiful grounds and elegantly furnished front parlor. You were almost convinced until you saw the children's quarters, and heard about the monthly fee and initial contribution to the endowment, ensuring "cradle to grave" care. You took Sara home!

I remember those years, and can imagine Sara's childhood: the preschool in the church basement, organized by desperate parents; the lobbying for "rights," the gradual creation of a service system for people with special needs; the coming of group homes, raising hopes of a decent, independent life for Sara. And then the waiting lists, and funding cuts...

Perhaps in recent years you have looked at local group homes and found them less than what you would want for Sara. And every year of adulthood has made her more dependent, less anxious to leave her Mother. Her brother and sister have both left home, and, probably, you have never yet talked to them seriously about Sara's future, not wanting to burden their young lives with a "problem" you could still carry - until yesterday.

Just before sunrise I began to imagine each person's feelings. Ben and Jenny, who love their sister, are looking with new eyes, and some anxiety, at their own situations. Ben's family seem to fill their little house - but can they make space for Sara? Can they care for her as well as their children and their jobs? Jenny imagines how she might share an apartment with Sara, and how that would change her college life. Should she give up school and come home to help you with Sara? Sara herself is forlorn and upset at her Mother's sudden absence. She is quite aware of your worries and longs to help. She knows that she is "a problem," and carries a heavy load of guilt and shame, now mixed with fear and sadness.

You ask me about safeguards for Sara. I believe the first and most important lies in her feelings about herself as part of your family, which now are mostly feelings of fear and sadness. Unfortunately many families of people with mental retardation do not consider this aspect of their lives. Out of love, they try to spare their son or daughter from family worries, from things "they cannot understand." Though she may not be able to put it into words, you can be certain that Sara's heart is involved with her family, and any attempt to "spare" her will be experienced as rejection, adding to her sense of worthlessness.

I have a friend, Mary, whose family never spoke about death. She lived away from her parents, who did not tell her about the illness and death of her beloved grandmother. She found out almost a year later on a visit to her parents house! Far worse than the loss of grandmother was her sorrow and anger that she could not say good-bye, could not accompany the illness in her prayers, or attend the funeral. She felt rejected as worthless by the people she most loves.

Mary and I worked together for months on Mary's feelings, and her questions about death, birth, and the meaning of life. I also, for Mary's sake, took the liberty of working with her parents, whose attitude toward Mary changed. Though they did not believe me at first, they began including Mary in all family gatherings and councils, talking to her "as if she understood."

When her mother died it was Mary who held the family together with quiet dignity. Like her siblings, Mary lives apart from her father and other relatives, but she has a strong sense of belonging, inclusion and responsibility as a full member of a large family.

Your present crisis is an opportunity to offer this kind of family belonging to Sara. No doubt you will meet with Ben and Jenny about the future; include Sara fully in your talks. She knows full well that you speak about her, let her take part in the comradeship of worry and grief, and the plans for the family's future, even if uncertain.

I know you expected me to write wisely about residential alternatives for Sara: about fees and endowments, entitlements and trusts, guardianship and wills. These are all important matters which must be considered, but first, I feel, comes the forming of a picture - of your family today, and especially of Sara, who at forty has much to discover about the world and

about herself. After Mrs. Smith's illness, the picture is a new one, with new roles for each of you, and new people becoming part of your lives. Let Sara help you build the future. Respect her capacity, especially the capacity of her heart, even as you respect her inexperience of the world beyond her home. She will need experiences and new friends in order to make choices about her future. Once her choices are a bit clearer, you can then set resources in place to support those choices.

The confidence you will build today in your family circle will be her first and strongest safeguard. She must not face new experiences and opportunities with an inner sense of confusion, rejection and worthlessness, quite unintentionally given to her by your loving attempts to "spare her"!

I do hope that Mrs. Smith will return from hospital fully recovered, and that this unexpected event will have served to open up discussions among you all about the next stage in your family life. Perhaps your family circle needs to widen, to include help for your wife, and to bring fresh ideas for Sara's life.

I will certainly be in touch with you again; meanwhile,

My best wishes to you all.

P.S. You may wish to consider a simple and effective idea used by some of my friends instead of full guardianship for people in Sara's situation. This would consist of a promise between three people –perhaps a parent, a sibling, and one other friend– to be Sara's primary advocates, responsible for whatever she needs. As years go by, one of the three will drop out, and the other two are responsible to bring in a new third. I have seen this work well. Of course, many more people can and should be involved with Sara - the three are the safeguard against "many friends who all believe the other is handling the situation." This is something you might set up immediately, and with Sara's knowledge and assistance.



## To an ecologist

Dear Dr. Peterson,

That was surely the shortest six hours in a 747 that I have ever travelled! It was a delight to make your acquaintance and share experiences at 30,000 feet.

I enclose the references and addresses you asked for, and a copy of *Crossing the River* with my compliments and thanks for the pleasant flight. Of the references you gave me I have, so far, been delighted by *The Cuckoo's Egg*, and horrified by *Shattering*.

*The Cuckoo's Egg* tells how the communication network among computer users grew on the basis of trust, which, once eroded by irresponsible "hackers", is being replaced by stringent security safeguards. Dealing with such issues of trust and violated trust have profound effects on the human community, not only on the designers of computer systems. Once violated by irresponsible people is the trust that makes our social networks work irrevocably destroyed? Can it be consciously re-created and if so, how? Or is strictly regulated high-tech security (based on mistrust) the only possible future? The charming astronomer author lets his own life show us the unconscious, perhaps innocent, growth of the information networks, and the painful awakening to a responsibility to protect and re-design something precious and threatened which can no longer "just grow naturally."

As I, who have no connection to the computer world, can relate to these community consequences, so you, who have never considered the "specialized" field of human services were excited by my descriptions of community regeneration around people with developmental disabilities. Why, you asked, do I not consider those people as genetic aberrations, like the "unsuccessful" mutations in a plant species? This led us deeply into considerations of what it is, really, to be human, and thus connected in body, soul and spirit to the planet, and to the cosmic environment of our Earth.

Some farmer friends once asked me to condense some of these ideas for their almanac. I am sending you the resulting article, "An Ecology of Lifesharing", just as a part of our high flying conversation.

A wonderful conversation it was indeed - but not unusual. People with the different perspective of a disability such as autism or mental retardation, lead those who directly relate to them into such human/cosmic questions, and into the painful, glorious paths of self-knowledge so essential for re-creating our world.

Until recently, we have tried to safeguard these vulnerable people by taking them apart into separate "safe" places. Reading *Shattering*, I was struck by the similar attempts to "safeguard"

plant species in seed-banks, because the infinite diversity of species is now so threatened by habitat destruction and genetic engineering. Seed banks, it seems, have problems and dangers quite analogous to institutions for “the handicapped” and other endangered people.

Alternative efforts, (which must be conscious, wise and linked to larger networks) organize the growing of seeds in many small areas, in different soils and climates - risking the dangers of natural growth for the sake of healthy stock and diversity of species. Recent efforts bring vulnerable “handicapped” people into individual relationships, with appropriate supports (which must be conscious, wise and linked in larger networks). As a richer variety of species makes the plant community healthier, so the local community is enriched by the variety of our individual relationships and by conscious efforts to include, listen and understand. World ecology is mirrored by human, multi-cultural community.

The more I think about this in light of your wonderful stories, the clearer become the parallels between laws of nature and social laws! You talked about the danger of seeing environmental issues too narrowly, and adopting a “quick fix” for one symptom without regard for long term consequences to the whole biosphere. Supporting my friends with disabilities in the human community is fraught with the temptation to see only their disability and look for quick fixes to the problems it creates. Since our conversation, I am greatly encouraged in my conviction that here too the quick fix denies the principle of biodiversity: healthy community is the balance, ever changing, between forces, elements and species in infinite variety, whether you look for it in forest, garden, wetland or town!

We so often adopt the quick fix for financial reasons - we think in the short term of making more, or spending less; the long term costs are so hard to conceptualize, so easy to disregard or misrepresent. You remember the sleepy student in our third seat whose only contribution to our talk was “Yeah - right - money is what you are a success if you make a lot of...!”

I could tell you many tales of friends with mental retardation who simply cannot learn that lesson. People who long to do useful work, are enormously proud of their work, take great joy in helping friends, “I do it for you.” As I watch these people, completely vulnerable to exploitation, being educated into selfishness as a “safeguard” to their community life, I wonder who, in the long perspective, is more in tune with the ecology of healthy community?

We have much to learn from each other, and much to lose by ignoring the quiet, seemingly unnecessary species (who needs spotted owls?).

I hope your conference fulfilled your hopes for greater understanding of the developing world - and that you are safely home in Denmark.

Let us continue to exchange thoughts...

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### An ecology of lifesharing

In times gone by the spiritual beings of the kingdoms of nature, of landscape, of weather, and of stars, created on this physical earth all the wonderful and varied art forms which we now call “ecology.” We human beings were part of this harmonious artistic work before we came to our individual consciousness, when we were led by the wise guidance of the creating spiritual powers. We were constantly aware of the spiritual beings in the landscape, of the elemental beings, of the group souls of plants and animals. But our awareness was less conscious; we ourselves were still embedded in our own kind of group-souls, our tribe, our ancestral tree, our nation. Through seasonal festivals and religious practices we shared in the life of our whole planet and the encircling cosmos. Some of us, whom the rest of us often call “primitive people,” still live in the memory of those times.

But the creative spiritual powers have withdrawn, standing back to give us human beings, now endowed with our individual ego-consciousness, the freedom to become co-creators of Earth’s future. It seems as though, in grasping this freedom, we must destroy every one of these ecological works of art –the rain forest, the living river valley, the Sea of Cortez– with the people belonging to them. We seem to understand them just in the moment of their destruction. Suddenly we become aware of the wisdom, beauty, and balance in the life of a “primitive” people in their relationship to the other species sharing their landscape.

The pain of these repeated destructions of ancient life can stimulate our conscious decision to build new ecologies. And a decision it is, requiring all the will, science, wisdom, and art we can muster! The creative spiritual powers can be called upon to help us, and they will respond. But we cannot expect that leaving it to Nature will recreate the old art from the chaos we have caused. Valuable, vulnerable species have been destroyed - left alone, our landscapes will be overgrown by the survivor species (in Pennsylvania, poison ivy, multiflora rose, wild vines of all kinds, woodchucks, starlings; each landscape has its own). The vulnerable species need our protection, we must create the balance of species, including ourselves. Sharing life means hard choices, based on deep respect for the whole variety of Earth’s inhabitants.

There are two divergent attitudes to the protection of vulnerable species. One is exemplified by the climate-controlled greenhouse, carefully sterilized, with poisons ready to eliminate any intruding form of life. This environment is highly specialized for the protection of one, or only very few, species. It results in weak plants, requires ever greater technology, has dangerous by-products. Life becomes ever less, through the combatting of sickness.

The other attitude is that of the farmer who does everything to increase life –in the soil, in the balance and manifoldness of species, in reverence for the helping spirits of nature, in awe of cosmic rhythms. This environment produces the robust health of abundant life.

If we bear in mind that the group soul of a plant or animal species is analogous to the individual human person, then we may be allowed to follow these two approaches into present day thinking about social questions. The gardener ruthlessly eliminates weak or sickly plants –an attitude impossible toward human beings– but the gardener’s selectiveness is to

plant species somewhat as a haircut for the human being. This belongs to one of the more helpful insights of Rudolf Steiner, a full grasp of which is essential for an ecologist.

It is not only in the kingdoms of nature that chaos reigns; the destruction of the old art forms of social order have created world chaos among human beings. Left to itself the social landscape becomes dominated by human likenesses of the thistle, bindweed and rat: the survivors. Each of us, at some time in our lives, through age, disability, or other circumstances, becomes vulnerable in the social chaos (think of babies, refugees, poor people, sick people). At such times we are unable to unfold our potential: our strengths and talents are masked, we need appropriate help and protection.

Amidst the chaos we have created in Nature, a species may be vulnerable, in danger of extinction, producing only weak and sickly specimens. A gardener may see its potential, give it a valued place with the right companion plants and suitable conditions, and be rewarded by a harvest of great beauty, usefulness or nourishment.

So also, our social chaos makes more and more people vulnerable. The controlled greenhouse response is to label them by the classification of their “handicap”, and segregate them into special environments or services (homes for the aged, institutions and licensed service systems for the mentally ill, shelters for the homeless). Certainly these services are a response, and often preferable to being left in the social jungle (though we often hear about homeless people choosing the freezing street rather than the shelter). Despite the good and merciful work of these services, the attitude of combatting sickness has the same negative side effects as the sterilized greenhouse, including increased mechanization and technology, and even the dangerous by-products.

The other approach has been made more visible in recent years by those who demand to be seen as “people first,” protesting that they are not their handicap, insisting that they be considered as contributors, as part of the social garden. Advocacy agencies, established to provide strong friends for excluded people, have become brokers of unlikely and original friendships enlivening the community. Support groups, established around “handicapped” people or problem relationships, have become circles of mutual support drawing unexpected strengths from each member. Mutuality, sharing of homes, work and resources begins to replace the specialized “home-like” services for the handicapped. Life-sharing is explored, in practice, as a concept as a dream.

As yet, the symptoms are small in number, modest in result, and the problems of safeguarding one another in the social and natural chaos are enormous. But, as a careful farmer must observe the small signs of a coming change of climate, so we can say, the tide has turned and is flowing strongly toward community of life –toward remembering of our origins and a sense for a biography transcending the limits of the visible world. The analogy between the garden and the social scene may be limited, and must be thought with caution, but it indicates a further truth: True care of the earth, and true community building are inseparable, lead one into the other, are two limbs of the new world-ecology of which we are to be co-creators.

—from *The Kimberton Hills Agricultural Calendar, 1990.*

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## To a young lifesharer

Dear Susan,

I really enjoyed our conversation last week. It was wonderful to listen to your story, and to your questions about how best to help John and Terry with their lives.

As you told me how the resolve has grown in you from “someone should do something” to “it will have to be me, but how?” I was remembering a whole parade of friends who have crossed that same threshold. Some have crossed it with forethought and some with almost none, on an impulse, a certainty of the heart. Your story of the day you took John and Terry to the mall, and almost kidnapped them into your apartment rather than return them to the nursing home, was dramatic, and seems to me to mark an important moment on your path.

Until that time you were experiencing waves of anger, sympathy, frustration, even incredulity and shock as you learned about these lives, so close to you in miles, yet so different from your own. When you decided that evening against a single handed rescue operation, you began quite consciously to cool your own rage, to think and plan, to search for allies, to listen more respectfully for the opinions of all concerned, and, in fact, to become more effective in making change.

Around that time too, you began to question your own life and some of your assumptions. This part of our conversation led us to use the phrases *owning oneself* and *helping each other to own ourselves*.

We were still working at this when it came time to go, and you asked me to write some thoughts to help us both understand what *owning myself* might mean.

Let us imagine life as a tightrope along which one walks between opposites of all kinds. If I walk out on an actual tightrope, I shall be paralyzed with fear, a failure in the eyes of the onlooker, and fall off one side or the other. The artists however, have, through long training, gained such *ownership* of every muscle, every technique and attitude, that they walk with confidence, swaying sometimes far to one side, but always regaining a beautiful balanced progress, inspiring and delighting the audience.

We cannot take this extreme analogy too far. The tightrope walker goes alone, and our concept of helping each other *own* ourselves does not mean “becoming independent, isolated, self contained.” When we *own* ourselves, our confident balance lets us reach out to help others, invite friendship, ask for help for ourselves and for others, be hospitable without being devoured by demands on our time, attention or resources. Perhaps you are, as I am,

already thinking of examples among our friends, or in literature, or of moments in our own lives when we have felt a touch of this kind of confidence.

I do not think many people *own themselves* completely, or all the time, but this is the destination and goal of all true and good paths of spiritual training and inner development. (There are other paths which work through increasing power over the individual, imprisoning the spirit.)

As human beings we depend on many different, often conflicting, forces and processes which, if we are to function at all, must be in mutual adjustment. Think of daily matters such as breathing, blood circulation, digestion, thinking, emotional life. All are related to different parts of the outer world (air, warmth, food, water, sense perceptions, other living things) and all have their own essential rhythms. Think of the changing balance between them during the day, as I run, or eat, or think or grieve. Any of these forces, if far out of balance, may, temporarily or for the long haul, *own* me, as expressed through a thoughtless act of anger, or an appetite for alcohol.

Another inadequate but helpful analogy: each of us is a whole orchestra, with the same instruments as many other orchestras; consider the place of the conductor, as I play my individual symphony of life.

When you talked about your argument with the agency you said “They seem to think they *own* John and Terry”. In contrast, you feel you would like to help John and Terry to *own themselves*.

This is a critically important time to consider these matters, because the new mindset of “choice” leads to extremes if not balanced by a clear concept of the path to *owning oneself*. It is always helpful to start, as you are now doing, with one’s own situation, by asking, “How do I make choices?” We will have many conversations about choice as you continue working with John and Terry. Today I want to consider it particularly in relation to *owning oneself*.

If you consider how much help we all take for granted in making a choice, you will be able to help John and Terry, and shield them from either extreme: “It’s their choice to live on potatoes and ice cream in a dirty house.” or “They can’t be responsible, we must choose what is best for them.”

So, dear Susan, next time we meet, perhaps we will go on to consider how each of us is to a very large extent the product of our nation, with its cultural norms, and of our family heritage, religious upbringing, and education. The path of spiritual development does not consist of denying or trying to escape these influences, but of facing and becoming aware of their great influence on us before we decide how to conduct our orchestra of life. This can be a sobering experience, even a painful one. Timely consideration of these matters will help prevent those half-instinctive conflicts so prevalent in today’s world, between people and groups unconsciously *owned* by national or religious beliefs. Friends such as John and Terry

are becoming a force of world healing as they, by their seeming need, raise these questions among us.

I look forward to working with you,

P.S. I just re-discovered this quotation, which I think says a lot about the requirements, rewards, and risks of helping each other to own ourselves. I also enclose a few pages which summarize some of the thinking our friends who work in supported living are doing about power in relationships. Finally, I have enclosed a list of the “Qualities of excellent lifesharers.” I’m as uncomfortable with the list as I am with anything that seems to limit the definition of lifesharing or could create a kind of checklist for judging others, but I think it captures some important aspects of the art of helping each other to own ourselves.

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...cooperation [must] be based entirely on free intercourse and free association between individuals. Here human individuality will not be forced into an institutional mold. How one person assists another, how one helps another advance will simply arise from what one, through one’s own abilities and accomplishments, is able to be for the other. It is no great wonder that presently many people are still able to imagine nothing but a state of anarchy as a result of such free human relations... Those who think so simply do not know what powers of our inmost nature are stunted when we are forced to develop according to patterns imposed by the state and the economic system. Such powers, deep within human nature, cannot be developed by institutions, but only through what one being calls forth in perfect freedom from another being. The effect of what arises in this way is not antisocial, but rather deeply social. The socially active inner person is stunted only when instincts originating in the prerogatives of the state or in economic advantage are engrained or handed down.

–Rudolf Steiner, *The renewal of the social organism*

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### Qualities of excellent lifesharers

These people own themselves and help others to do the same. They exert the minimum power over others, asserting such influence only when it is necessary to provide structure for a safe space, or to help someone in crisis to come to themselves.

They are competent, owning mastery of work skills and social skills but without personal pride. Their mastery and competence enables them to include others in the work. They divide tasks according to people's abilities and needs for growth, creating ever more valid social roles for others, including very vulnerable people.

They call forth respect from all who meet them, magically transforming those who come with power over through their own power from within. Some of these people have experienced total loss of outer power -as refugees, in prison camps and institutions. They know the power of the powerless. They are servant leaders, serving others by raising awareness of a larger cause. They lead by example, and by the generosity of their sharing, on the path of inner development out of which just and good social forms can grow.

They are artists in the art of living; therefore their physical and social surroundings are artistic and draw out the artist in everyone.

Excellent lifesharers know about the rhythms of time and the growth of living organisms, They understand pioneering enthusiasm and the honeymoon period of new initiatives. They have worked with persistence and waited with patience while individuals and groups develop their power within.

Failure and disappointments have taught them balance and long perspective. They receive crises as opportunities for awakening and change, for the bell of conscience to sound. They stand by others in crisis, offering help and encouragement not to avoid the crisis, nor to seek the quick-fix, but to face a step in self-knowledge, on the way to greater power within.

Excellent lifesharers are firm and wise, clear in their thoughts but seldom judgmental. As cultivators in the social field they teach the first environmental lesson "There's no such place as away to throw things or people." Relationships change; crises, remorse, shame, forgiveness are worked through to a new understanding of common responsibility.

Around these people grow very lively lifesharing scenes in vivid contrast to the older, more limited attitudes to vulnerable people in facilities: "We can't handle this one. Discharge him." "I left the place, and I left my friends there." "Clients stay -staff move on." In the best lifesharing situations, there is a lively balance of long term security of tenure with freedom and encouragement to individuals to move on, yet maintain and develop their relationships. Lifesharing networks result.

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### Forms of power

Leaders of successful supported living agencies identify the use of power as one of the most important and difficult issues in their work. Several of them find this way of distinguishing between three different types of power helpful in their work:

- **Power-over** other people arises from the ability and willingness to make decisions for others and to enforce their compliance by authoritative control of rewards and punishments. Typical systems and agencies embody the assumption that people higher in a hierarchy will exercise power-over the people beneath them. Professionals and staff unquestioningly expect that people with disabilities will do what they are told by those authorized to plan for them and see those who do not comply as further and more deeply disabled. Power-over others is the most common and familiar form of power. People expect its use, feel uncomfortable at its absence, fear the uncertain consequences of denying it, and easily fall back upon it in times of stress. “Real politicians” and “real managers” and “real organizers” rise and fall on their ability to manipulate power-over. But power-over others poisons the relationships necessary to support people with disabilities to take their rightful place in community life. This appears true even in structures that attempt change by swapping the order in a hierarchy so that the people with disabilities assume power over their helpers.
- **Power-with** other people arises from people's ability and willingness to listen to and be influenced by another's perceptions and suggestions and to offer their perceptions and suggestions in turn. Power-with requires the kind of respect that grows with a willingness to be personally involved with one another and to share by choice in a common project that will shape and shift patterns of relationships among people. Differences provide information and the occasion to clarify and strengthen relationships by negotiating creatively. Because power-with depends upon and reinforces cooperation, its exercise depends on people's mutual restraint and willingness to learn from their experience together. Not all exchanges of influence have positive motives or good consequences, so people need to assume responsibility for questioning and testing the fruits of their collaboration. Power-with defines a strong foundation for the kinds of relationships necessary to support people with disabilities in community life.
- **Power-from-within** arises from a person's willingness and ability to discover and creatively express the abilities and concerns that they find spiritually meaningful. In civic life and in the world of work power-from-within brings people beyond seeking a role to finding a vocation, a calling. Power-from-within gives a person courage to act when important values are threatened, even if the short-term prospects for success are poor. Several leaders in supported living identify power-from-within as the source of their own ability to overcome their fears and doubts in order to create and protect innovations in difficult circumstances. Because power-from-within expresses a person's deepest beliefs, conflicts

can be painful and very difficult to resolve; so many people learn not to share their convictions. People acting on the basis of power-from-within need to exercise personal discipline to sharpen their discernment of what ultimately matters to them and to strengthen their abilities to creatively express what matters to them in everyday life with other people.

Power-with and power-from-within have particular relevance for supported living agencies. Assistive relationships cannot be based on the coercion and fear that come with the exercise of power-over. Support develops on the basis of mutual influence through the support worker's listening and responding to the person with a developmental disability and, in turn, offering the person information, suggestions, guidance and identifying and negotiating differences. Even when there is a definite element of control in the relationship—as when a person has been declared incompetent to make money decisions or when a court makes some form of supervision a condition of release from jail—power-with provides the only constructive context for a support relationship. Either person's use of power-over marks trouble in an assistive relationship that can only be repaired by moving to the ground of power-with. Team relationships cannot be based on coercion and fear. Learning and mutual support require trust and the ability to identify and negotiate differences.

Community relationships cannot be based on coercion and fear. The supported living agency strengthens necessary community relationships by looking for common ground and supporting people with disabilities to make clear requests for inclusion, assistance, or adaptation. Even in the relatively few instances when these requests are backed by enforceable rights, outcomes depend more on creative negotiation and joint problem solving than on giving orders. As anyone who has lived with many attempts to do even simple things like make public buildings physically accessible will know, this is because there are so many non-functional ways that even well meaning people can give the appearance of compliance with rules. Assertion of rights gains most ground when it leads people to establish power-with relationships.

Although the context is hierarchal, relationships within the service system cannot be based completely on power-over because the supported living agency is low down in the hierarchy. Because of its position, the agency is expected to take and implement instructions from system managers and multi-disciplinary teams rather than to be a source of action. By establishing power-with relationships in the network of people who manage the service system, supported living leaders multiply their ability to respond to the individual preferences and needs of the people with disabilities their agency supports.

Power-from-within gives the people involved with supported living agencies the energy and courage to stand up to unjust situations, to continue to face and learn from difficult problems day after day, and to find meaning in their lives despite slow progress or failure. Many effective supportive living workers say that they are led and sustained by some people with disabilities they know whose power-from-within is very strong for those who take care to

notice and listen to them.

Assistive relationships form the daily testing ground for power-with and power-from-within. Each relationship includes many moments of truth in which people will either struggle for collaboration or fall back into coercion or withdrawal. Whether assistive relationships grow stronger from these tests depends partly on the people in the particular relationship and partly on the way the supported living agency develops as an organization.

Five recurring organizational issues test and strengthen the use of power in a supported living agency. They are: negotiating necessary resources; building effective teams; keeping balance between the work of the whole organization and the work of its teams; setting and maintaining direction; and, maintaining the agency's integrity.

Together, these issues provide the agency with chances to build up alternatives to power-over. Each issue offers the opportunity to shape stronger collaborative relationships and deepen understanding of the links between supported living work and what its participants find personally meaningful. The way an agency manages these issues determines the amount of energy it can focus on realizing its values. The more practiced people become in organizing their efforts through the exercise of power-with and power-from-within the less organizational relationships will be dominated by power-over.

Any member of a supported living organization can constructively exercise power in each of these situations. Power-with grows when people intentionally draw and re-draw boundaries by moving toward some relationships and away from others. People strengthen the use of power-with in the agency when they...

- ...bring people together to focus on a common project, especially when this brings previously uninvolved people into the project
- ...encourage people to say clearly how they see and understand a situation and what they want from it
- ...inquire about the position of people who disagree or are unwilling to become involved in order to find out what it would take to gain the person's cooperation
- ...practice creative search for mutually beneficial actions
- ...advocate for suggestions that structure shared action
- ...cooperate with other's projects
- ...question limiting assumptions by inquiring why a desirable action appears impossible
- ... figure out ways to evaluate and learn from the effects of their actions

People strengthen the exercise of power-from-within in the agency when they...

...invest time in strengthening and clarifying their awareness of what is personally meaningful to them

...look for ways that the agency's work offers chances to express what is most important to them, especially in frightening or confusing or discouraging situations

...speak clearly and strongly about their sense of what matters to them as valuable and fundamental, especially when their agency's behavior seems to be negative or out of control

...listen respectfully and thoughtfully when others speak of what matters most to them

— from John O'Brien & Connie Lyle O'Brien, *More than just a new address*

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## To a lifesharer facing a wrenching decision

Dear Mrs. Bailey,

Yesterday you let me share, by phone, the deep questions you are facing, which must very soon lead to life changing decisions. Naturally, our conversation had intimate and emotional moments, as well as practical ones. You agreed to let me try to capture the essence of your situation in a letter, as a help to others.

As I heard your story (and please correct me if I have misunderstood any of your points), you were recruited five years ago by the local citizen advocacy office to be a friend for Arthur. The ideas of citizen advocacy made sense to you, and you embraced them with enthusiasm. As part of the training for new advocates you learned about the typical damage done to souls like Arthur's by the absence of relatives or other people, specifically "his," to be there for him over the long haul. When you met him, and learned his biography, you were moved and resolved to become that kind of long-term friend.

At first he was unresponsive, and even seemed ungrateful for your friendly efforts. Through conversations with the citizen advocacy coordinator, you learned to understand this as the only defense of a soul so often disappointed that it cannot risk another broken promise, another hope of relationship dashed. Your resolve deepened into patience, and from your initial, purely social relationship you began to make practical changes in Arthur's life. You helped him move from the closing institution to a group home run by XYZ, INC. You met the agency staff and became known as Arthur's advocate, attending all meetings about him, and doing all manner of little things to widen his experiences of life. You learned about his great physical needs, often helping out when the group home staff were shorthanded. You began to understand him better, though he never uses words, and to feel his growing trust in you.

After a year, XYZ, INC. told you that Arthur would be moved to another home, many miles away, where there were others with similar medical needs - a more economical use of their skilled nursing staff. He would face another complete change of the people who run his life - and you would be far less able to care for him at that distance!

So, you took Arthur home with you. It seemed to you to be the only, and the obvious, way to be true to your commitment, to be a faithful friend. For three years you have devoted your life to Arthur. He has had some professional help, especially when he was ill, but you have asked for little help for yourself.

And your creative lifesharing has been successful! Arthur has learned to trust you, and has grown and blossomed in many unexpected ways, giving you both great joy. His needs are

still great, and begin to increase as his body ages. You are still connected with XYZ, INC. the agency who, at least in theory, provides service to Arthur, receiving State funds for so doing. In practise, because Arthur is “well placed” and XYZ, INC. are short handed, your contact consists of an occasional call or visit by one of their staff to complete some paperwork.

Now comes the crisis! Your own doctor has told you very sternly about your own needs - you absolutely must change your routines, avoid heavy lifting and get more sleep. There is no way you can continue to care for Arthur - and you called me with the agonized question, “Must I tell the XYZ, INC. agency to take him away?”.

This is how you and I began, on the phone, to answer the question. We referred to the lesson we, the human race, have learned in the 20th century (it was always true of course but our world situation makes it clear and inescapable). The lesson is: There is no “away” to throw either things or people or relationships. There is only movement and change, to another place, to another condition, all within one, whole, environment which is affected, for better or worse, by every such change.

Grasping this lesson alters Arthur’s question, and the understanding of your commitment as a faithful friend. Undoubtedly, the conditions of your friendship will change. It is necessary to face this fact sooner rather than later, because of your own medical needs - but it was always inherent, as it is in any relationship. (Relationships are like plants - they are either growing or withering - life does not stand still).

Your agony consists in the fear that Arthur’s blossoming life will be blighted by the cold wind of yet another rejection, that he will indeed feel worthless and “thrown away”. We have to find a way in which both your lives can change and grow new shoots. The relationship need not be cut off: it can continue to flourish. For many people death itself is only a change of state in relationships, which after all are a matter of soul and spirit, even when expressed through physical earthly bodies!

Having accepted that both Arthur and you have needs, and that both he and you are vulnerable, we could see that it is the relationship which has to change, as part of the whole “relationship map” around your shared lives. Perhaps that map itself needs enriching through more friends forming a network of mutual help. In this richer network you can change your role, without being in any way unfaithful to your commitment.

How, you asked, shall I find all these new friends? How can I go around asking for help for myself? I tried to help you think, as the first step in this daunting prospect, of one person who could see things in the way we are thinking of, and become your “asking person”, at least through this period of change.

You must think of this task as a gift from you and Arthur to the right person. I believe, by the end of our conversation, you had thought of a possible person to ask. What is his task to be?

We are asking him to be a “social artist,” creating a new, small cell of community in the form of a circle of support, or group of friends helping each other to help you and Arthur. He will explore, with your advice and consent, what professional help is available, and what financial and human resources XYZ, INC. can contribute through Family Support or other programs. This may take some initiative and creative discussion, not taking “no” for an answer, but the person you have in mind seems able to do this firmly and without making enemies. He will have the benefit of your long experience with XYZ, INC. and the bureaucracy.

He will not allow support to come only from “professional” sources, but search among your friends and neighbors for those who are ready to change their roles in relation to you. These people undoubtedly exist, but it will probably take an invitation to bring them out. Perhaps they saw only your independence and competence, never thinking of you as vulnerable. Perhaps they have been too shy to offer help, not knowing how their modest skills could be useful in such a specialized field. With your help, and Arthur's, your “asking person” will suggest many small actions, well within their power, which together will build the help needed. He will neither belittle the struggle, and the responsibility, nor ask people to shoulder a load too great for them.

It may well be that your “asking person” will, with your and Arthur's help, invite several people for a visit to your home, to experience your life for a day or two before sitting down to plan changes with you. XYZ, INC. people should be part of this visit, in order to understand that it is something quite other than an “evaluation of your living arrangement” or a “report on Arthur's placement.” Instead it would be an honest search among fallible people for answers to your question and your invitation. The result of such a visit is usually not an authoritative plan, with “teeth” to assure its implementation as written; the result is growth in understanding among responsible people. The answers are almost always by-products of a process among people whose only commitment is to stick with it ‘till the next step shows. You, and your asking person, should consider the form of these visits and invitations.

There are a number of other social forms, such as personal futures planning, which may serve you well at different times in the process of transition. You may decide to invite a facilitator experienced in the use of these tools, for one or more occasion. It will be essential, however, that you retain the control, the “ownership,” of your friendship with Arthur, just as you have always done when you could express it in physical, practical ways as well.

We do not know what will come of this adventure in metamorphosis. It is not so simple as deciding among the residential options offered by a provider agency. We must be open to any combination of helpful things, to be orchestrated by the circle of which you and Arthur are fully part. Perhaps he will stay in your house, with helpful people coming in as needed. Perhaps your third floor can meet the needs of a compatible person who can offer help instead of rent. Perhaps XYZ, INC. can find a place nearby, of which you and Arthur both approve, and where you can visit each other. Perhaps a new friend will take Arthur home, as

you did years ago. Perhaps one arrangement will lead on to others, but always in ways which include you and enlarge your and Arthur's web of friendship.

Remember, always think of the process in the mood of hospitality. Your invitation to co-creation is a gift to your friends!

It is a privilege to work with you, and I look forward to hearing of your progress,

## To a lifesharer in crisis

Dear Alma,

Of course I remember you and the meal we shared at last month's conference. I'm happy that we met in time for your family's crisis.

You're right, it is strange that the crisis hasn't come directly from any of the members of your extended family but simply because the six of you have lived together for years in what you now discover that your state calls an "unlicensed group home," simply because four of you receive SSI payments because of developmental disability. Being told that you are technically in violation of the law is shocking news indeed for someone who has never so much as gotten a speeding ticket.

It also makes sense to me that your conclusion about Mary is correct. The worry this situation puts all of you under, along with Mary's history of acute sensitivity to stress in the people she counts on, probably does account for her renewed episodes of very difficult behavior. And, it is ironic that the people who seem to have caused all this uproar now seem to be using the upset they see in your usually well ordered household as a reason to question your fitness as "service providers." As you quite rightly say, "We never wanted to be service providers. We are just an extended family, quietly living out our beliefs and our care for one another on this farm."

But when Mary and Joan and Reg and Ted joined your family, so did the state's human service system. They have been assigned a legal duty to insure that your extended family members are protected and appropriately treated. I think if you traced the history of your state's policy about people with developmental disabilities, you would find that the state became involved because of vigorous and sustained advocacy on behalf of people with developmental disabilities by groups of parents (like The arc and United Cerebral Palsy) and that the rule book they are now bringing into your home grew, page by page, in response to real incidents of abuse and neglect and mistreatment. It does seem likely, as the inspector told you, that the state started to use the list of SSI recipients to locate "unlicensed facilities" because of the strong public reaction to the horrible boarding home fire last year that killed so many elderly people. Of course, you are right to say that your brick home is as safe from fire as the chief of the local volunteer fire company (your husband, Art) can make it; that there are only six of you and not forty six; and that you are motivated by a desire for service not profit.

But, in one sense all that is beside the point. Though you have not willed it, you are now

part of a world wide struggle to find better ways of protecting vulnerable people and insuring that their gifts enrich our planet's life. In this struggle you will find many thoughtful people who are working hard to understand and evolve our present situation in the direction of greater consciousness and greater mutuality. You will also find many people mindlessly going through the routines of their life with no conscious desire but to avoid bother. For the sake of your extended family, you all need to join in as conscious participants in this search for better ways.

I know that you do feel insulted when someone half your age, who admits that he has never even slept under the same roof with a person with a disability, zealously quotes you requirements wrapped in jargon phrases like "client choice," "age-appropriate possessions and activities," and "maximum social integration." And, if you are like me, maybe underneath your feeling of anger at the insult there is also a question about your own competence, "Should I have known about this? What if he's right? Have I been hurting or depriving my extended family members?"

I think it may make sense to look for the best possibilities through the clutter of the jargon. This event, now so unwelcome and upsetting, can serve as a wake-up call for your household, and for the people who come to inspect it.

Take "client choice," for example. You correctly point out that everyone under your roof has chosen to be there and chooses every day to stay there. As you say, this seems mighty inconsistent with the inspector's threat that he has the authority to start proceedings to "place your clients appropriately in a better facility." (Though maybe the inspector's threat was motivated, at least a bit, by his fear at the fierce reaction Art had to finding him reading rules to you at your kitchen table.) Let's think about a next step: the inspector needs to know your family better, he needs to confront the reality of Ted's choice to live with you. He can best do this if you avoid the temptation to deal with this matter alone: be sure that all six of you hear what is going on (each person will understand in their own way) and that all six of you spend time together with the inspector; invite him to share meals, have Ted show off the chickens that are his pride and joy, invite him to the weekly pot luck supper at your church. Ted, though he is "non-verbal" will find his own way to communicate his choice to be with you to the inspector if he has information about what is going on, if he is sure of your support for his continuing to live with you, and if he has a chance to pick the medium in which to communicate his message.

Take "age-appropriateness." Historically, many have understood people with mental retardation as somehow immature, younger than their age and treated them accordingly as if they were really little children in big bodies. Seeing people this way does everyone a real disservice, because it blinds people to the fact that a person with mental retardation is a fully formed, mature spirit living through a body which is "disabled." So blinded, we miss the gifts people have to share. I have no idea whether you and Art treat your extended family

members like children. But enough people do to make it a good question to ask yourself. And, because the answer may be more in your collective behavior than in your conscious thoughts, it could pay to borrow the inspector's eyes to look for a moment at this dimension of your life. If the answer is no, you have no worries from the inspector (though, as a city boy, he may need some orientation to the routines and rhythms of farm life). If the answer is yes, learn from it and change, even if the words do sound horrible and academic.

Take "maximum social integration." This simply means that people flourish when they have a variety of chances to be with other people, to share common and civic activities, and to make friends. People with developmental disabilities often have isolation forced on them because the people who might help them develop and find ways and places to express their capacities retreat from the reality of social rejection into a narrow and insulated life. Again, I have no way to know how it is with your extended family, but there are good questions to ask,

- Does every person, all six, have at least one committed friend outside the household whose company they enjoy regularly.
- Are there people you welcome and trust as advisors to your whole family; do you give them opportunities to know you in good times and in bad times; and, do you consult them regularly?
- Does every person, all six, have at least one place that they go that matters particularly to them and the opportunity and help they need to go there?

Of course, these issues of choice, and being respected as a whole person, and being connected with other people and places are life long struggles for all of us. That's why it's so important to use this upset in your life to ask and talk over this basic question, "How well are we getting to know one another as whole people, each with our own unique biography, talents and destiny; and, what could we do to deepen our knowledge of one another?"

So, "This is your wake-up call," not delivered by the mechanical voice we laughed about at the conference hotel, but by a real person in the disguise of a state licensing inspector. You can expect him to do his job, and so you must find out what it is and how the world looks to him. But you can also thoughtfully invite him to join your extended family a little bit. This will require you to reach through your anger and fear (I notice, for example, that everyone in your letter has a name except "The Inspector," maybe as misleading a label as his calling Joan "a Down's.") You can't expect him to go easy on you with his rules because you are good people; you can expect him to open his heart, if you will open yours.

Please let me know if I can be of any assistance in this crisis time. I know you will all come through it stronger and more at peace than ever.

My best wishes and hopes for your struggle,





## To a case manager

Dear Evelyn,

I did appreciate your presence at Charlotte's support circle meeting last night. It is so helpful when your busy schedule allows you to be there as part of our group, wrestling with Charlotte's questions together.

Before you joined us, when Charlotte had first moved out on her own, and we had begun trying to support her as a group of friends, the "Case Manager" was an unknown outside authority, rather threatening because of your power to approve (or not) the plan on which depends her financial support from the county. Now you are a member of our circle, helping to fill the gaps between Charlotte's dreams and our capacity to achieve them!

Another challenge became very clear last night, when George, who is so frustrated with "the system," turned his fury on you as its representative. I was embarrassed, and admired the way you "kept your cool," but I believe we should not pass over the incident. I hope you will agree to let us tackle it in the next meeting, for the sake of better understanding and enlightened help for Charlotte.

Whatever we think of the present requirements of our "system," we cannot criticize someone for doing her job well (as George in his righteous wrath appeared to do).

And you, dear Evelyn, are not only doing your job well - fulfilling all the required disciplines of accountability for public funds - but you are going "beyond the call of duty" to join us in human responses to Charlotte's courageous step.

I want you to know that we recognize this, in your attitude to her, and in all the little extras you have done to help us all. It was really great of you to take Charlotte to the train on Friday when Mary was sick and nobody else could jump in at the last minute. (I was so afraid she would have to cancel the long-awaited trip). Thanks from us all!

I shall be in your office on Monday - we have to wrestle again on behalf of Peter. My respect for your work with Charlotte will help me deal with what seems irrational behavior on the part of the county. For Peter's sake we must come to a better arrangement.

With encouragement and thanks,



## To a family living co-ordinator

Dear Olive,

Congratulations on your appointment as a co-ordinator in your Family Living Program! What a wonderful, absorbing job you have taken on. And how wise of your agency to pick you: the mother of a family who have always included unrelated members, and who are so well known and loved throughout our local community. Because you are already the busiest person I know, I am awed by the added responsibility you have accepted –to support six families, each with one or two unrelated members who have disabilities; and, at the same time, to meet people in need of a home, getting to know them well so that you can introduce each one to a suitable family.

What an art, to work sensitively among such hopes and fears, such woundedness, need and goodwill! You tell me that you find it possible because the responsibility is shared by so many: your own family who forgive your absences and give you so much help; your colleagues at the agency; the county case managers; and the wonderful fellowship of families and other co-ordinators across the state.

Before your appointment, when you were a host family, I came to you with many questions about the dangers and safeguards around people with disabilities.

You invited me to meet Jane, the co-ordinator who supported you at that time, and who introduced Clarence into your family. Because of my questions and interest, you and Jane took me to meetings of your state committee and to your retreats and training events.

The news of your appointment inspires me to compare what I have learned about dangers and safeguards with the work unfolding in your family living network. People who live in specialized institutions are cut off from the relationships, many and varied, which form community. At the same time, if a particular group of people are segregated, as most people with disabilities have been, the rest of society is starved of their presence, of the possibility of many and diverse relationships with them. This situation has persisted for so long that it cannot be cured by simply “releasing” vulnerable friends into ordinary life: isolation, misunderstanding and abuse are to be expected. So we are constantly looking for ways to help lonely individuals bridge the isolation, to understand lives very different from our own, to learn new ways of living together.

Even when people found a friend, roommate, advocate, host family I was still nervous about isolated relationships - for people made vulnerable by inexperience, or a compliant and

trusting nature. You will remember our arguments, when I dared to be cynical about your enthusiasm for “family as safeguard.” For weeks we bombarded each other with stories of great, supportive families, and of horrors and abuses hidden behind the curtains of “family privacy,” and of supposed “rescue operations” through which human service workers destroyed good families, and of formal safeguards more intrusive than the mistakes of family. We went on to discuss great, open, hospitable communities which support all families, preventing the dangers due to stress and isolation, and the tyranny of some community mores, conventions, and traditions.

I had learned to fear isolation, not only for the person with disabilities, but for the family, who can be tyrannized by the behavior or overwhelming needs of that person. I recall several times asking you “Who, in fact, is the most vulnerable person in that family?” I told you of my own experience, when I lived in an expanded family, of the two case managers responsible to our friend David. The first one only saw David and hardly spoke to anyone else in our house. Her last visit was during a flu epidemic; all of us except David were extremely sick, so David greeted her at the door in a not-so-clean shirt. Though he told her of our plight, she showed no concern beyond a formal letter next day about David’s unmet hygiene needs!

The next case manager, Mary, made a point of meeting us all, would join in whatever we were doing, asked David to show her where he works and introduce all his friends. Sometimes she stayed for supper. Though her caseload was the same as her predecessor’s she took some time for all of us. Explaining this, she said “How can I help David unless I know all his people? If life is bad for you, how can it be good for David?”

I must say that your Family Living people have taught me that there really are social safeguards which work, even in our dangerous world. Here’s what I see you doing. You do not tell people what to do unless you have “walked a mile in their moccasins.” You, Olive, will have no credibility problems with mothers and fathers, you are one of them, and have been where they are. Years of challenges and trials, far from weakening you, have made you our wise friend, trusting, generous, competent and full of cheer. You will be welcome in everyone’s home, any time. I see no competition among you, no “turf” issues. You share information and help each other out. Because of this, you are always learning from and teaching each other. You have no perceptible hierarchy: co-ordinators do not behave like bigger fish than family members; you all listen to each other. You have some formal training courses, but your meetings are designed by your group, to meet your current needs. However, I see continuous training taking place, most of it informal –and it’s often hard to say who is trainer and who trainee!

You help the whole family in so many ways - a little extra money here, an invitation to a special event, with someone to stay in the home to make it possible, a few days rest for a tired mother, some therapy for John, an alteration to the house, and always your friendly presence,

someone to call, in the good times and the bad. You are sensitive to growth and changing needs.

Family living is not for everyone, and not for ever. It is good to see that when a person leaves a host family, though not formally part of your program, he or she is still part of the network of your growing community of concern. So your Family Living program has become a community safeguard for many people in quite different settings. Isolation gives way to mutual interest through your continual hospitality. Somehow you manage to balance this with respect for each family's individuality, You are really helping each person, each family, to "own themselves". This cannot be easy!

I remember your description of two co-ordinators, working for different agencies to support families as you are doing. Mr. North believed that "his" families were accountable to his agency, which in turn is accountable to the county for the use of public funds. Mr. North carried out his duties in a very proper and disciplined way. He had standards for host families, listed his expectations of them, and supervised the service they provided to "his" clients, placed in their home.

Mrs. South believed that public funds were given to the family living program in order to help people, who never had a family life, experience its rich diversity of unique relationships. Her agency looked at its program as a service to the community, supporting Mrs. South to help people and families design their own lives, determine their dreams together, create new ideas and grow into ever greater responsibility.

Both Mr. North and Mrs. South are people of conscience and integrity. I think we meet them both, throughout state and county government, and in our agencies. Each is concerned for the safety, freedom and growth of vulnerable people, and sincerely believes that the North, or the South, method is an essential safeguard.

As we struggle with implementing "Community life for everyone," North and South will clash ever and again. I worry about this, because the clash is so often harsh and adversarial - like pro-life and pro-choice - and this strife is no good for our families. Perhaps what excites me most about your network, Olive, is that you, in your meetings, retreats, offices and kitchens are making warm, stimulating, hospitable, inclusive safe spaces, in which North and South can come to understand and respect each others integrity - and in which the people most affected (your families) can understand both, and make their own choices.

I must tell you what I heard on Saturday. Young Sam, my neighbor, who is in your son Ted's class, was talking to his mother, about this great outing Ted was looking forward to. Sam was begging his mother to let him go with Ted, who had told him about the fishing and the games and campfire at night. I was only half listening, thinking it was some children's camp affair, 'till Sam played his trump card, "You and dad could come too. Ted says it's for whole families and all the people they live with. Ted says that's why he liked it last year, he

met all kinds of new people.” Then I realized this was the annual retreat of your family living program.

What a great way of inclusion: to help people with disabilities and their friends create a culture so attractive and hospitable that new people flow toward it along natural paths like Ted and Sam’s.

With all good wishes for your new job,

## To a friend

Dear Kay,

Last week we were arguing about the “community” which we hope will surround the friends we are helping to follow their dreams despite certain disabilities. You, in your mostly rural area, have had some success with searching out remnants of the old, “natural” community, and encouraging them to include some nonconforming people. My doubts stem from watching the rural community I knew twenty years ago being overwhelmed by suburbia, with its overpopulation, overstimulation and speeding up of time. Supporting people in informal lifesharing becomes ever harder. Just one example, nobody walks or bicycles to work any more. The dormitory developments, shopping malls and dying downtown areas are entirely based on the automobile. Increased traffic has made our roads impossibly dangerous to cyclists. Now imagine the situation of a non-driver who finds a supportive home and a good job a few miles apart.

I could not agree with you that community will come “naturally” if we withdraw the specialized “system” surrounding people with disabilities. I am convinced that we require a new quality of consciously made, consciously built community. Community cannot be made from outside, or by one person. Community is association: it is owned by its members, or it is something else.

You told of successful support circles building cells of community in your area. I have seen those too but I also see them faltering, as the whole circle, even the strongest supporters, comes under stress from the pressures of suburbia and widespread recession. The circles which are still flourishing, as far as I have observed, all contain at least one member who is supported in order to have time and resources to help the others: in one circle it is a case manager; in another, a person working on a grant to study and build such new communities; in another, an employee of an enlightened agency which encourages its staff to work in this way.

You, who have been much wounded, were cynical about including “human service professionals” in our circles. You feel a threat of co-option by “the Empire”. I challenged you to think of human service professionals as “People First” –are they not as much in need of deinstitutionalization as their former clients?

Community is fostered by a knowledge and open sharing of our vulnerabilities. I believe many people, bearing many labels (such as client, provider, bureaucrat, professional and lay person) are admitting to each other that none of us really knows how to build the commu-

nity we need as we approach the year 2000. As we do this research, we need each other's skills and support, born of the most divergent experiences, opinions, wounds. We must make safe spaces in which to listen to each other, and out of which can grow truly inclusive community. Like all true community, it will be about welcome and hospitality, and it acknowledges that those who have accepted "disabled" lives are not unhappy accidents slowing up progress toward the Great Society, but teachers in a lifesharing which can face the predictable disasters of the 21st century.

I am truly worried by the adversarial tone of some of our discussions. It is so easy to polarize into dogmatic opinions and warring rights groups. It distresses me to watch friends, especially people with mental retardation, being trained to "fight for their rights" - and to see the response of neighbors who defend *their* rights in opposition. If indeed we are less quick to dismiss the disabled as unhappy accidents, hopefully to be eliminated by amniocentesis and genetic engineering, I fear we may fall into the opposite mode of grudging them a share of rights, privileges and resources. So much depends on our image and concept of humanness! I am amazed how swiftly my friends evade that discussion - taking refuge in pouring blame on another person, group or system. Do you think we can really make human community without sharing our search for the meaning of our very humanity? I know, you asked me to explain that challenge in our last phone call -and I promised to try. The next day I was challenged by two friends disputing the abortion question. I'll end this letter with some notes I made after their fiery argument. This is a good illustration of how fighting over opinions clouds and even prevents true research and deeper understanding.

The whole furor is due to the new power to predict and *control* the process of incarnation and birth, which a short time ago was still a holy mystery. It comes down to individual commitment and community support. If I know this child will be born with a disability, I face two questions.

First, the situation throws me back on my concept of parenthood: is my child my property, or am I the responsible conduit for leading a mature, inviolate spirit through the process of incarnation and childhood in order to participate as an adult in world evolution?

Next, am I personally willing to make a home, a life, for this child with this disability? Or, do I suggest to this eternal inviolate spirit to go back and try again to build a body more suitable for fulfilling a life-work in the world? How do I know that this person has not chosen exactly this "disabled" body in order to fulfil this particular life's mission, which perhaps ought to begin right now, and not be delayed while another pregnancy or parent is sought? How do I help a young mother listen to the higher being of the coming child in such a way she can know her answer to those questions, and be supported, heard, and empowered to act accordingly?

These are incredibly difficult discussions, opened up by our new technical control over birth and death. It's so easy to fight each other "pro-life/pro-choice," like Serb and Croat,



Arab and Jew. What should we do instead in order to learn how to carry these huge new responsibilities together?

Two simultaneous efforts may help:

- Make safe spaces for serious discussion and envisioning around the real questions of life, incarnation, death and the purpose of life on earth. Widen the circles to take in seemingly opposite views for the sake of the wholeness of life.
- Recognize the community responsibility implied in one mother's decision to make a home for a baby, child, adult with a disability. We have been taught the first steps if we walked in the shoes of Mary's parents, listening how it was for them when Mary was born (unexpectedly). So we can know how it works without community being consciously built around a family. Now, are we willing and able to begin this process before the child is born, by helping the mother listen, divine, decide, and live with the decision whatever it is? Who is the "we" who make a free commitment to each other, to this mother and her child?

If we learn that lesson, then children with disabilities will have taught us what to do around all mothers, single, homeless, poor, and even affluent and not apparently in need. The child is always in need of help to make sense of a life in an increasingly dysfunctional world. These problems will not go away. We must not allow them to divide us and turn us into warring "rights" groups. We must face them hand in hand, soberly, with that interest which leads to love.

I look forward to our next discussions, Kay. It is so helpful to have a good friend with experiences and opinions so different from my own,

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### Community

At one time people lived in homogeneous groups, composed of more or less the same family, with the same roots. In these groups –the tribe, the village– people spoke the same language, lived by the same rites and traditions, had the same code of behavior and accepted the same authority. There was a solidarity among them. This solidarity came both from their flesh and blood and from the need to cooperate to meet material needs and to defend the group from enemy attack and natural dangers. There was a unity among people of the same group which etched itself deeply on their unconscious.

Times have changed. Contemporary society is the product of the disintegration of these more or less natural or familial groupings. Nowadays, people who live in the same area are no longer part of a homogeneous group. Towns are made up of neighbors who do not know each other –and this will soon be true of villages, too. People are afraid, and so shut themselves up in their own houses. Human community is no longer to be found in the street, the neighborhood or the village. Mobility has brought a mixture of people, religions and philosophies.

This state of things brings a loneliness which people have more or less difficulty in coping with. The family, sometimes shrunk to just a couple and their children, can no longer be self-sufficient. It seeks out friends. People cannot live as if they were on a desert island. They need companions, friends with whom they can share their lives, their vision and their ideals. So it is that people come together, not because they live in the same neighborhood or are related, but because of a mutual sympathy; they come together around ideas, around a vision of man and society, a common interest. Some of them meet occasionally. Others decide to live under the same roof: they leave their own neighborhoods and relations, sometimes their work as well, to live with others in a community based on these new criteria and this new vision.

– Jean Vanier, *Community and Growth*

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## To a friend in lifesharing

Dear Martha,

I have been thinking about your challenge to list the essentials of a lifesharing household. I talked to Jane and some other people, and we tried to put our many thoughts into a form. I am sending you this picture, which needs some explaining. I think it will be easiest to understand our form if you first look carefully at the picture and then read the notes that follow.

You see that we have drawn three concentric circles with the house in the middle. In the circle closest to the house are qualities we would all like to find there, we called them the “signs of health” in the house-community. In the next circle are those things which, if they are done and attended to, will help to foster and bring about the “signs of health.” We called them “nurturing activities.” They can be done or brought about by members of the household and they also involve other people. The outer circle contains essential and helpful things which friends near and far can do to enhance the health of our lifesharing household.

Jane and I discovered something in our talks which we want to share with you and all our lifesharing friends. It is a saying, *the process is the product*. Our conversations were full of life. Sometimes just Jane and I were working at trying to list the essentials; several times we had five or six friends sharing experiences, arguing, laughing, telling some shattering stories, throwing our lists into chaos. These were rich experiences for which each of us was deeply grateful, and from which we all learned and grew, perhaps, a little wiser and more tolerant.

Then Jane and I went over our notes and made these circles. It was as though we encapsulated all the lively ideas, the fellowship and learning, into little dried up pills. Jane called them seeds. That made us put petals around the outer circle to encourage the concept to come alive again!

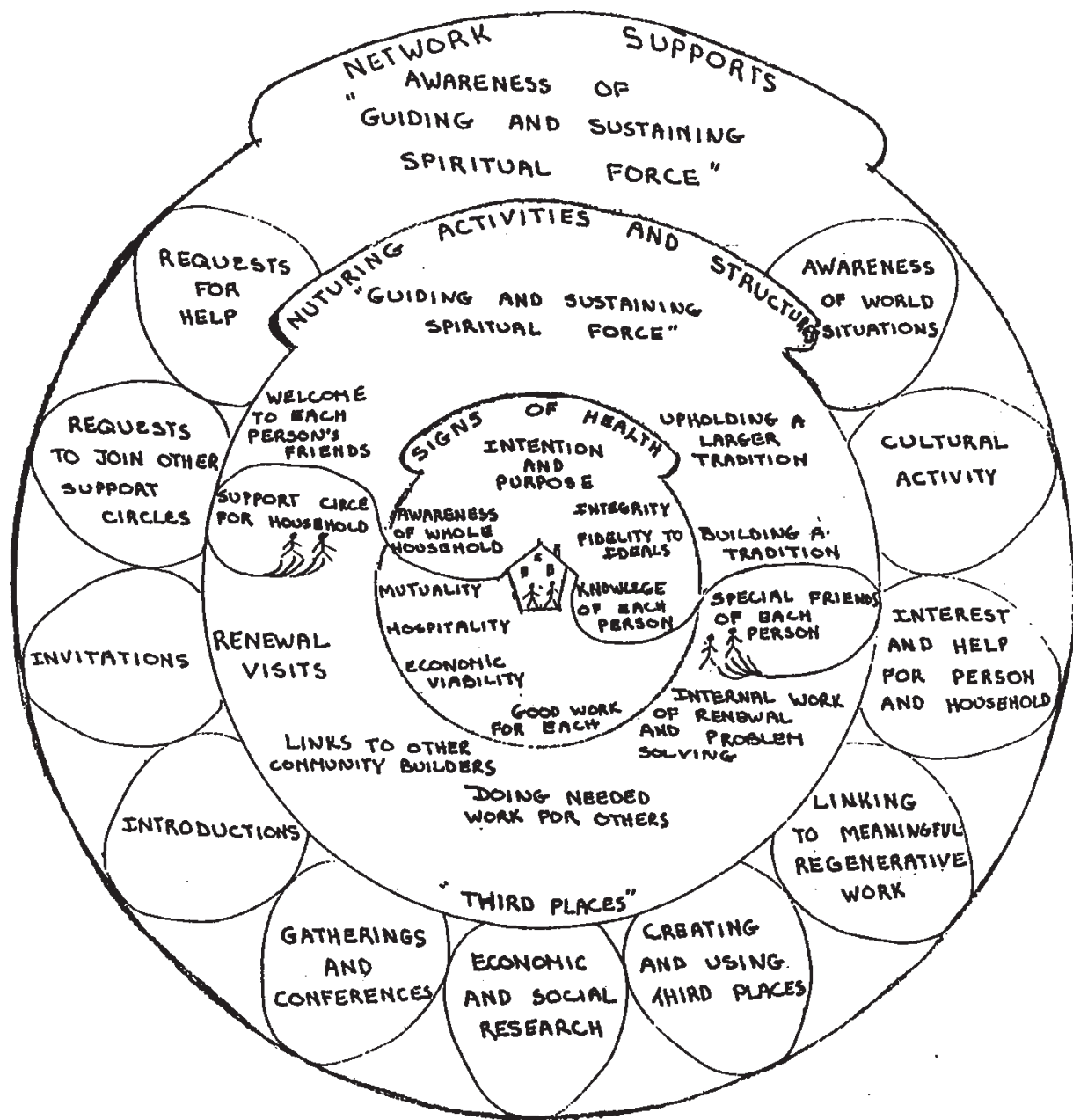
What I am trying to convey is simply this: lifesharing is best learned while sharing life. Books, lists, concepts and diagrams can be very useful as aids to discussion and learning together. But we must remember that our lifesharing, and the creative, imaginative research it involves, become lifeless when written down. Written formulations wait for the next group of people to unwrap the concepts in the warmth of fellowship, nourish them with laughter, water them with tears ...

It is strange how often we come back to these images of plants and gardens, seeds, growth and decay. One of our friends had read that the laws of nature and the laws of social life are

the same... in that same conversation we imagined our lifesharing relationships to be like seeds of health in the social soil which is losing its structure... next time we meet with a few friends we could turn to that topic.

So I will invite you and Jane, and some other friends, to work on these circles together. Perhaps we shall change them. We shall certainly change ourselves and each other in the process!

I look forward to our conversation,



## A tentative conceptual map of safeguards for lifesharing households

The way from aggregate to community begins with a small association - be it a biological family, or other primary relationship. We have met many varieties of this primary association, in our quest for that quality which makes living together into lifesharing. Each is unique, all face challenges. We call this cell of community the *Lifesharing Household*.

Lifesharing is coming to be known as a consciously willed process - a decision between two or more people to work on the business of living together. As with a marriage, the primary relationship, when healthy, creates more life, more relationships - the habits of such growth vary, as with the plants. Isolation, for more than certain periods, is however always a harbinger of stress or disorder.

It is this nucleus, or growing point which we have called the **lifesharing household**.

As a seed in growing puts forth root, leaf, and stem, each with different functions and appearances, so the lifesharing household comes to consist of people living under one roof, and other people very closely associated with them. The diagram pictures some elements of a lifesharing household. It is hard to draw, because the outer manifestations of lifesharing are so different - that is of its essence. A healthy community treasures uniqueness, variety, manifoldness.

Lifesharing is an art: the Art of Living; the Social Art. And, like all arts, there are disciplines to be learned, though the masterpieces will be as different as a Rembrandt from a Grandma Moses! Our diagram is a first attempt to digest what we have seen and learned about the present state of the art of lifesharing.

In the center of the picture, you see one lifesharing **house**, with the people who live in it. Maybe there are two people or maybe many more. The house is surrounded by several circles, but it also reaches out two "arms" to embrace people who are part of the **household** without living under its roof. To explain further, let us look at each circle in turn.

In the first circle are the ever-present challenges of a household. As we examine these, we will find that several of them seem to work against each other, and it will be hard, if not impossible, to keep them all in mind, and in balance, at all times. A healthy house tries to do that, as a healthy organism keeps a living, dynamic balance between extremes of hot-cold, wet-dry, stress-relaxation. So, we have called this circle **signs of health**.

The second circle might have been called "Safeguards" - but words like nurture and support are more true to what people are saying and doing. **Nurturing activities and structures** help our house to work on the matters in the first circle.

Now we can understand the two sheltering "arms" of the household. The people who live in our house try to be aware of the *whole household*: its purpose, its present health, its eco-

conomic viability. Enthusiasm for the intentions and loyalty to the ideals, will call forth efforts, even sacrifices, from individuals. To balance this, there is a need to know each person well, to notice changes, turns of destiny, new opportunities –to help the right question arise at the right time.

Households have discovered nurturing activities to help: the **support circle** for the whole house, and the **special friends** or advocates of each person. Notice that the “arms” go *out from* the house to embrace helping friends. This signifies that the help and support is *mutual*, everyone becomes both giver and receiver. This is a very important finding of lifesharing households.

The third circle illustrates some of the activities by which a household contributes to organizing a **network of support** for lifesharers. In this network, interested friends support lifesharing households, and in turn are nurtured and stimulated by them.

### The first circle: Signs of health

The house has a clear **purpose and intention**. This helps people to choose to live there, and to be interested in supporting it. A household which is established for the sole purpose of caring for one or more of its members struggles with the tendency to become a staff/client service. Mutuality, in the sense that each cares for the others as needed, comes about more easily when the reason for associating is clear, and larger than the individuals’ single concerns. For example, growing food for a neighborhood, or providing hospitality for refugees, or running a cleaning and landscaping service, or helping guests to become hosts to new guests, or involvement in a cultural or religious purpose, preserving a historic building. Does that mean that only people of “able body and sound mind” can be part of such a purposeful household? On the contrary, people with disabilities thrive when the emphasis is on their ability, when they are needed by the others to play a role in the household’s larger purpose. The support circle and individual advocates are drawn into the household by this larger purpose, as well as by their interest in the people of the house.

**Fidelity to ideals** requires keeping intentions in view and being aware when other necessary considerations seem to cloud them. Beginning with clear ideals and intentions, a lively and conscious household will evolve and change, embracing new opportunities and friends, pursuing the various interests of its members. It is also possible that a low-key, peaceful household may evolve habits in which, since life seems to be “no problem”, the original ideals become clouded. Either direction opens possibilities for danger and disintegration, especially for the person who does not loudly demand her rights.

**Integrity**. The household is a living organism. Every living organism has a skin, or *in-teg-ument*, which plays a vital role in its healthy function. To be “skinless” is to be oversensitive, at the mercy of every outside touch. And death results swiftly from a skin being made impermeable. This is even true for the hardest skins, namely, those which protect new life - the

seed-coats, nut shells and eggshells. Probably the skin or sheath is the first image that springs to mind when we hear the word “safeguard”, and it is endlessly helpful to keep in mind as lifesharing manifests its individual expressions.

**Hospitality** enriches the house, but may need to be moderated at times, to maintain the integrity of the order and rhythm which sustains it. Attention to private spaces and individual needs will help. The confidence of “owning oneself” enables individuals and families to offer gracious welcome without being overwhelmed.

**Mutuality** as a basic attitude distinguishes our house from a “service provider”, where one part of the population cares for the others, in a permanent stereotype of “givers” and “consumers”. In our house, everyone is there by choice, and all care for each other. It is our home and we are all at home there.

**Work.** Lifesharers are learning, often from people who have been deprived of the possibility to work, that everyone carries a deep need to give, in love and service, through the work of head, heart and hand, and to know that gift is received and valued, having meaning in a larger whole, making sense, and doing good. Note that in our diagram the work of each person is considered separately from income generation or financial viability.

**Economic Viability.** Through this challenge, the horns of the lifesharing dilemma may well protrude. Hospitality opens the door of our house to someone in need of a home, exploring a possible lifesharing relationship. The newcomer has needs, talents, and resources. All goes well. There comes another guest, and another, each enriching, but also challenging, the relationship. One has capital enough to add a wing to the house. After a year the others find it impossible to continue the relationship - who has “security of tenure”? Is the relationship now imprisoned by legal/fiscal obligations? Or, in another situation, there is a primary relationship, but insufficient income. One member of the household carries the load of worry about bills, works two jobs, has less and less time for family life and the stress is felt by all. There is a possibility to register one of the family in a “disability” program: that brings some funds, but also some licensing requirements, with their predictable effect on the relationship. Once the place is licensed, why not offer a “bed” to another person in need?

The economic problems are endless and households are working at them ever more consciously. In these discussions, two voices commonly respond to every new idea. One says “it would never be allowed.” The other, “That will cost too much.” It is important to let these voices sound in every group, to bring wishful thinkers back from cloud-cuckoo land. However, many good ideas for mutual support in community are nipped in the bud by listening too soon to these “practical” voices. For example,

- There are people who want to grow good food on fertile soil, and people who want to eat it. “It’s not economically viable” prevents many people from doing what they know to be right: e.g. keeping a small number of free range chickens rather than a battery house. Community Supported Agriculture grew through a few people who refused the prevailing despair. In one



such arrangement, 100 families choose to support one family whose vocation is farming - not to buy their produce, but to support one hundredth the part of the farm and family budget - receiving one hundredth of each year's produce. This does more than provide food - it builds a small, economically sound community. Trauger Groh describes this well in *Farms of Tomorrow*.

- The Mondragon cooperatives, described in Roy Morrison's *We Build the Road As We Travel*, grew out of widespread economic despair, from the idea of one man and a few students.

Lifesharing households must become wonderfully creative in our community economics.

### The second circle: Nurturing activities & structures

**Internal Work of Renewal and Problem Solving.** Many communities and households have a tradition of special times for reviewing their life in the light of higher ideals. These moments are sometimes formed around an individual's destiny, sometimes around a current question or problem, sometimes around a festival of the year. Whether they involve the whole community or a smaller group specially connected to the subject, these moments have importance far beyond the apparent occasion. They require an effort of will, and are easily overlooked in the rush of daily life. Noticing the need for such a moment, and working to prepare and carry it out worthily, can be the contribution of a friend of the house, or of any fully involved member.

Households evolve many different social forms, appropriate to their size and age, for calling on the participation of all members in the work and decisions of the organism. A house which runs efficiently without any such forms, because *one person makes all the decisions*, manifests the need to grow the sheltering arms of support circle and special friends.

**Building a tradition.** Many households work to create a rhythm and structure in their social life, this is as important to the health of their community as good architecture, or sound nourishment. The larger the household, the more complex may become the organs of its living body. A tradition of celebrating seasonal festivals, for example, has many benefits. It...

...links the house to others in the area who also celebrate

...gives opportunity for moments of renewal and refreshment

...makes a time to gather the support group, special friends, and other community builders in celebration of the guiding and sustaining spirit; in awareness of others across the world; to confirm direction, ideals and purposes; to divine the role of the household and its individual destinies in a world which makes sense

...gives a sense of biography to the household as the years pass and can be remembered

...provides special opportunities to give and receive (some households offer a Christmas Play every year, some invite the neighbors to a harvest festival).

The danger of nurturing social forms getting lost in the daily rush is greatly lessened by purposefully building traditions. Regular meetings of the household support circle will certainly fail over time if they become a bureaucratic duty. Building a traditional form, to which everyone brings their gifts, ensures an expectant enthusiasm which carries each occasion. Some houses have a strong weekly rhythm, some a special tradition of birthday celebrations. Traditions give a sense of history, roots and responsibility. Over time, traditions may lapse into habits, or restrictive rules, unless they can be consciously reviewed and refreshed with new eyes and new voices.

**Upholding a larger tradition.** Some households are part of worldwide networks in which each household builds a part of their common tradition.

**Links to other community builders** who don't share the household's traditions or style of living provides new perspectives and different kinds of energy to the household. In addition to other conscious lifesharers, other community builders may work to create community through the work of economic development, the creation of social forms such as citizen advocacy or support circles, or various forms of cultural work which enrich, celebrate and sustain community life

**Renewal Visits** With the experience of lifesharing comes the wish to be part of a larger whole, the need to share experience and disarm problems with others, sometimes with newcomers who are not part of one's daily life, not even "like-minded", but who bring a fresh look at our household. This is a delicate matter—the tender shoot of a new tradition—and one of the most important aspects of our project.

We know three strong principles which ensure the integrity of this new form...

...the visitors must be invited by the host household

...they must wield no power or direct consequence (funds, licenses, approval)

...there are no experts and there is openness to mutuality: hosts can become visitors, and visitors will likely become hosts.

**Welcome** to each person's friends. The challenges of mutuality and hospitality (in our first circle) are emphasized as our household welcomes each member's friends and finds how to accept offers of help and extend help to others, without losing its own integrity and rhythm. If the household is practiced in this, such activities as renewal visits will seem natural. An isolated household often finds it hard to invite such visitors, but after a successful experience usually gains confidence in welcoming and including friends.

**Third places**, places which are neither home nor work, are essential elements in a healthy social environment. Such settings are easily accessible and welcoming; whenever one goes there, one can expect to find a few friends. The third place is a casualty of our dis-sociated life. Such places relate to all the challenges of the first circle: to the cultivation of "my friends, your

friends, our friends”, and to the free and unpredictable growth of informal relationships and supports.

In *The Great Good Place*, Oldenburg describes the evolution of Third Places in various cultures, with essential insights into their function for healthy community. Pubs, diners, clubs, streets have all served this purpose. Architecture, location and design are all important, but the Third Place thrives or wilts in the soil of social relationships. We found more good thoughts on such settings in McCamant and Durrett’s fascinating book, *Co-Housing*.

The creation of third places is an important force of community regeneration. Lifesharing households are enriched by creating such places: a coffeeshop open to their community and the public - a lending library and snack bar adjacent to the pick-up barn of a community garden.

**Doing needed work for others** makes a central contribution to the development of each member of a household. Many people have been prevented, by disability or lack of expectation, from experiencing the realization of being needed - being seriously asked to help - feeling that one’s presence is valued, makes a difference. Our household actively fosters this experience, not only between its members, but with friends and neighbors. Only to receive is stifling, if not balanced by opportunity to give, and be taken seriously.

**Guiding and Sustaining Spiritual Force.** (We borrowed this phrase, gratefully, from Darcy Elks, as being neither vague nor sectarian.) The decision to work on the art of lifesharing, rather than accept a tolerable living-alongside, may or may not arise from a religious or moral conviction, but we think it inevitably leads people to such larger questions. It appears that one does not enter lifesharing arrangements and remain the same: lifesharing implies inner as well as outer change. Living closely with others means meeting oneself in daily inescapable reflection, and often brings direct experience of another as an inviolate spirit, invisible to our outer eyes. Such experiences are the fruit of the mutuality of lifesharing, and lead to deep consideration of the real nature of the human being and the earth, and the meaning of life. At this level, sectarianism is transcended along with handicapping conditions of soul or body. The manifold goals and qualities of life become coherent.

It is unfortunately necessary to consider safeguards against exploitation of vulnerable people by sects and cults, which invoke morality and religious conviction. There are no quick answers in this sensitive area, which touches on such matters as freedom of religious expression, and the reality of personal choices. The origin of the concentric circles of our diagram lies in such a problematic. For example, cults isolate people and strive for uniformity; such isolated and coercive settings are inherently dangerous. Lifesharing in a healthy community implies many different kinds of relationships, in a lively, dynamic interplay of contradictions and opposites.

A guiding spiritual force in the sense we mean it here, has a gesture of open minds, open hearts, open arms, and a movement toward ever greater understanding and deeper knowledge. There are many settings in which highly moral people create an exclusive and dogmatic, closed area around the spiritual force which sustains them. One of the gifts of many people with

disabilities has been to open a safe space in which people from these closed settings can meet and converse with others. The essential gesture of lifesharing is helping each other to own ourselves.

### **The third circle: Network supports**

The third circle identifies activities which enliven lifesharing households by keeping the web of relationships necessary for human development alive and growing. Those who wish to promote safety for lifesharing will participate in, support, and sponsor such activities with whatever resources are theirs to freely give. The art of lifesharing is refined by developing grace and skill in such activities as these.

- Increasing awareness of the world situation
- Participating in cultural activity such as shared music, drama, dance, and pageant
- Building practical, helpful interest in each person's life and in the life of the household
- Helping people define meaningful work and forge the social and economic links necessary to its pursuit
- Creating and using third places
- Conducting and participating in economic and social research to identify common problems and build shared solutions
- Convening and supporting gatherings and conferences which permit reflection and renewal
- Making introductions among people with diverse interests, who may never otherwise have the opportunity to meet because of the divisions imposed by a disconnected and disconnecting society
- Forming invitations that lead new people into lifesharing and conscious community building
- Making and honoring requests to participate in conscious support circles around other lifesharing households
- Asking for help with openness and generously
- Strengthening personal and community awareness of guiding and sustaining spiritual force

## To a lifesharer exploring safeguards

Dear Ruth,

As I promised at our retreat, I am sending you some materials on the process we came to call “visits.”

To get the most from reading this material on visits, you need to know a bit about the history of this paper and about my second thoughts on even sending it to you.

You want a way to deal with the thorny problem of being, in your hearts, a lifesharing community, and being seen, by the state, as “a facility for the care and treatment of the mentally retarded,” and thus subject to regulation. You have found compliance with these regulations problematic. They intrude a foreign way of understanding your household relationships and activities. Through the lens of the regulations, your friends, equals, and companions on life’s journey become clients, who are to be habilitated according to plan in order to attain skills; your household, which you experience and guide as a breathing whole, collapses into a means of behavioral treatment; and, despite your keen appreciation that lifesharing means sharing and working through vulnerabilities together, the state only considers your friends with developmental disabilities vulnerable and prescribes protections in the form of odd, abstract rules (such as your states’ fingerprint checks on “staff”).

Individual inspectors, deeply impressed with what they can plainly sense about the quality of your home life, have found honest but creative ways to interpret your life in terms of the regulations. And administrators, similarly impressed and increasingly aware of the limits of typical services, have been more than willing to make room for you to co-exist with their rules.

These accommodations are enough to get by with, but you (and I) remain concerned that there is much more at stake here. We must search, not for ways to get around the issues, but for ways to get into them. One reasonable beginning for this search could be to develop some alternative to regulation, owned and operated by lifesharing households, which would both satisfy the state and serve the households as an act of consciousness raising and a means to build a sustaining culture.

You are correct in remembering that our project set out to do this. Initial expectations from our friends and sponsors ranged widely, but all focused on a tool of some sort. Some thought administratively, “This will be an alternative to licensing inspections for informal living arrangements.” Others were optimistic, “This will help the lifesharing culture develop a

common tradition of festivals and celebration.” Others were practical, “This will be a kind of lifesharers accreditation with reviews by lifesharing peers.” Others were worried, “This will be a dangerous abstraction, setting up yet another group of experts, and soon imposed by the system.” Others were skeptical, “This will be a bit of touchy-feely nonsense with no real teeth to assure compliance.”

Our initial conversations and reflections with people who live in lifesharing households confirmed for us that the most obvious thing we have in common is a passion to protect the freedom which is integral to our calling. Much as many of these people liked and respected us, they were not going to allow us to construct and apply a yardstick for measuring what they do out of freedom. The idea of a tool was reshaped: we decided to bring small teams of experienced lifesharers together to review life in households willing to cooperate with us. Perhaps out of the experience of these groups, which we called review teams, some common content would emerge.

The review teams proved extremely powerful as a research tool. We were amazed and excited by the learning and the sense of mutual engagement they generated. We learned much about the process: the less the team acted like reviewers and the more they simply joined in the life of the household as concerned visitors the more valid seemed their sense of the household; widening the team to include people with diverse experiences immeasurably enriched the learning, even when some of the people involved had never shared home life with people with developmental disabilities; the less the team delivered “feedback” reports and the more they stimulated conversation with lifesharers about important, and perhaps unspoken, concerns the more useful, messy, and anxiety provoking they were seen to be. But the review team experience frustrated, and for us ended, the quest for a lifesharing measuring tool.

We became painfully conscious of what now seems obvious. The only path to learning about lifesharing that has integrity must itself be an example of a lifesharing relationship. The visit must be conceived in the free exchange of invitation and response and carried out with deep honesty and respect for each person’s experience, perceptions, and way of understanding the host household and its unique development.

We became reflective about “visiting.” Not assessing, or accrediting, or reviewing; simply visiting with care, consciousness, and an invitation to comment on what the visitors learned from the visit. We tried to capture some of the etiquette of visiting in the enclosed paper [See Appendix 3].

This reflection, plus the stimulating frustration of trying to expand the process, brought the central importance of conscious invitation into clear focus for us. (The short reflection following this letter captures some of what it seems like to us when we are genuinely welcomed and genuinely welcoming. This ideal attitude of invitation is essential to all lifesharing; the stress and specialness of a purposeful visit only sharpens awareness of the

everyday art of inviting others in.) The stimulating frustration came from our discovery that, as long as we did the groundwork and the organizing, many people were willing to make time to visit and a number of different kinds of lifesharing household were willing to have us come and visit them. But we had limited success in getting others to initiate visits (perhaps including us as assistants or observers) and we grew uneasy with the sense that some people were beginning to see us as a team of experts responsible for safeguarding.

We concluded that each lifesharing situation would need absolutely individual adaptations of each element of the visit. From the invitation, to the method of selection of visitors, to the number and timing of visits, to details of preparation, questions explored, and ways of communicating conclusions, everything must be sensitive, flexible, open to new ideas and learning from mistakes together. This is just the opposite of the “objective, legally defensible, uniformly applied standards” which are key criteria for practitioners of licensing and service evaluation. Lifesharing visits are not for the evaluation of the host. They are occasions for education and exploration: themselves lifesharing moments, created in lifesharing settings for the advancement of the art. The path to a widely acceptable, alternative form of regulation ends here, at least for now.

Nevertheless, we are left with the conviction that something is indeed wanted and needed among lifesharers. We recognize that each situation which we visited has, by coincidence, undergone huge changes in the year or so following our visit. We learn from this, once again, that the process is the product.

Simultaneous with our research into many forms and variations of visiting, we got involved with many different people and settings, concerned in various ways with building community. These encounters strengthened our resolve to uphold three insights in action.

- Lifesharing is not simply something done with people with disabilities or through the creation of lifesharing households; it is (often under other names) a growing phenomenon crucial in this era of human evolution, whose significance grows as its practitioners come to recognize and know one another.
- There are no safeguards for lifesharers, or for lifesharing, apart from the conscious, carefilled work of building up healthy community in a broken and increasingly dysfunctional world. Efforts to pick out some as most vulnerable and take procedural steps to protect them have ironic results. (The short essay on healthy community, which follows this letter, offers a glimpse of this point of view).
- The most urgent need is for the cultivation of more people who are more able to capably practice lifesharing and more actively aware of its historical role and meaning. (At Appendix 1 you will find an essay that places lifesharing in a somewhat wider context.)

My reservations about sharing this are probably obvious from my review of its history, but I will be explicit::

- This material represents one stage of some people's learning. It has not been, nor do we think it ever should be, endorsed or adopted or acclaimed among lifesharers. We don't want to seem to be arrogantly proclaiming the (even a) solution.
- As soon as the words were on paper our knowledge grew. This is, in a sense, yesterday's news. Think of it as our footprints, not our path.
- We have nightmares about well meaning administrators adopting and imposing "visiting" as a safeguard. This wouldn't work; indeed, it would be deeply counterproductive.
- The only way to understand the realities of visits is to make (at least) one and to play host to one. Lifesharing is only learned by sharing life. If the idea tickles you, lets talk about how you might visit, or host some people in your own home. If that seems a bad idea, then leave this stuff alone.

So, having told you at length all we did not find out, what advice do I have?

One of the strangest effects of the increasing effort to protect people with developmental disabilities as individuals is its ineffectiveness. The most important thing for those of us who share our lives to contribute is to insure that all of the members of our household look out for one another in ways that are respectful of each person's gifts and vulnerabilities. The best position from which to meet efforts to regulate you is as a strong, fallible human group struggling to accord one another dignity, challenges to grow, and mutual protection.

Your whole household is collectively responsible for the integrity of your threshold. When inspectors and administrators receive heartfelt invitations to join in the life of your house, not as agents of the state but as valued individuals who deserve a welcome as much as any other stranger, they will be able to feel your integrity as a household, and, as they share a bit in it, they will be disposed to respect it.

Openness needs to go another step, to systematically include "outsiders" for at least two reasons. You need to consciously extend your household to invite, include, and support people who are committed friends of each individual and people who are committed to the development of your household as a social organism. Closedness, self-righteousness, and exclusiveness have no place among lifesharers. People deserve a measure of privacy, and sometimes people need to retreat for a bit in order to deal with difficult times, but this can never justify making your home an island. Building bridges is not just important as a safeguard, it is also the only way to spread the experience of lifesharing.

Once your own house is in order, I believe that the next important thing is to actively engage in open conversation and debate with the people who want to regulate and inspect you. You must be neither a compliant push over, hoping that the strangers will go away if you pretend to be nice, nor a strident defender of yourself, hoping that the strangers will go away if you shout at them. What the world needs is for all of us to widen our circle of



sharing, respecting and learning from those who see the world differently as we give them opportunities to learn how it really is for us. Only open dialogue which honors differences as a way to mutual understanding will do.

I look forward to your response to these thoughts. Please call or write to keep our conversation moving.

In hopes of an invitation,

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### Invitation

I open the door for you.

I will have time for you; I will give you my time.

I welcome you to my house as it is, not as I think you would like to see it, or as I want you to think it is, or even as I think it should be or wish it were.

I acknowledge that you and I are interested in something larger than each other, something to be explored together, something for which this unique encounter of ours is important.

We will both be changed by this encounter; we do not know how; we are open to the future.

### Acceptance

You open the door for me.

I feel honored.

I wipe my feet as I step across your threshold.

I accept your invitation, and will try to bring you my best self—but I come as I am, not as an expert or the all wise counsellor.

As I share a small part of your life, I will try to look deeply into it, because you asked me to do so. I need your guidance to ask questions, suggest where you would like me to look especially.

Because we know ourselves to be part of a larger effort, in the service of which we undertake this unique encounter, I feel I have your permission to go beyond conventional friendship and common politeness, to look deeply into your life and tell you what I see.

I may hurt you, I may be mistaken, I may see accurately but express what I see clumsily.

You may be angry, perhaps even hurt me.

We know these possibilities ahead of time and will not try to avoid them.

I promise you, I will not cover up any hurtful parts by a polite departure from your life. I will, with your help, continue the process our visit begins, making time for mutual understanding, reconciliation, and forgiveness.

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### Healthy community

Just as healthy soil contains myriad species and substances including those associated with disease, and every human body provides a home to many microorganisms including those associated with sickness, so healthy community contains many potentials including those associated with oppression and neglect and abuse. In any of these living organisms, health results from knowledgeably balancing a wide field of sometimes opposing forces, but not from single minded attempts to destroy disease in individual segments.

Trying to maintain health just by identifying and eradicating all toxins brings ironic results: life cannot thrive under sterile conditions. Sterilized soil develops petrochemical fertilizer dependency. A sterilized gut can't digest real food. A risk free environment imprisons people and stifles and stunts their growth. To cultivate health, we have to create an environment in which potentially destructive forces are harmonized and limited by rhythmically calling balancing forces into play. Nurturing health calls for reaching out to include a wider environment more than for reaching into isolated individuals. The more damaged the environment we are part of, the longer we will need to understand it and to develop the art to build up its life sustaining diversity.

Trying to restore health simply by isolating and destroying particular symptoms multiplies the probability of new maladies: some development only comes by living with and through suffering. Poisoning the "bad" bugs enlarges the niche available to other crop destroyers. Knocking out every infection with antibiotics encourages the growth of more complex, better adapted bacteria. Blaming and ejecting one member as the cause of disharmony masks conflict in the community and sets the stage for the next episode of scapegoating.

To restore health we have to allow illness to express –and perhaps to mend– our imbalances. We can often soothe discomfort and frequently limit destruction without stamping out symptoms before we have read them as signs. Circumstances may lead us to reach for the pesticide or the antibiotic or the

tranquillizer, but we will intervene mindful of the cascading effects of intervention and without the illusion that we are increasing health by decreasing disease.

Trying to understand health solely by expanding the catalog of specific causes of ever more precisely categorized diseases blinds one eye. Some illness may be adequately described by squinting down the barrel of a microscope, but health can only be understood in stereoscopic depth and through a broad scan. Laboratory intervention of ever stronger agents to search and destroy pests contributes nothing to observing, understanding and strengthening the ecological balance of a particular field. Assaying the agent of a symptom ignores the question of the meaning of this disease in this particular person's life. Analyzing negative incidents to lengthen the list of bad practices forbidden by regulation fails to raise consciousness of how the people in a particular household can live well together in the face of a specific difficulty.

To understand health we look at health. To see health we recognize ourselves as co-creators of health in a widening web of earthly, human, and spiritual relationships. To weave a stronger web of relationships, we increase individual and collective consciousness of the ties that include us and carry us through time by taking practical action based on the interdependencies we realize. To nurture consciousness, we open ourselves to recognize our diverse interdependencies and to request other's collaboration.

Cultivating health depends on acting together to overcome the fear that we struggle alone and futilely for survival against a hostile and meaningless environment. Empowered action follows a deepening understanding that we develop in what Scott Williamson, founder of London's Pioneer Health Centre called, "progressive mutual synthesis" with our environment: the growing health of each organism enriches the environment and the enriched environment increases the health of each organism within it. Knowledgeable action depends on learning to balance focused effort to impose order with effort to create conditions through which order will increase over time.

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## Some notes on renewal visits

*True safety seems to lie in our ability  
to be vulnerable with one another,  
to ask for help and  
to receive help.*

*-Orion*

The continuing work of building community in a lifesharing household can be renewed simply by inviting a group of concerned people...

...to share, briefly but fully, the lives of people in the house

...to reflect carefully on what they have experienced and

...to join in a circle with members of the household and candidly share impressions of its strengths and the challenges facing it.

This is so because conscious community can develop when the household as a whole 1) recognizes that it faces issues that exceed its capacity to resolve alone; 2) invites new perspectives, and 3) develops fresh understanding based on a new realization of the interdependencies that form the community. Health grows in community as its members change their own relationships in response to what has been seen as an isolated or external problem. Renewal visits create one occasion for this necessary work.

## Benefits

The process of group visiting with an obligation to reflect and permission to comment creates an opportunity for an exchange of gifts between the household and the guests themselves.

- Issues important to the life of the household can be surfaced, clarified, and debated from new points of view.
- Guests can increase their consciousness of issues in their own lives and in their own households.
- New energy, new perspectives, new ideas, and new personal connections can flow into the household.
- Deeper understanding of the art of lifesharing can grow between hosts and guests.
- Guests can choose to become hosts; hosts can choose to become guests. This expands and strengthens the circle of renewal and can, over time, decrease the sense of isolation and strangeness that may inhibit the process at first.
- A new kind of relationship can form between hosts and guests. Guests may maintain an

attachment to the people whose lives they have entered, and a continuing concern for the well-being of the household.

### Limitations

Because any process of renewal depends on freedom, its benefits are conditional. A visit for shared experience and reflection creates an occasion for renewal, but the depth and endurance of renewal depend on the free choice and responsible action of hosts and guests. Renewal cannot be imposed, it must be invited. People cannot be assigned to share the life of a household, they must give themselves to the people they visit. Hosts cannot be expected to respond to a visit with plans of correction; they must decide to be open to new possibilities and diligent in pursuit of newly clarified ideals.

However much these visits can contribute, they are **not of themselves sufficient safeguards** for the healthy development of community life.

- Renewal visits draw some of their power from being a portrait of a household done by outsiders at a single point in time. But meeting the challenges of individual growth and household development requires standing with people through time. Both individuals and households need a variety of external relationships.
- There is a natural reticence to invite any kind of visiting group. Renewal visits, which are both supportive and challenging, which are interesting and thought provoking but have no obvious power, build the confidence of a household to overcome this reticence and become creative with visits of many kinds, both inviting groups in, and seeking opportunities for household members to be visitors to other settings. This confidence may lead households, out of interest, to seek evaluation by other standards from which other and different benefits may be derived.
- Welcoming caring strangers and attending to the way they mirror the life of the household can raise consciousness, but it cannot substitute for regular, disciplined work among the members of the household to deepen their understanding of the commitments that bind them together.

### The Structure of a Renewal Visit

While there are many variations in scheduling and particular activities, a renewal visit has four essential parts:

1. Invitation
2. Sharing life
3. Reflection
4. Forming the circle of hosts and guests to share reflections from the visit in a renewed experience of their interdependence.

Because the quality of the renewal visit depends on the quality of the relationship that develops between hosts and guests, each part of the visit has its own disciplines. Experience suggests that these disciplines, when undertaken in the spirit of mutual caring, permit a strong circle of old and new friends to share their reflections on what the visit has taught. These disciplines are no more than an expression of an attitude of respect and care for one another. But, though simple, they can be difficult. Preparation and attention to detail at every stage expresses consideration for every person involved, and always brings very good results.

### The Invitation

Only the **hosts** can speak the words of greeting that begin a renewal visit. No one can welcome renewal visitors to any door but his or her own. The more the members of the household have time to understand the occasion for the renewal visit and consent to share their lives briefly but intensively with the guests the better the visitors will be able to sense, describe, and mirror the life of the household.

- First, those who want a visit get consent from the rest of the people who live in the house to approach a person who could lead a group of renewal visitors. Who is a potential leader of guests? An important aspect of this visit is that it be owned and managed by lifesharing people themselves. Taking part in visits, as either guest or host, is a great learning experience. Previous experience of a visit is certainly helpful, but we are wary of developing a cadre of experts, or professional visitors. The future can only be imagined, since so far the only visits we know about have included one of us associated with our Project. We hope people who read this book will experiment with inviting their own visits. Leaders, we feel, can be anyone with the interest to devote time and energy to what amounts to creating a work of (social) art. Households may do well not to invite as leader of their first visit, a friend who is so close and defensive of the household as to lose objectivity. Let this friend rather help host the guests, and be a relevant other whose views they hear. A leader need not lead each event of the visit. Characteristics of the chosen leader can be balanced by the other guests. For example, an efficient, interested leader may, through her whole experience and life-style, tend to fall back on checklists and interviews. Other guests can compensate for this by going with the flow of the household, using their leader's skills creatively but not allowing them to dominate. Likewise, a well organized but overly evaluative or critical written report can be balanced in draft by other guests.
- Together with the potential leader, members of the household clarify the intentions of the visit and identify and deal with questions and concerns.
- Some understandable reservations about the visit arise from heightened awareness of vulnerability and can't be discussed away. Sharing home space and time with visitors is

disruptive; sharing aspiration, concerns and beliefs with outsiders raises the fear of being misunderstood; and inviting frank comments on the patterns of everyday life from strangers builds anxiety about destructive criticism. Accepting these uncertainties as signs of the way to a deeper understanding of life together makes for a strong welcome.

- Once the decision to host a renewal visit is made and a household representative delegated to coordinate arrangements, the renewal group leader and the household's representative jointly invite other members of the group. In selecting renewal group members, they seek people whose different experiences and perspectives will complement one another. This is one of the sensitive moments in the art of lifesharing - the chosen leader working with the household to create a group of visitors. Their considerations will include:
  - The people of the house - that each may find someone among the visitors who is in some way a peer". If there are people with disabilities in the house, the visitors should include at least one person with similar experience. Is there a mother with young children? Who will empathize with her? Are there common interests: sports enthusiasts and musicians understand each other across the differences of race, skills, age or disability.
  - The intention of the house. Visitors should include people with similar, but also quite different goals and ideals.
  - Any special issues at the time of this visit? Seek some people who can be expected to be knowledgeable. (Though often help comes from the most unexpected sources).
  - Size of the visiting group, relative to the size of the household.
  - Length of the visit, and of its parts.
  - Inclusion of a visitor experiencing a problem at home, or in need of the renewal of working with the group and the refreshment of making new friends.
  - People who live nearby will be able to continue the friendship and support generated by the visit.

**Guests** who gladly accept complete the invitation. Willing guests come with the caring intention to share their hosts daily life and ideals. They give full time and attention to their hosts, arriving rested and ready to join in the life of the household and the work of the renewal group. Guests say yes with the sober recognition that they are beginning real relationships with people and places who could become a part of their lives after the visit.

In accepting the privilege of sharing other's lives, guests commit themselves to...

...understanding, as best they can, the spirit and traditions of the host household rather than reducing the host's experiences to their own terms.

...listening with concerned attention to the dreams, concerns, and frustrations of household members and respectfully questioning to gain better understanding

- ...seeking to understand both the lives of the individuals who make up and support the household and the life of the household itself
- ...working to overcome their own internal barriers such as:
  - judging the household rather than experiencing and working to understand its life
  - letting one's own beliefs impede a search to understand the host's ideals in the host's terms
  - too quickly and easily offering advice and solutions
  - allowing a sense of competitiveness or misunderstood "duty" to drive a search for flaws
  - letting the visit fall entirely into social conversation
- ...dealing carefully and respectfully with the concerns and confidences offered by members of the household
- ...joining fully in the renewal group's reflection by offering observations, listening to learn from others whose sense of the place differs, and seeking clarity and inspiration in creating a true picture of the household.
- ...supporting the final circle - in which guests and hosts draw together to listen and respond to the guests' impressions of life in the household, by speaking the truth clearly and forthrightly, by finding artistic ways to convey impressions and express thanks, and by encouraging other members of the circle to discover and speak their truth through poem, picture or story as well as intellectually.
- ...seeking the support of the renewal group and members of the household to live up to these high ideals during the visit

### Sharing Life

**Guests** lay the foundation stones of the renewal visit when they arrive and join the routines of the household. This includes...

- ...sharing meals, sharing household chores, staying overnight
- ...joining in the usual rituals of the household (such as shared songs, dances, cultural, or religious activities)
- ...accompanying household members to work, and, as appropriate, joining in the work
- ...accompanying household members in their recreational pursuits, and, as appropriate, joining in
- ...attending any regularly scheduled planning, problem solving, or other meetings either about the household or, if appropriate, about individual members.



The shared experience of everyday life in the household forms the foundation of the renewal visit. But the guests' task includes entering into the spirit of the household as well as into its activities. This means taking time to learn as much as possible about...

...the history of the household

...the biographies of each of the members of the household, especially the choice to join the household

...the ideals that bind household members together

...the traditions and rituals that give the household continuity

...the human environment of the household including relationships with friends, family members, assistants, and sponsors

...external human supports available to the household as a whole

...the human supports available to each member of the household

...the dreams, plans, concerns, and frustrations of each member of the household both for self and for the household

...how and for what reasons new members join the household

...how and for what reasons people leave the household; and, what sorts of contacts remain

...the ways the household goes about identifying, learning from and solving problems for the household as a whole and with its individual members

...the work household members do and its relationship to the life of the household and to their personal sense of satisfaction

...the economic situation of the household and the ways the household makes economic decisions and deals internally with money

In discovering the household and its members, guests should remember the motto, "Do not judge a man until you have walked a mile in his moccasins".

- Guests should avoid asking people questions from lists. Introduce questions like the above, in the context of sharing time and activities with household members. Some subjects, such as finances, may involve a more concentrated meeting, arranged by mutual agreement.
- Respect absolutely people's choice not to respond to a question
- Unless it somehow fits the tradition of the household, formal interviews with groups of household members are much less desirable than conversation in the context of daily activities. There is an important balance here - on the one hand to organize interviews and work so hard that one misses the flow of the hosts' life: on the other hand, to go with the

flow and miss the kind of insights that require time out for serious talk.

- It may help for one or more guests to construct displays of some of the facts about the household with knowledgeable household members. Displays which illuminate the human environment of the household and its economic situation could be helpful.
- In conversation - or as appropriate to an activity - guests will exchange some details of their own biography, but usually guests will listen somewhat more than they speak.
- Guests may encounter a difficult situation if one of the hosts tries to enlist the guest as an ally against other members of the household. In general, the guest should try to make it clear that part of the agreement with the hosts is to share what they, the guests, learn from their experience during the group's reflection time and ask the person to respect that agreement.
- No matter how extensive the preparations, household members may be confused about the purpose and intention and activities of the guests. This seems to be because of the novelty of an organized group visit aimed simply at arriving with the hosts at a careful understanding of the household. It is hard to visualize how things will proceed and there is often some anxiety arising from fear of misunderstanding and hurtful criticism. Guests should be aware of this and avoid interpreting the confusion as inhospitality or unique problems in communication. "So this is how it all comes together," and "You really did understand" are frequent comments in the closing circle.
- Guests need to remain vigilant to avoid falling away from their commitment by judging aspects of the household or offering easy advice or solutions that show off the guest's superior knowledge. Naturally, in the course of conversation hosts and guests may exchange information or opinions. But the guest must be careful to maintain focus on understanding the spirit and ideals of the household in its own terms. Many guests will have to beware of thinking too fast: to follow the truth of a situation, it will be necessary to slow down the intellect and thoughtfully relate to experience rather than to concepts and labels.
- Throughout the visit, guests will shift their attention from the household as a whole to the individual members of the household and back again. It is important to balance time between the two.
- In response to the hosts' hospitality, the guests may want to offer the household a gift by, for example, preparing a meal for the household or putting on a simple entertainment.
- Being cheerful and helpful about the inevitable inconveniences, miscommunications, and misunderstandings that will arise during the visit will smooth the way.

**Hosts** contribute much to the quality of the time they share with their guests.

- Hosts should welcome the visitors in whatever way is usual for them to greet a visiting

group.

- Hosts will need to offer guests some guidance about the household routines.
- Openness to questions - and a willingness to refuse questions that seem unfitting (while explaining why) - build trust between host and guest.
- Thoughtful consideration by each host about what he or she hopes to gain from the visit and how he or she can contribute to gaining it will clarify conversations.
- Conscious thought about ways to receive the guest's impressions can be a source of self-knowledge for hosts.
- Being cheerful and helpful about the inevitable inconveniences, miscommunications, and misunderstandings that will arise during the visit will smooth the way.

#### **The Withdrawal Time (also known as Reflection Day, or Team Conciliation)**

This is perhaps the most challenging part of the visit. The visitors are each filled with impressions, opinions, experiences. They may have seen little of each other during the sharing days, and they are often strangers to begin with, having little in common except these days of intense absorption in the life of the host household.

The guests need to anticipate this day in their very first meeting, and think about ways to structure it. Thus, the element of reflection begins on the first day, and is carried among the guests throughout the days of sharing, with a growing sense of responsibility and wonder.

There are probably many ways to achieve a worthy reflection of the host household. We describe two, to encourage further work and experimentation.

**Method I.** The leader is responsible for the structure of the visit and the reflection time. The leader describes the disciplines and the structure in the first meeting of the visiting team. Team members organize their impressions and notes accordingly.

Withdrawal time begins with the overarching description of the host setting, its history and purpose. Each team member speaks out the information they have gathered and the leader organizes this on a large paper. Then follow qualitative impressions, organized under two headings:

1. Strengths
2. Issues.

The same procedure is followed for each person of the host household.

Outstanding strengths and issues are then gathered from all these papers, and related to any specific concerns the hosts may have asked to be considered. From this digest, a picture is created. This process may take two days and nights of diligent work.

**Method II.** The visiting group is co-responsible for creating a structure and discipline appropriate to the occasion. They will do well to agree at their first meeting on a framework to carry through their sharing days. For example, one group decided to organize their impressions in a fourfold structure

1. Physical features of the setting
2. The flow of life (in and out of the household, its rhythms and structures)
3. Relationships, (within the household and with the human environment)
4. Identity (purpose, ideals, clarity of mission)]

During the sharing days, democracy prevails among the visitors, they learn about each other's talents and skills, so that by the last day of sharing it is clear who shall lead the consequent and disciplined work of reflection. It is essential that this retreat not be "dragged out". The hosts are in tune with the process –the separation is only on the physical plane. The mood and effectiveness of the picture-building process is reflected by the hosts. Therefore, leadership and structure for the withdrawal time are essential. Probably, the minimum time for withdrawal is one full day, preceded by an evening meeting which contains, as a minimum

1. A conscious change of mood, perhaps with prayer and an artistic exercise.
2. Agreement on the structure to be used and decision on the exact method and goals of the next day. This enables the group, after sleep, to "hit the ground running" in the morning, and reflect confidence and enthusiasm to the waiting hosts.

It is extremely important that the visitors' retreat days take place in a private room, not part of the host household.

#### Forming the circle

The circle should follow immediately after the visitors' withdrawal day. Make it clear that everyone is still under the impact of first impressions, that what is being offered is no finished portrait but a mere sketch. Experience shows that it is most important to the hosts to receive it, however, rather than wait for days or weeks for a written account. Guests offer their sketch as a gift of thanks, in a lively, sincere way, with as much artistry as they can muster, but without glossing over serious issues and challenges. Hosts will want to reciprocate, comment and question, after which the visit should end with appropriate celebration of new friendship.

**The Final Picture** is usually decided upon during Reflection Day, and takes the form of a written report, produced by one team member, with input from the others. A convenient method is for one member to make a draft, using the notes from the reflection time, and circulate it for revision to the other guests, before sending the final product to the hosts.

Both in the Circle and in the final picture, it is important to keep three voices distinct.

- **Voice One:** This is the picture you allowed us to see, the story you told us. Any ideas spoken by this voice we heard from some of you.
- **Voice Two:** These are impressions we had out of ourselves during our visit. We offer them for what they are worth.
- **Voice Three:** If you asked us to pay special attention to certain issues and questions, here are our views on those. And here are our views on some other issues, and things we might do about them. We offer all of these as humble suggestions only.

Written reports are shared with others only with the hosts' permission.

**Return visit.** After the hosts have had time to study the written picture, they may comment in writing, or they may invite some or all of the guests to return for discussion.

**Future.** We hope to hear about guests who re-visit after a year or more, about people who were hosts visiting the households of those who were their guests - and many other ways of tracing the aftereffects, and the cumulative effects of visits.

## Summary

**Invitation** from the host household to a potential leader of guests. Contact person chosen from among the hosts.

**Finding the guests.** Suggestions from hosts and from guest leader - each suggestion discussed, then invited by either hosts or leader - at their discretion. (For first-time hosts, leader with experience may help by drafting a letter of invitation and of information about the nature of the visit).

**Informing relevant neighbors, supporters, board members, etc.** Hosts will want to do this, to prevent the shock and misunderstanding of a supporter being phoned by a total stranger asking questions about the household. Guests will want to see such letters of information, to know what people are expecting.

**Preparing the guests.** Leader and contact person will decide on and assemble written materials about the household, travel directions, timetable of the visit, and brief information about the other guests.

**Preparing the hosts.** Guest leader sometimes makes a pre-visit, talking to hosts about the impending event, discussing how the guests will be accommodated, where the reflection/withdrawal can be held, etc. Hosts like to have biographies of guests ahead of time.

**Number of guests and length of visit.** Agreed between hosts and leader, depending on size and nature of household. 4 - 7 guests seems good in most situations. 3 - 4 days sharing, 1 - 2 days reflection, 1 1/2 to 3 hours for final circle. Written report in 2 - 3 weeks, sooner if possible.

**Arrival and Orientation.** Guests should arrive together if possible, and after finding their accommodations and a brief tour, should listen together to the hosts' prepared welcome and orientation. This includes the history, aims and ideals of the household and any special questions the hosts wish the guests to consider.

**Sharing.** The next days are spent living, working, eating, sleeping, playing, talking together. When the household cannot provide bedrooms for guests, they are accommodated nearby (some have camped, some lived with neighbors or in a local motel) but spend all waking hours with the hosts, or with the relevant others suggested by the hosts to enrich the picture. A mood of *wonder* grows in these days.

**Withdrawal for Reflection.** Using the selected structure, the chosen leader of this part of the visit guides the visiting group through a consequent, concentrated, respectfully candid sharing of their impressions, information, emotions. Though intense, the hygiene of breaks, meals, exercise and artistic interludes, is helpful. As the impressions are ordered, a picture begins to form. The mood is one of *compassion*.

**Creating the Sketch.** As time draws near for meeting the hosts again, the creativity and enthusiasm of guests is needed. Color and mood are equally as important as content, and *conscience* guides the giving.

**The Circle.** All guests, the whole household, and special friends at the discretion of the hosts. The sketch is offered - conversation ensues - farewells take place. The written picture is discussed, and return visit planned, if wanted.

**Departure - A Critical Point!** Guest leader needs to insist on method and timing for the written report. Guests are returning to busy lives, it is easy to default on intentions.

## An open letter to a state administrator

Dear Commissioner,

Recently you have invited people to help you discover new ways to approach the problems your department currently addresses through its licensure and inspection procedures, namely the assurance of service provider accountability for matters of health, safety, and proper treatment of people with developmental disabilities. The openness of your invitation, and the interest people have shown in it, makes us happy to respond.

Our response, though, may seem puzzling. Nearly four years of careful research has not given us a set of new procedures or instruments to recommend for your department's adoption. If we can explain to you why this is so, we feel like we will have made an important contribution to your thinking.

In brief, we believe that our system is in a deep crisis which offers many important opportunities for people with developmental disabilities and their allies to contribute in important ways to the well being of our whole commonwealth. The enclosed essay, "The Changing Situation of Citizens With Developmental Disabilities and the Accountability of Certain Places in Between," provides a more detailed description of how we believe this crisis has developed.

We believe that the opportunities arising from this crisis can only be realized if concerned people work to create what Hubert Zipperlen has wisely called "the culture of the thinking heart."

This guiding image, the culture of the thinking heart, discloses that we can only be responsible when we accept the personal and communal discipline of actively integrating commitment, action, and thinking. This discipline is what we need from one another; without it no system of safeguards and no approach to service can realize the opportunities in our crisis.

There are many aspects of our crisis—such as concern about scarce funds and growing demand, or arguments about how the system should be structured. But we think that the magnitude of these concerns could easily overshadow some smaller, interrelated elements of the crisis with high potential for catalyzing important change. These aspects of the situation are signaled by growing numbers of people who remain and want to remain involved with people with developmental disabilities and are...

...cautiously excited by the direction captured and summarized by your department's *mission* statement. Caution arises from enthusiasm tempered by the fear that widespread self-

interest, cynicism, and inertia will dilute the promise to hollow words.

- ...ready to listen to people with developmental disabilities when there is a forum in which people meet as equals, but increasingly bothered by how hard it is to create such a forum in the context of the day to day services that people rely on.
- ...frustrated by the limits of adversarial processes for establishing satisfying change in people's lives. Court victories and stepped up compliance mechanisms don't seem to reliably lead to better lives. And the costs of conflict and compliance are becoming increasingly apparent.
- ...willing to explore ways that people with developmental disabilities can become full, contributing members of the life and associations of their communities but frustrated that no one really seems able to say exactly how to do it.
- ...aware that your department, and its associated service providers, have been assigned an impossible mission by a society in which far too many people are too busy trying to survive apart from the relationships necessary to build healthy community. This impossible mission might be summarized like this: take people whose safety and development depend essentially on healthy, diverse community relationships away from the possibility of those relationships and then develop them and keep them safe in a way that avoids public scandal. With great effort, it may be possible to protect excluded people from obvious harm and to teach them some skills, but it is impossible for humans to flourish and to grow as strong and as resilient as they can be without membership in healthy community.
- ...disappointed by the unresponsiveness of many current service forms. It seems unreasonably hard to respond flexibly to what matters most to many people with disabilities and their families and friends. Good ideas spread slowly and often result in new words for business as usual rather than significant change. This disappointment deepens as many of us live through a second or third generation of service reform and as powerful criticisms of service practice (such as those associated with Wolf Wolfensberger and John McKnight) gain currency.
- ...practicing many different forms of lifesharing with varying degrees of consciousness.

As we reflect on these aspects of the current crisis, we hear three exciting themes:

- Many people deeply feel the necessity of building up healthy community.
- There is a growing sense that the progressing breakdown of the existing service system is closely associated both with great danger and with the far from certain but real possibility for regeneration of community in our Commonwealth.
- There is a profound hunger for realizing good relationships among people with developmental disabilities and people who are not so disabled. People are attracted to people who



are sharing their lives in conscious, committed ways and a number of people discover that they feel called to find ways to do so, often to their surprise.

We believe that these themes offer you a signal opportunity for leadership. We want to encourage you to continue to bring your personal commitment to action on these themes fully and consciously into your administration.

As you do this, you will be acting on the most surprising finding of our research. We began by assuming that lifesharing was a small, circumscribed effort, itself in need of safeguarding. We thought it might be possible to somehow define the phenomenon and keep it from perversion. We have concluded that it is in fact a very powerful impulse, currently (and positively) beyond the possibility of conscious control. In addition to finding its expressions where they were expected—in shared housing, intentional community, community participation projects, and citizen advocacy efforts—we found that this impulse expresses itself among many people involved in a variety of extraordinary everyday activities having nothing directly to do with people with disabilities. It also expresses itself in some family living arrangements, some supported living initiatives, and also among a significant number of staff of ordinary service arrangements. We judge that this impulse is not a small breeze that needs sheltering but a mighty wind that we must make sails to catch. Lifesharing, we believe, does not need safeguarding: it is a primary safeguard for humanity in these turbulent times. What we must learn is how to invite and support more people to do it with consciousness and commitment.

This finding does not diminish the fact that some of the most conscious lifesharers among us correctly believe that their life work is often lonely and isolated and misunderstood, threatened by perverse and dangerous economic practices, made unduly difficult by the mindless behavior of systems that assume power over people with disabilities, and open to dangerously partial imitation by unthinking enthusiasts. Their awareness of the difficulty, fragility, and imperfection of their particular efforts may, from time to time, obscure their awareness of the breadth and depth of the force they are expressing. But their efforts, their learning, and their concerns provide essential guidance to the task ahead.

What would be perilously dangerous, if understandable, is any form of encapsulation of the effort to build healthy community through lifesharing. Encapsulation could easily be self-imposed by lifesharers out of concern to preserve purity or to avoid rejection and damage by the ignorant, the cynical or the malicious. Or it could be imposed by well intentioned people who want to leave lifesharers alone to get on with their lives, undisturbed by the exigencies of the system. Of course, each lifesharing household must continually see to its own integrity, maintaining its own threshold and upholding its own sense of how its members choose to live together. To do otherwise would be to destroy its potential for contribution. But the members of these households must use some of the strength that comes from their way of life to go out and meet others concerned for the future of our communities, including people who operate publicly accountable systems. Arrogant certainty has no place here: free and

honest engagement in mutually challenging dialogue does.

We ask you to bring your own personal gifts and to invite your staff to bring their personal gifts into deeper conversations with practitioners of lifesharing. We urge you to help establish clear expectations that all parties will grow in consciousness and commitment as a result. And we remind you that lifesharing is not just words, but day to day experience: it is best appreciated and its implications clarified as and when it is lived and shared. You and your staff cannot send down a lifesharing policy; you can let the experience of lifesharing inform your thinking and your practice.

One way to understand what we are proposing is by analogy with the work of regenerating soil that has been killed by unwise use of chemicals. Compost is essential to this work, compost in which the breakdown of organic matter is controlled to maximize the amount of nitrogen and minimize the possibility of overheating and anaerobic decomposition. The key to such control is the long term work of consciously preparing and applying trace elements essential to the process. This work too expresses the culture of the thinking heart: its effectiveness is not a matter of mechanically mixing in some compound, but of diligent, skillful, conscious commitment to renewing the soil. Such commitment recognizes the health giving power of informing a medium with the properties of another substance through an extensive process of dilution and dispersal.

We believe that the possibility of healthy community has been deeply damaged throughout our world. One genuine possibility for regeneration opens with the progressing breakdown of the current forms of human service. This possibility cannot be realized if the breakdown is overheated and too rapid to fix the elements essential to regeneration: committed relationships with the potential for greater consciousness and more forceful action. Lifesharing exists in small but potent and substantial amounts. One vital task is to inform the wider field with the virtues of lifesharing, a dispersal that can only occur when conscious servant leaders see to two kinds of long term work: strengthening lifesharing efforts, so that the essential substances are available, and thoughtfully creating ways for their dispersal through meetings created by freely given and freely accepted invitations.

An important agenda awaits our continuing conversation. It includes such crucial topics as...

- What is the proper role, and what must be the limits of work based on the assertion of rights? If work for rights exceeds its proper limits, an escalating cycle of coercion and defense destroys the capacity for the relationships essential to healthy community. Clearly the state needs sufficient power to stop the neglect and abuse of vulnerable people by exploitative people who will not reform when otherwise confronted. But this legitimate need has become a justification for the mindless extension of state authority into more and more aspects of life. We need to challenge one another's assumptions even further.

- How can public money support people with developmental disabilities who choose to share their lives with others who cannot, in conscience, accept the definition of their shared home as any kind of program?
- How can we systematically and carefully increase the numbers of people who share their lives with consciousness and commitment? Here the findings of our project may prove immediately useful. For example,
  - We met, and continue to grow from knowing, many people who embody the best qualities of lifesharing.
  - We gathered the insights of many people into a conceptual map of the social forms that build up healthy community.
  - We quickly learned that our ‘visiting’ process was not a procedural alternative to licensure visits but that it is a powerful form for increasing shared consciousness.

We are eager to join you in creating the possibility that all the people of your state can enjoy the benefits identified your mission statement. Our awareness that the kinds of everyday lives described in your document do not exist and must be consciously created for most citizens and not just for people with disabilities, strengthens our sense of the importance of the task. Our belief that our system’s crisis is deeply linked to a world crisis signaled by surging nationalism and racism, fragmentation of essential relationships among people, their social structures, and our natural world, and a growing sense of overload, dread, and isolationism among the world’s citizens calls us to act together now.

Only in concerted work to build up the culture of thinking hearts is there any hope for ourselves and our world.

With our very best wishes for your work,

## **The changing situation of citizens with developmental disabilities and the accountability of certain places in between**

Helen Zipperlen

(The following remarks draw on experience of several western countries but refer to the history and present situation in the USA)

People with developmental disabilities, ever more present in general society, are generating profound discussions in government, human service agencies, church and community groups. The questions are no longer about a separate, special category of people, but about changes to our society, about regenerating true and healthy community. People from all walks of life are encountering life-changing relationships, and “imagining a better world, trying to live in it as if it were now”\*. Human service programs are changing in response, becoming freer and more individualized. Economic problems and pressures constrain new programs, challenge the new relationships, yet stimulate creative new solutions.

A small, quietly effective movement has accompanied these changes since World War II in Europe, coming in the 60’s to the USA. I have coined the title “the places in between” for this movement. In this essay, I will consider two main representatives; Camphill and L’Arche, with some of their associates and derivatives. Always standing a little apart, partially independent of the swinging pendulum of human service fashions, these small communities work out of spiritual world views, and values common to all people irrespective of “disability”. They “have imagined a better world and tried to live in it as if it were now”. Their existence has influenced the new situation: but where do they now stand –what is their role and contribution, and what dangers must be faced?

### **The changing situation...**

From virtual invisibility in institutions and back rooms, to an accepted minority with civil rights, moving toward individual independence –this has been the change for persons with disabilities in less than 30 years. It affects and challenges not only those with developmental disabilities, but also the many people whose lives they touch - their families, human service agencies and employees, civil rights activists, town planners and zoning boards, law enforcement officers, teachers and social workers, medical professionals, and an ever increasing number of “ordinary people”.

The change is by no means uniform or complete –people still live in large public and private institutions, spend their days in sheltered workshops or day activity programs, provide the basis for human service agencies to operate state funded group homes and related services, and move as clients along a “continuum of services” into supervised apartments. But, in response to changing attitudes, recent developments include state funded programs helping families to keep a disabled member at home, or introducing a person with disabilities

to a host family. In community supported living programs social workers help design the unique menu of services enabling an individual to live where, how, and with whom he/she chooses.

No longer can the average citizen regard a person with disabilities as part of a race apart – belonging in a special place, only to be associated with specially trained staff. Every citizen is now challenged to understand the person who looks, sounds, behaves or moves “differently”. They are part of life, from kindergarten to church, supermarket to office –and should these sites perchance remain exclusive to the “normal” ones, the “different ones” cannot be overlooked on the streets or in the buses. Nor can one any longer assume that only those who overcome or normalize their differentness will be part of our society, while those who cannot or who are not willing to change will be cared for by specialists somewhere else. Nowadays every citizen is challenged to change his/her own attitudes and behavior in regarding hitherto devalued people, and accept their inclusion into daily life. One soon becomes aware that thousands are vulnerable for lack of a personal friend, and, instead of family and home, experience homeless shelters and jails.

Personal and professional values are challenged by these dilemmas, and lives are changed by new ways of relating with “different” others. Responsible citizens ask “How can we keep vulnerable people safe in our society?”<sup>1</sup> Earlier efforts to care for the “handicapped person”, though founded in good will, resulted in a system which became for many a devaluation and an imprisonment. Furthermore, we come to know that vulnerability is not confined to persons with developmental disabilities - it is part of every life, and can come upon the strongest at any moment! We have all been helpless babies, totally dependent on the responsible, continued and loving actions of the older people around us. How many competent and valued citizens have suddenly found themselves totally powerless, refugees on freezing mountains, waterless deserts, or festering mudbanks? More and more people are rephrasing the question “How can we make a community in which we can count on each other’s strengths, and support each other’s vulnerability, and value the truly human in every person more highly than business or politics?”

#### The “places in between”

At the time of World War II, western societies still considered “the handicapped” a race apart. Many families hid them in back rooms, or, on the advice of doctors, sent them to the institutions. Schools were not responsible for children declared “uneducable”. Some might be trained, but, since they were unemployable, why, and for what? Hitler, considering them a stain on racial purity, eliminated them along with the Jews.<sup>2</sup>

However, here and there these children-with-a-difference encountered friends - people who perceived beyond the distorted body and the damaged soul an inviolate individuality as human as their own. For these friends, a child with mental retardation or cerebral palsy was not an unhappy accident, but a source of deeper thought about the nature of humankind

and of society.<sup>3</sup> Rather than dismiss this child as uneducable, these people questioned the meaning of education, and the prevailing emphasis on intellect and competition. A label of unemployable called for consideration of the true meaning of work. A young adult eager to do work of importance to a friend, yet unable to compete for a job or manage his money, urged his friends to consider their own goals, and to imagine a more human economic system.

Several groups came together before and during the War years to provide havens for handicapped children, seen as society's refugees.<sup>4</sup> Rudolf Steiner's insights into the nature of the human being, the earth, and the social organism, proved outstandingly fruitful for people in many walks of life. They also formed the basis for some of these new havens. These places differed from other "schools for the handicapped" in several respects. Those who cared for the children lived, together with their natural families, with them, not as employees, but as a community sharing all aspects of life, work, administration, culture and worship. Music, architecture, gardening and care of the land, weaving, baking, woodwork as well as the care of houses, all were part of an environment of deep study and reflection on the meaning of life. These communities were places of healing for people of all kinds.<sup>5</sup>

After the War, in the 50's and 60's, these communities developed new places for themselves and their friends with special needs, now no longer children. In these places the emphasis was less on education and therapies, and more on living and working together as adults. The existing movements were joined in 1964 by Jean Vanier's L'Arche<sup>6</sup> - now a significant, world wide spiritual community.

It is good to remember how unusual the lifestyle of these communities was in the eyes of the human services of the time. Large segregated institutions were prevalent; the people of Camphill and L'Arche lived in mixed households of a dozen or fewer. IQ tests graded people according to "mental age"; those following Rudolf Steiner's indications strongly asserted the importance of chronological age, the importance of the seven year periods and other milestones in biography. To them, a 25 year old person was an adult, whatever his IQ, disability or "mental age". Further, in these close-knit communities where no employer/employee relationship existed, staff/patient roles were unnecessary though various levels of responsibility clearly existed. Most importantly, the significance of friendship, of freely chosen, unpaid relationships, mutual care, respect and dignity, was clearly known.<sup>7</sup>

### **The places in between, in the USA**

The 1960's and 70's brought a new wave of change into human services. John F. Kennedy's President's Committee on Mental Retardation made mental retardation a respectable subject for discussion and research. Families began to bring their children out from the back rooms. Special education and sheltered workshops received funds and encouragement.

Wolfensberger's "Normalization"<sup>8</sup>, though often misunderstood and misapplied, had an enormous impact. Burton Blatt<sup>9</sup> led the crusaders against inhuman conditions in the institutions. Agencies developed small group homes as alternative living sites.

Camphill and L'Arche received considerable attention at this time. The Governor of Pennsylvania asked Camphill to start 250 Village communities immediately - and similar requests came from other States. Great frustration was expressed that although people with disabilities were clearly thriving in Camphill, at minimal cost to the State, the Villages, being based on developing human beings and unpaid human relationships, were not replicable. Camphill and L'Arche have grown slowly, at least in the USA.<sup>10</sup> There have been attempts to create similar places using paid staff,<sup>11</sup> and one Village community was founded in the 60's emulating the social forms of Camphill without its philosophical/spiritual background, and has continued, successfully, to the present.<sup>12</sup>

Over the years a number of independent families have opened their homes to people with disabilities, often after some experience of life in Camphill. These houses resemble in some respects a single Camphill home, without the Village context.<sup>13</sup>

These expanded families own their homes, share daily life without paid staff, are usually long-term, stable parts of the local community, are hospitable, and are involved in activities such as community gardens, co-ops, festivals and artistic groups, children's activities and schools. Today many innovative programs are involving people with disabilities in the social groups and cultural life of their neighborhoods.<sup>13</sup> Some of the expanded families have for many years been participants, initiators, and main carriers of community activities, not only for the member with disabilities, but for all members of the family according to age, talent and interest. From a different direction they approach the goal of so many today, "imagining a better world, and trying to live as if it were now."

This stream, represented in the USA by L'Arche, and Camphill Villages, Innisfree Village and the expanded families developing out of the village experience, this is the stream I have called the "places in between". Though small in number, these groupings of pioneers with disabilities and the friends they have called, play an important role in that change of attitude toward "the disabled" which is in reality a recognition and valuing of the eternal spiritual human being in each of us.

A few examples may illustrate why I have chosen this curious title.

**Interdependence.** When the first wave of deinstitutionalization freed many lifelong patients into a competitive "community" in which few could survive, a dramatic need for more careful preparation gave rise to programs to train for *independence*. In most cases this meant training to survive the "culturally normative" settings of the majority of suburban commuters and apartment dwellers - an independence training that also fostered isolation. The "places in between" chose a different path, small communities of varied individuals practising *interde-*

*pendence*. Thereby, for 20 years or more, they have created islands whose values are now prevalent in today's widespread efforts toward true community integration.

**Professionalism.** The exposes of the old institutions, and the resulting demand for better services to people with disabilities gave rise to a new professionalism around the syndromes such as mental retardation, autism, and cerebral palsy.<sup>15</sup> Though the objects of these professions changed titles, from Patients or Inmates to Residents or Clients, from numbers with no biographies to full names with massive files created by interdisciplinary teams; nevertheless they were still the job of the caregiver, the problem of society, and the object of things done for them, or to them. It was the Village communities who first explored *mutuality* - the need of all people to give, to do work for other people, to be appreciated as a person rather than a problem. Inverting the professional pyramid topped by doctor or psychiatrist, the "places in between" emphasized primary relationships between people who spent time together.<sup>16</sup> To the rise of professionalism, Camphill's Karl Konig spoke: "Only help from man to man - the meeting from Ego to Ego - the becoming aware of the other's individuality without inquiring into his confession, world-concept or political affiliation - but simply the meeting of two individualities eye to eye, will create that curative education which can stand up to that threat against the inner existence of the human being."<sup>17</sup> Wolfensberger's constant emphasis on the need for personal, freely chosen relationships in the lives of devalued people, has promoted the more general spread of these ideas, which now form the basis of Citizen Advocacy and the growth of Support Circles.<sup>18</sup>

**Treatment and Training** The old institutions for the mentally ill and retarded as well as many of the newer residential services, used a medical model; professional hierarchies and treatment programs. Treatments ranged from the electric shocks and icy baths of old institutions, a succession of drugs and chemicals to alleviate epilepsy, schizophrenia and other conditions, to all manner of behavior modifications with benign to aversive tortures, all intended to remove those differentnesses which prevented the person's "normalization". Today's community integrators tend to reject "treatment", as something done to prisoners in institutions by white coated researchers. This rather sweeping pendulum swing of opinion is supported by observations of "difficult" people, who, when they become secure among friends in their own, supportive environment, often abandon problematic behaviors. It is suggested that many dangerous behaviors, even whole syndromes, have been the result of inhuman, inappropriate conditions - that they are, in fact, messages of despair and frustration rather than treatable illnesses.

Staff training and staffing patterns are important in treatment and residential facilities. Licensing authorities and review bodies often use them as a measure of accountability and compliance with standards of care. Those who look askance at treatment facilities now raise the question "does one need special training in order to share life with a friend who has developmental disabilities - or does such professionalism impede the mutuality of respect, love, and willingness to change which are so essential to the new community?"



Those who continue Rudolf Steiner's work have developed very different approaches to teaching and training. "Anthroposophical Curative Education" as practiced in those children's schools and villages (including the Camphill schools) bears little similarity to the "special education" of State curricula. It is rather an art and science of the incarnating and developing child, integrating medicine, music, artistic, loving surroundings, and nourishing food for body and soul, with a deep understanding of the temperaments and syndromes among which we all build our individual destiny. Training in Curative Education is a path of inner development for the trainee. Teacher and trainee live together, sharing daily life in an artistic environment in which the growth of each enriches the others.<sup>19</sup>

This mutuality continues in the working Villages where adults of extremely varied abilities share responsibility for the economic, social and spiritual life of their community. Training here is life itself. Acceptance of each other's differences and contributions to an interdependent lifestyle is not easy. Interest is constantly sparked, by an individual, perhaps by an economic challenge, or by a group wrestling with such social concerns as who lives where, or whether to approve a teenage driver to transport others in community cars! This interest and shared responsibility stimulates study and concern with such matters, for instance, as human temperaments and syndromes. Though everyone is accepted as a valued spiritual being, each wrestles with unique problems and capacities of soul and body. Questions arise, perhaps in one of the new community integration programs, such as "Do we need special training to live with developmental disabilities, our own or our neighbors?" A person of Camphill might reply, "Imagine a household in which one person constantly steals food. Social pressures, hints, counselling, and tolerance, escalate into rules which at first everyone accepts (no eating between meals - no food in bedrooms), rules which become increasingly irksome (locked refrigerator) unacceptable, (locked kitchen) and antisocial (who has the key?). Yet nothing seems to help and the person becomes socially ostracized (a fat slob, a greedy thief). Then a visitor offers a diagnosis! This person has a disease that makes him/her eat! The whole household becomes motivated to learn about Prader-Willi Syndrome. Life is still hard, but the individual is perceived quite differently... Or, I recall that there was once a man with Downs Syndrome, unlabeled, undiagnosed, whose curious character traits caused much consternation and insecurity among his neighbors. An understanding of Downs Syndrome as such, spread respectfully by a couple of his friends, changed his social environment rapidly. He is now an accepted and beloved neighbor, bringing all the warmth and laughter which we have learned to expect from people with this soul-configuration."

Long practiced in Camphill, the so-called "Collegial meeting" has recently appeared in a new dress, under such names as "Personal Futures Planning"<sup>20</sup> and Lifestyle Planning. This community building exercise attempts to gain insights into the biography of an individual, who has invited a group of friends to consider in a reverent and disciplined way, his/her past, present talents and wishes for the future. When light is thrown in this way on the path of an individual life, the group "conspires" to make the desired steps happen. These moments of

insight into the wonder of destiny form deep bonds of responsibility between all participants. The inviting person receives support, and the exercise can be both “treatment and training” for *each* person involved.

Many other examples show that the “places in between” are a reservoir of insights and skills in great demand by those who realize that lifesharing with a disabled friend means changing myself. L’Arche, Camphill and their derivative groups, then, seem to have had a role in every decade –moderating the pendulum swings of human service fashions, provoking questions, and maintaining proving grounds for new ideas.

### Accountability in the 1990’s

With the changes of the last 30 years has grown a complex system of attempted safeguards; monitoring the service delivery system, and following the person with disabilities into each new situation attempting to control abuse and ensure “quality of life”. Most of these regulatory safeguards stem from government, in response to pressures from advocacy organizations often reacting to disasters experienced by vulnerable people. The history and the dilemma of regulatory safeguards is well described by Schwartz.<sup>21</sup>

It has been difficult, if not impossible, for the places in between to fit into the categories and standards applied to residential facilities and sheltered work situations for “the handicapped”. As misfits, they have often influenced laws and the regulations derived from them, and have induced a creative tension, often a highly beneficial partnership, with their local responsible authorities. By the 1990’s, many different situations existed - for example - L’Arche houses are monitored and funded as Group Homes by the State. Some Camphill Villages are licensed and funded by their relevant State authorities, in at least one case under specially developed regulations. Other Camphill places receive no State funds and are not licensed. The expanded families have tried many different jackets among the regulatory possibilities offered by their States –Personal Care Boarding Home, Family Care, Foster home, Respite provider– the jackets are never a good fit, and families change jackets often. The discussion continues.

Meanwhile, the new wave of Family Living Homes, Community Supported Living arrangements, etc., all struggle with the effects of monitoring and regulations on the informal, unique relationships they seek to foster. Some people are quite informally sharing homes and lives with friends who have disabilities, without special funding or human service support. Many of the “Camphill derived” families have developed informal relationships over years, requiring considerable financial support from private sources or fundraising. The Camphill villages, once regarded as “avant garde”, now appear paternalistic and even institutional to the new wave of community builders. Yet those which are not licensed are a concern to authorities and advocacy groups, for who shall monitor their treatment of vulnerable members?

## The Intentional Community

Are “places in between” then, to be seen as “providers of residential and other services to people with special needs?” This has never been a comfortably fitting label for a movement which for 30 years has attempted to make true the most desired goal of many people with disabilities - to live as full participants in a community of freely chosen relationships! The isolation of the Group Home, the loneliness of the independent apartment, have been experienced and recorded. To mitigate the loneliness and isolation, there have arisen Citizen Advocacy, Support circles, training on the job instead of in segregated workshops, and programs to integrate isolated people into church and community groups. All of these are attempts, often successful, to *build community* round each person and relationship. John O’Brien’s “Imagining a better world (or at least Neighborhood!) and starting to live in it as if it were now” is quite an apt description of the intent of Camphill and L’Arche.

Camphill and its derivatives may also be seen as “Intentional Communities” - parts of a substantial movement of alternative lifestyles, ever present in American society, but growing rapidly since the 60’s.<sup>22</sup> In fact, there has been friendly interchange between many of the Intentional Communities, who in turn regard Camphill as something “other” because of their large population of people with disabilities, and some “trappings” of a human service agency.

One may look back to the rural villages of the past with a certain nostalgia - the interdependence, competence, valued social roles, reliance on neighbors, hospitality, ordered social life, shared worship, strong values and morality, simple pleasures and healthy food ... memories are golden, - but one knows there were dark sides and dangers. McKnight’s work in urban community organizing recreates these rural values of the past in contrast to today’s professionalism.<sup>23</sup>

Likewise, the intentional community has utopian aspects - a small group of freely chosen friends, living together in pursuit of a common ideal, sharing their talents and resources, using consensus and respect rather than competition, determining their own form of government and economic system - surely an ideal situation for the vulnerable. In the 1950’s, living in community, especially if it were a religious or spiritually based community, was certainly so considered. The rise of the “cult communities” and especially the ghastly mass suicide of Jim Jones’ group in Guyana, changed that perception forever.<sup>24</sup> Nowadays, intentional communities must be accountable.

## The central dilemma of “community”

One can mandate a human service, organize and fund it, hire staff, write principles and codes of practice, and accountability charts. This often results in the ambiguous situation described by Schwartz, McKnight and others.<sup>25</sup>

Wolfensberger has always emphasized the need for “freely chosen, unpaid relationships” with people who have traditionally been excluded from the community. This is the basis of the new movement of inclusion - the basic community building relationships, whether with citizen advocates, support circles, congregational groups, lifesharing households, personal futures planning circles, or any of the other “tools and crutches” of community.

But, these relationships cannot be dictated, mandated, hired or coerced - or by their very nature they are *not* freely chosen, unpaid friendships! They must grow from within the people involved. Community builders who long to “create a better world and live in it as if it were now”, use methods more like gardening than building! The gardening analogy is extremely helpful and yet easy to forget - groups may often fall back into *designing* a society of a certain shape and size, thinking of people as an architect thinks of bricks - uniform and manageable, to be cemented in place (pillars of the community?). Gardens are also planned and designed - but only to a certain point. They depend on many imponderables, and must be *nurtured*. Ground must be lovingly prepared, conditions made as favorable as possible, seeds planted, weeds removed (but not poisoned), and all the elements and kingdoms of nature brought into balance. The process cannot be hurried!

The new wave of “community-where-we-are” gardeners are asking “How can we foster more lifesharing with vulnerable friends?” Each can only begin with him/herself - and many do! But what then? The question strangely echoes that asked of Camphill communities in the `60's!

From a concern about safeguards for people with disabilities, then, it follows that ways are needed for expressing responsibility toward the most vulnerable members of any human relationship. As we have seen, persons with developmental disabilities challenge those who truly meet them to widen and deepen their thinking, their ideas and their life goals. Thus, we find ourselves reconsidering matters of equality, of brotherhood, and of freedom, in order to find a true and firm basis for this responsibility. Currently accepted roles, such as the disabled client, the competent, certified professional, and the licensed care-giver, are dissolving in a tide of mutuality. The recognition of individual human beings has a shadow side rooted in selfishness and power-seeking. The process of facing oneself, of being faced by a brother or sister without protective roles and systems, is profound and glorious, but initially also frightening. Fear and subconscious avoidance of these encounters may be expressed in self defensive strategies, even aggression. Social and antisocial forces thus abound in every setting, with abundant possibilities for abuse, exploitation, exclusion, isolation and even elimination of the most vulnerable. Further, no setting can be healthy or sustainable for any of its members, as long as its vulnerable members are suffering. And as we have learned, the most vulnerable in any relationship may not necessarily be one with recognized developmental disabilities. Let us consider some examples.

Paul has cerebral palsy. He, who had spent most of his life in an institution, came to live with the Millers - a strong, united family, reasonably successful and secure. Both parents

came to love Paul, gladly giving him the help he needed, and allowing him to find his own ways of helping and contributing to family life. The two small children accept him as a kind of uncle; all seems to go well. Imagine what could follow, and who could be considered most vulnerable, if and when: -

Father loses his job and is unable to find another...

The baby grows up jealous of his mother's care for Paul... Entering puberty, the eldest girl develops a drug problem... Mother's exhaustion, trying to hold things together, father's unhappy presence around the house, new pressures on the marriage... They must sell one of their two cars just when their son passes his drivers test.

Paul, though affected by all this, has meanwhile made friends at work, has transportation and recreation available because of his physical disability, has a support group, a girlfriend and sufficient income. He has been helped toward all of these by our concern to safeguard the person with developmental disabilities. We can say "he is doing well in his family living placement", but, if the Miller family disintegrates, Paul will be homeless again (and there will be those who consider him to have caused the disintegration).

Imagine another scene, if Paul and two other friends (who presently have no recognized disabilities) share a house in which each has some equity, on the basis of free choice in a growing friendship. One of the two friends develops problems leading to a crisis...

Imagine Paul living with his parents, who give him the help he needs to get to work, take part in social events, and have a reasonable life. As the parents get older, each develops some infirmities. Paul helps as much as he can, but there are physical limits to his caregiving, though none to his love and concern ... and who shall help *him*, when his parents no longer can?

All these situations widen our concepts of "safeguards", of accountability and responsibility. Concern for the most vulnerable becomes concern for the whole relationship organism. Protection from harm in a dangerous and fearful world often tends toward an escalation of armed police, armed citizens, and "security" devices, behind which people become increasingly isolated. Lifesharing built on trust between friends leads in the direction of the community which some of us remember, many dream of, and a few create, in which children are free in each others homes, doors are never locked, citizens know and help each other, and, if there be a policeman he is the unarmed representative of a lawfulness accepted by all.

Those who attempt the second path have come to some *suggestions* –not final solutions! The way is long and full of variety. In these explorations, the new lifesharing relationships will converse with the evolving "places in between" to the mutual benefit of all. In the context of this essay I will call all these relationships "lifesharing households" –a term covering an infinite variety of outer forms, (including but not limited to those around a person with developmental disabilities), and based on recognition of the inviolate human spirit in every individual.

## Our accountability to fellow human beings who are vulnerable

These suggestions have been gathered from people with developmental disabilities, those who are concerned about them, and from people in many kinds of lifesharing settings. I have tried to organize their ideas and experiences, with the understanding that they are not a statement of principles, nor guidelines for a cookbook on lifesharing, nor a checklist for evaluators. These personal relationships are so individual, so precious, that the deepest respect is called upon in writing about them. Many do not wish to be publicized, and only agree to help with an essay like this one because of the dangers facing people with disabilities and others who are vulnerable! I will not catalog the dangers here - they are well described daily by the media and most pungently by Wolfensberger<sup>26</sup>.

It is generally true that most of the very bad experiences of vulnerable people stem, not from actively evil intent, but from the unconsciousness of people around them. It is not surprising, therefore, that most of the suggestions of lifesharers are about raising consciousness.

First, the decision to share one's life is a conscious one, perhaps including an awakening to the fact that *not* sharing or total independence is a grand illusion. Traditions, such as marriage ceremonies, surround the reverent celebration of a new lifesharing commitment. "Will it last?" is an obvious question - and there is much talk about long term commitments, of faithfulness, and of the effect of discontinuity in the lives of vulnerable people. A helpful attitude is the farmer's proverb, "A farmer should farm as if he would live forever, and live as if he would die tomorrow."

Consciousness is usually highest at the start of a relationship, decreasing as habits form over the years. To keep alive the sense of wonder in the growing, changing relationship, friends are often invited to help, to witness, and to share the struggle and the wonder in different ways. Conscious friendship goes an extra step beyond the goodwilled neighbor, who may at a critical point feel "it's not my affair", and be reticent to interfere, deferring to "the family" or "the professional".<sup>27</sup> Each person in a lifesharing household needs a conscious friend (who *may* be called a personal advocate), to be especially aware of his/her interest. The relationship (or household) calls upon a specially conscious group of witnesses - friends who guard and mirror, support and share, challenge and grow together. It is a typical experience that these special friends first become involved with the gesture of givers and helpers, but find themselves *receiving* a special quality of fellowship and support. Many households actively foster this mutuality of giving, receiving, and sharing support, and the original relationship becomes a seed of health, rooted and flourishing as a growing community. Three phenomena result.

1. The integrity of the original relationship inspires an awareness of the spiritual being of each person, which imbues the community of friends. Ethics, values, and wrestling with moral dilemmas, thus pervade their work; spontaneous needs arise to worship together, or

celebrate a festival, write poetry or otherwise acknowledge a “guiding and sustaining spiritual force”. Frequently, this occurs regardless of individual religious affiliations, resulting in a new openness; people attend each others churches, or share deep experiences with people of entirely different faiths.

2. Activities multiply around the relationship and its conscious friends. Growing awareness of spiritual relationships is expressed in care for the land, be it a tiny garden or a community farm. Environmental awareness and ethics lead to community initiatives such as recycling. Hospitality, in which everyone is both giver and receiver, expresses the healthy community. A person typically perceived as needing and receiving care, becomes host to guests in his/her house, or with friends opens a coffee bar, - the examples are endless - the image arising is a continuous process whereby guests become hosts to new guests, in growing community.
3. Economics change in response to people’s conception of each other. The idea that people with disabilities must always pay or be paid for so that others could care for them and control their lives, is giving way to deep questions about partnership, free choice, “empowerment”, and mutuality. There are more questions than answers. The suggestion is to keep questioning old habits and new assumptions, to keep trying new financial arrangements to express new relationships.

The most important suggestion is to avoid isolation, to maintain links to other lifesharers across the land as well as to the local community.

Ways to implement the wish to meet each other, share experiences, mirror, challenge and encourage, are being sought. The experience of mutual vulnerability is profound when the people in a lifesharing setting invite others with the gesture “please come in, share our life for a while, and tell us what you see”, and when the invited guests respond without power or the authority of preconceived principles. Early explorations<sup>28</sup> show that community is fostered by this gesture, just as it is swiftly killed by inspections and evaluations with the power to reward or punish. It is also discouraged by peer-evaluations based on preconceived principles.<sup>29</sup>

The suggestions of lifesharing households about accountability are beginning to flow - and this flow must be encouraged by hospitality and the repeated creation of “safe spaces” for awakening and discussion. Government, responsible for social accountability, can encourage this flow just as the regulations and licensing of “providers” warped and discouraged it. Experiences and suggestions in this direction are being gathered.

## Notes

1. Schwartz, David B.; *Crossing the River*; Brookline Press; Cambridge, MA.
2. Hong, Edna; *Bright Valley of Love*; Augsburg Press; 19' (see also Wolfensberger and many other accounts of Nazi death programs)
3. Pietzner, Carlo; *Spiritual Meaning of Mental Retardation*; Anthroposophic Press; Spring Valley, NY; 198r
4. Examples: Bethel Homes in Germany, founded by Bodelschwingh;  
Anthroposophical homes and schools in Europe based on the work of Rudolf Steiner;  
Camphill Rudolf Steiner Schools, Scotland, founded by Karl Konig
5. Pietzner, C. (ed); *Candle on the Hill*; Floris Books; 1990
6. Vanier, Jean; *Community and Growth*; Paulist Press; Ramsey, NJ; 1979
7. Regulation as "providers of service", economic pressures, and the passing on of the pioneers may have caused a subtle erosion of the quality of some encounters and relationships
8. Wolfensberger, W.; *Normalization*; N.I.M.R.; Toronto; 1972
9. Blatt, Burton; *Christmas in Purgatory*; Allyn & Bacon' Boston; 1967 - Also *The Family Papers*; The Center on Human Policy, Syracuse, NY
10. For up to date information: L'Arche, 523 W. 8th St., Erie, PA 16502 and Camphill Village Kimberton Hills, Box 155, Kimberton, PA 19442
11. Such as New England Villages, near Boston
12. Innisfree Village, Crozet, VA 22932, founded by Heinz Kramp
13. Examples: Lyris, One Whitney Rd., RFD 1, Box 411, Greenfield, NH 03047 and Cadmus, 207 N. Plain Rd., Great Barrington, MA 01230. The latter is an interesting loose association of five such households a few miles apart.
14. For example The Developmental Disabilities Planning Council in PA, MA, Ohio and other states have funded numerous successful "Citizen Participation" projects
15. Well documented in the journals of the American Association on Mental Deficiency (now A.A.M.R.) 1719 Kalorama Rd N.W., Washington, DC 20009
16. Martin, Denis; *Adventure in Psychiatry*; Faber, 1962 describes an early experiment in inverting the professional pyramid
17. Konig, Karl: *Camphill Brief, On the Meaning and Value of Curative Education*; Christmas, 1965

We have only to grasp the idea of curative education in a sufficiently comprehensive way to become aware of its true vocation. It is not only the practice of child psychiatry, nor alone the effort, pedagogical and psychological, to master the problem of maladjusted children, damaged by environment or of stranded adolescents. Curative education wants to become a worldwide activity and helpfully confront the 'threat to the individual person'. The curative educational attitude must express itself in every social service: in the care of souls, in the nursing of the old, in the rehabilitation of the mentally ill as well as the physically handicapped, in the guidance of orphans and refugees, potential suicides and the despairing, and in aid for the underdeveloped, by worldwide peace corps and other similar endeavors.

It is the only answer which we can offer today - inasmuch as we still want to be men - to a mankind dancing at the abyss. Not congresses of philosophers, international meetings,



religious gatherings nor gigantic scientific assemblies will be able to change anything in this dance of death. For there each one only wants to hear himself and must try to earn respect for himself.

Only help from man to man - the meeting from Ego to Ego - the becoming aware of the other's individuality without inquiring into his confession, world-concept or political affiliation -but simply the meeting of two individuals eye to eye, will create that curative education which can stand up to that threat, against the inner existence of the human being. This will be effective, however, only if one takes into consideration a fundamental knowledge derived from the heart.'

18. For information on Citizen Advocacy, contact: Georgia Advocacy Office, 682 Cherry St., Suite 905, Macon, GA 31201 and One to One Citizen Advocacy, Box 86, Beaver, PA 15009
- see also Mount, Beth - Beeman, Pat - Ducharme, George; *What are we learning about Circles of Support*; Communitas, 73 Indian Drive, Manchester, CT 06040
- see also Wineman, Steven; *The Politics of Human Services*; South End Press; Boston; 1984
- Mennonite Central Committee; *Supportive Care in the Congregation*; 21 S. 12th, Box M; Akron, PA 17501
19. Pietzner, C. (Ed.); *Aspects of Curative Education*; Aberdeen University Press; 1966
20. Pealer, Jack; *Personal histories* - and other publications of Ohio Safeguards; PO Box 1943, Chillicothe, OH 45601
22. An excellent review and bibliography is the 1990 *Directory of Intentional Communities*; Pub. F.I.C. Sandhill Farm, Rte 1, Box 155, Rutledge, MO 63563
23. McKnight, John; *Beyond Community Services* and many other articles; Center for Urban affairs; Northwestern University; Evanston, IL
24. See note 22 also Flo Conway and Jim Siegelman; *Snapping*; Dell (Delta Book); New York; 1978.
25. See note 1 and 22.
26. Wolfensberger, W.; *The threat to the lives of devalued people* (and other articles); The Training Institute; 805 S. Crouse Ave.; Syracuse, NY 13210
27. McKnight, John; *John Deere and the Bereavement Counsellor*; see note 23
28. Camphill Village Safeguards Project; *About Visits*; Kimberton, PA; 1990
29. It will be important to discuss Peer Review from many sides beyond the scope of this essay. Much can be learned from Accreditation Council on Services for People with Developmental Disabilities (ACDD); 8100 Professional Place; Suite 204; Landover, MD 20785

The beginning of Camphill, (and of any budding Camphiller up to this day) consisted in being confronted with a bundle of hampered, distorted humanity. One met children that were entirely one-sided, disturbed, destructive, unable to control bodily functions and means of emotional expression until one could have doubted at times of stress if these were human beings after all. Gradually, and with great pain, one had to learn to see the apparently invisible. One had to gain trust in the true individuality of each and every child, however deeply it was disfigured by layers of disturbances, distortions and ailments. It was our task to discover, for example, an immensely wise and noble human being, a true king, behind the mask of a child or youngster screaming in distress and pain. The child may have had a misformed body consisting of a very large head and weak limbs that were powerless appendages to a chest which became more and more disfigured between the weight of the mighty head and the inadequacy of the limbs, and yet to find the king within him was our difficult task. Once the true being of the child, youth or adult could be perceived and the trained eye could begin to see through the veils of handicaps, maladjustments or retardation, a totally new human relationship could be built up. One began to speak as human being to human being and not as mask to mask. It was a process of the breaking down of hardened boundaries and this process was not limited to one's relationship to the individuals in care, rather it could also start to encompass one's relationship to other co-workers, to friends, relatives, acquaintances and even further right into one's relationship to the land, to nature and to the earth. Thus 'learning to see the invisible' was a cardinal part of our training. Admittedly one learned to see one specific and limited aspect of the invisible, but thereby one was trained to cross, evermore consciously, a border of perception. Eventually one learned to make others as well aware of this invisible element which one had learned to see, and so could widen the circle of those who felt united because they also had begun to see with increasing consciousness a deeper layer of man's humanity. In this way, by necessity, the daily work in Camphill developed certain faculties in the human being which could become an essential contribution in coping with the task arising in mankind through the fact that perceptions of the etheric world have begun to mingle with perceptions of the physical world. An invisible world has begun to become perceptible to multitudes of people who find it difficult to stand up to these new experiences and to integrate them into their inner worlds. Those who have learned through inner trials to see imperceptible layers of existence can help others who are less advantaged to cope with this new world of physically invisible experiences.

—Baruch Luke Urieli, *Camphill Correspondence*, June 1993

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## People and organizations interested in lifesharing

These people are the real authors of this book. From them we have learned about lifesharing. With them we continue the correspondence and conversation reflected in the Letters of this book. Theirs is the daily work, theirs the struggles, joys and insights.

Of course, this list is only partial. It grows daily and you will add to it and make your own.

We have neither limited our list to those who live under one roof with a person with an obvious disability, nor can we possibly include everyone we have met who is engaged with sharing life on a small planet. So why a list?

First, as an acknowledgement and salutation. Secondly, because we are often asked to suggest contacts for people considering lifesharing or seeking colleagues in a new area. Many of these organizations have excellent lists and directories to lead you further in your specific search.

### People

#### B

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Ohio Safeguards  
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Newtown, CT 06470

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Canada

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Spring Valley, NY 10977

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Nick & Andrea Stanton  
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Rud & Ann Turnbull  
 Beach Center on Families and  
 Disabilities  
 3111 Haworth hall  
 Lawrence, KS 66045

V

Dan Varner  
 KenCrest Services  
 Mont Clare, PA 19453

W

Bill West  
 ARC of PA  
 123 Forster Street  
 Harrisburg, PA 17102

Wolf Wolfensberger  
 Syracuse University  
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 Syracuse, NY 13244-2280

**Organizations**C

Camphill Soltane  
 Box 300A, Nantmeal Rd.  
 Glenmoore, PA 19343  
 (215) 0933

Camphill Special Schools  
 RD 1, Box 240  
 Glenmoore, PA 19343  
 (215) 469-9236

Camphill Village  
 Copake, NY 12516  
 (518) 329-4851

Camphill Village Kimberton Hills  
 P.O. Box 155  
 Kimberton, PA 19442  
 (215) 935-0300

Camphill Village Minnesota  
 Route 3, Box 249  
 Sauk Centre, MN 56378  
 (612) 732-6365

Camphill Village Ontario  
 RR 1  
 Angus, Ontario L0M 1B0  
 Canada  
 (705) 424-5363

Citizen Advocacy of Chester  
 County  
 209 Church Street  
 Phoenixville, PA 19460  
 (215) 933-1299

Communitas, Inc.  
 Box 374  
 Manchester, CT 06040  
 (203) 645-6976

Community Service, Inc.  
 114 East Whiteman Street  
 Yellow Springs, OH 45387

F

Friendship Community  
 1149 E Oregon Rd.  
 Lititz, PA 17543-9208  
 (717) 656-2466

G

Gheel House  
 Box 610  
 Kimberton, PA 19442  
 (215) 495-7871

Green Pastures Estate  
 38 Ladd's Lane  
 Epping, NH 03042  
 (603) 679-8282

H

Highlander Research and  
 Education Center  
 Route 3, Box 370  
 New Market, TN 37820-9233  
 (615) 933-3443

House of Peace  
 1 High Street  
 Ipswich, MA 01938  
 (508) 356-9395

I

Innisfree Village  
 Route 2, Box 506  
 Crozet, VA 22932  
 (804) 823-5400

J

Jubilee Partners  
 PO Box 68  
 Comer, GA 30629

K

KenCrest Family Living  
 Room 630, One Plymouth  
 Mtg.  
 Plymouth Meeting, PA 19462  
 (215) 825-9364

Keystone Service Systems  
 907 N. Front St.  
 P.O. Box 5500  
 Harrisburg, PA 17110-5500  
 (717) 232-7509

**L**

L'Arche  
 523 West 8th Street  
 Erie, PA 16502  
 (814) 452-2065

L'Arche  
 1701 James Street  
 Syracuse, NY 13206  
 (315) 437-9337

LifeSharing Foundation  
 205 North Plain Road  
 Great Barrington, MA 01230  
 (413) 528-0705

**O**

One to One Citizen Advocacy  
 P.O. Box 86  
 Beaver, PA 15009  
 (412) 775-4121

Open Hearth  
 P.O. Box 139  
 Parker Ford, PA 19457  
 (215) 495-7420

Orion Communities, Inc.  
 RD 1, Box 240  
 Spring City, PA 19475  
 (215) 495-7420

**P**

Philadelphia Community Farm  
 RR 1, Box 180  
 Osceola, WI 54020  
 (715) 294-3136

**S**

Shannon Farm  
 Rt 2, Box 343  
 Afton, VA 22920

Speaking for Ourselves  
 Suite 619, One Plymouth Mtg.  
 Plymouth Meeting, PA 19462

Supports, Inc.  
 468 North Street  
 Meadville, PA 16335  
 (814) 337-8146

**T**

Triform  
 Water St., RD 4, Box 151  
 Hudson, NY 12534  
 (518) 851-9320

## Books helpful in understanding lifesharing

These are a few of the books which have helped us along the way. We cannot tell if they will help you, and of course neither you nor we agree with all the authors, certainly not expect to “believe in” all the ideas. Important to the “Culture of the Thinking Heart” is the process whereby we invite ideas, sympathetic, familiar, strange and different, to share our life for a while in the same gesture of hospitality with which we welcome guests to our home. We listen, confidently to what they make of each other, and of us. In this sense of hospitality we share this list with you and welcome your additions and comments.

These titles are part of a collection of books in the library of Camphill Village Kimberton Hills.

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Baron, Steve, ED.; *Integration and Independence: The School Leaver with Special Needs*; Association of Camphill Communities; 1989.

Baron, S.R. and J. D. Haldane Eds.; *Community Normality and Difference: Meeting Special Needs*; Aberdeen University Press, Farmers Hall, Aberdeen, AB9 2XT; 1992.

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Gelderloos, Orin; *Eco-Theology*; Wild Goose Publications; Pearce Institute; 840 Govan Road, Glasgow, UK G51 3UU; 1992.

Gore, Albert; *Earth in the Balance - Ecology and the Human Spirit*; Houghton Mifflin; 1992.

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- McLaughlin, Corinne; *Builders of the Dawn*; Gordon Davidson; Sirius Publishing; Shutesbury, MA 1986.
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- O'Brien, John; *More than just a new address*; Responsive Systems Associates; 58 Willowick Dr.; Lithonia, GA 30038-1722.
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# Chronology of the Lifesharing Safeguards Project

We began our project in the fall of 1988 with two goals - to find out more about Lifesharing and to devise a tool or method for detecting its presence.

At that time, the word Lifesharing was being explored. The Developmental Disabilities Planning Council was supporting experiments in Co-operative Housing, in which people with disabilities and others explored shared housing arrangements. Adults with disabilities were becoming part of private host families, in Family Living Programs but also quite informally, introduced by friends or community groups such as Orion. Were all of these “Lifesharing households”? The houses of Camphill have a similar structure - does that make a Camphill Village a “lifesharing community”? Financial arrangements varied from state funding, to fee-for-service, to room and board arrangements and informal sharing of expenses. Were some financial arrangements consistent with Lifesharing - did others preclude the use of the term?

Would recognition as a Lifesharing household free its members from the necessity for State licensing and regulation? If so, how would vulnerable members of the household be “safeguarded”? The demand for a tool to detect Lifesharing came from this latter dilemma. Just before our project began, the Commonwealth Institute had helped to bring about a series of Lifesharing Conferences, where representatives of many different settings gathered to share their experiences. Here it became clear that Lifesharing would be characterized by invisible factors of relationship rather than by outer form or financial structure. If one could describe that relationship, then it might be apparent that some outer and financial arrangements are more conducive to Lifesharing than others.

It was also clear that lifesharing is not specifically connected to disability, but describes a quality of human relationship. It is also more than a housing arrangement, including work and the meaning of life.

Hence, we described the Lifesharing Safeguards Project in our first proposal as follows: -

Relationships exist for which the motive is neither money, nor a job, nor charity, nor “solving the problem of the handicapped”, but interest of one person in another - an encounter of soul with soul, a meeting of I with I. An encounter may found a friendship, leading to a decision to live together and to share life. Out of this one to one friendship can grow a network of support; shared friends and interested neighbors. There are daily needs, including any special needs due to “disability”. The important thing is the relationship of person to person, out of which grows the free decision to share life. Disability is not the primary thing, it is part of the life to be shared, which

entails adjustments in everyone's lifestyle; from living space, to work, to transportation, to food habits, timetables, and the use of money.

When people become members of a natural, informal community, regulatory safeguards cannot be applied without making the situation unnatural, thus defeating the whole objective. Instead, attention must focus on the whole relationship-structure surrounding the vulnerable person, i.e. the health of the whole community.

The "Safeguards Project" is exploring the principles of that healthy community which values and includes all people in regenerative activity.

Already at the beginning of our project we suspected that the "tool" we had undertaken to create would, to accomplish its purpose, have to be owned by the Lifesharers themselves, not administered by some external body. Failing this, we feared that it would soon become a new set of regulations.

We set out, then, to meet Lifesharers wherever they might be found - beginning with those we already knew from the Lifesharing Conferences - and to discover with them and through their eyes what makes living together into Lifesharing. The "tool", we felt, would emerge, as we helped lifesharers raise their daily experience into conscious information, telling us how they would detect and enhance the quality of Lifesharing in each other.

We created a work plan and set of outcomes in response to the RFP, although we had little idea what our voyage of discovery might reveal.

With the welcome help of the DDPC staff we have adapted our workplans over the 4 years in response to our discoveries, and to the rapidly changing environment of our work. To illustrate this changing scene - in 1988 informal lifesharing was the concern of a small minority of people. Most people with mental retardation, for instance, lived in special settings, cared for by special people, and this situation was the generally accepted norm. By October 1991 we were participating in the State-wide Department of Public Welfare convention on "Everyday Lives", celebrating an intention toward individual choice, diversity and informal community support. The Safeguards dilemma has not vanished; it may in fact be even more poignant than in 1988, but we now have research partners Statewide!

## What we did

### **1. Explore existing settings in which lifesharing relationships could be expected to be found.**

These included: -

- 11 intentional communities including people with disabilities (7 Camphill, 3 L'Arche, 2

other)

- 3 other intentional communities
- 10 families intentionally including several people with disabilities
- 2 small licensed settings
- Very many Family Living situations, both formal and informal
- Many support circles

**2. Discover as many points of view as possible on the dangers and threats perceived: “safeguarding who or what from what or whom?”** The variety is immense! We listened to parents, advocates, County and State regulators, providers of services, church members, township supervisors, people with disabilities in all kinds of situations, especially those wanting to do things considered dangerous by their parents and others.

**3. Become acquainted with existing safeguards and groups concerned with protecting**

- Vulnerable individuals
- unusual relationships
- freedoms and rights

and with generating supportive relationships and healthy community. We have taken part in four “Personal Futures Plans” with different facilitators, one “Framework for Accomplishment”, one PASSING, two SRV’s, and three studies on SRV derivatives. We have interviewed the head of the Accreditation Council about ACDD standards, studied (as history) the “mutual criticism” of the Oneida Community and the Benedictine Order’s system of Visits. Our questions have elicited further work on Camphill’s Collegial meeting and we have spoken with L’Arche friends about their internal review visits. We have followed the evolution of Citizen Advocacy and taken part in three CAPE teams. We are involved in developing “circles of support”. We have drawn on the experience of Michael Kendrick’s Safeguards project in Massachusetts, Supports, Inc. in Meadville, the Highlander Center in Tennessee, The Beach Center on Family and Disability at the University of Kansas.

**4. Tell people and groups about each other, statewide, nationally and internationally. Develop a sense of history, to put the present work of**

## **lifesharing into perspective and lessen the danger of creating another “human service fad” or craze. Build a subscription library for lifesharers.**

We have listened to reports about the situation of vulnerable people world wide - through John O'Brien, visitors from Australia, friends in South Africa, and the director of SOS Children's Villages in Czechoslovakia to name a few.

We have established an arrangement with a friend who now travels regularly to Russia, returning two or three times a year to bring us reports from the grassroots. Our questions to him have already affected the contacts he makes and the places he sees. He told us of the day when the Russian “parliament” was to vote on whether the life of a handicapped person has value ... but on that day “parliament” was abolished by a coup ... the question will reappear.

Nearer home, we encourage a friend researching the history of mental retardation with the help of the Elwyn library, the archives of Camphill, and other sources.

## **5. Encourage new initiatives in different aspects of lifesharing.**

Our encouragement has taken several forms - small conferences, introductions of like-minded friends by letter or in person, help with travel expenses, direct requests to individuals to explore and report, or to start a new group. Some examples:

- A. Transportation is a huge problem for most lifesharers. We brought about a new grassroots group, suggested they work with Janet Anderson on a DDPC mini-grant. The group, largely composed of the people most affected by the problem (non-drivers), has developed its own organization, decided against the DDPC grant, researched local allies and joins with another local volunteer group, informally doing great work. We, the Safeguards Project, had no connection with this beyond the first two meetings.
- B. Camphill in North America became aware that many of its members had few friends beyond their family and fellow members of their Camphill Village. We sponsored several discussions between Camphill people and the Citizen Advocacy community in Pennsylvania, and with Citizens for Valued Lives in New York. Many individual stories have resulted. At least two groups have been born to work on the question. There is now an awareness of personal friendship and circles of friends as distinct from and enriching to the larger intentional community.

## **6. Develop a review and renewal tool for lifesharing.**

We initiated or took part in twelve experimental visits. We held many conversations, in several states, about the possible need for and use of such visits.

We had the opportunity to initiate a further eleven visits and made a decision, (which may

have been mistaken) to decline to initiate them ourselves. We felt ourselves becoming the nucleus of a “Team of Experts”, removing ownership and responsibility from the lifesharing households themselves. Instead we urged the eleven households to take their own initiatives, invite their own guests. We offered help, and asked if we might observe, participate or otherwise come to know about the events and their results. We call these our eleven “almost visits”, and now have a new phenomenon to study - what are the factors preventing invitations!

Foremost among these factors we would place the psychological damage done by the “regulatory gesture” - not the requirements, but the feeling of being “owned” by an authority which judges how a relationship measures up to alien standards. We found this expectation of evaluation and judgement deeply rooted in most of the lifesharing settings we encountered. Even the healing power of friendship and mutual need does not quickly overcome the unconscious damage. Trust and confidence, the feeling of “owning oneself” will take time to build. We have been deeply moved by this experience, which went far beyond our expectations - even beyond David Schwartz’s eloquent description (in *Crossing the River*) of the regulatory dilemma.

## **7. Look at the long haul –aging of people, aging of settings, evolution of relationships**

We made an honest and unsuccessful attempt to count the individuals and organizations with whom we have been involved on this subject. One experience stands out. The founder of a household of seven women asked us to help move the organization into a new phase. We responded by forming a group of five friends, with no power or standing, to “be there”, and help reflect the lives of all seven, seeking there for clues to the future. With no plan, program or goals, we have been privileged to accompany a fundamental metamorphosis - not yet complete (what is ever completed?)

Through our Visits we have met examples of “Founders Syndrome” and at least four ways this has been addressed in lifesharing settings.

We are involved in the aging of Camphill Villages in North America and abroad - a study by itself!

We have tried to help many families with aging members and developmental disabilities, and many older people living alone. Our approach has become one of partnership - between family, support circles, case managers, county government, organizations, etc., etc. - many eyes, many hands.

## 8. Influence on state and county policy

We did not intend to impact government policy directly, because lifesharing is a matter of community building - for too long we, general public, have left human services to government.

During the 4 years of our project, however, we were surprised by the arrival of Community Supported Living Arrangements, Everyday Lives, State policy based on individual choice.

This clearly demands and depends upon a responsive community - yet also upon a well informed and well supported County administration. We decided to get involved in this process and learn from it. Forums such as the State's Community Supports Subcommittee and the Commonwealth Institute give a wider perspective. Meeting active people in several Counties through the needs of individuals and families keeps our feet on the ground.

We received an invitation from the State Family Living Committee to look with them at safeguards and regulations. We are involved with people developing both family living and supported living around two transforming institutions. We have renewed an old friendship with our local ARC, and with another in Lehigh County. This work shall continue.

### What remains to be done

In 1988 it seemed urgent to write a concise description of the qualities of lifesharing and the characteristics of lifesharing households. A review process consistent with the nature of Lifesharing seemed to require a new "tool or method".

Our 1990 interim report began to describe Lifesharing, recognizing that it is a matter of consciously nurturing community rather than a new category of human service. We watched lifesharing settings become seeds of healthy community and described the importance to this process of personal advocacy (friendships), circles of support and festive renewal visits.

Now, in 1992, the declared intent of government in Pennsylvania and other states, is to support individual people in their chosen lifestyles, helping them to choose their own friends, colleagues and professional services. The experience of the pioneer lifesharers we have discovered since 1988 is needed as never before.

There are many pitfalls ahead! Already, agencies funded by Government produce Supported Living Programs. We must beware that the general public does not once again leave the "different ones" to the specialists who administer these programs.

Some lifesharers are so aware of this danger that they refuse to have anything to do with "The System", and work heroically to support people with and without recognizable disabilities in informal partnerships.



“Systems people” work equally heroically to help people move from institutions into lifesharing in our towns and countryside.

Government has issued the challenge of Everyday Lives which could be described as “helping each other to own ourselves”. As we embark on this process, it becomes clear that no person, agency, system or organization will remain untouched. All our Everyday Lives will be changed.

The “products” of our 4 years work will result from our continued involvement in this process. Our next “watchword” is to work for a true, free and challenging COLLABORATION between all people, groups, organizations and government departments concerned. We are indeed grateful to the Developmental Disabilities Planning Council for having launched us on a work to which we see no end!