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COMMUNITY-BASED CARE  
AND CARE IN COMMUNITIES:

# A Dialogue About Reponding to the Issues Facing People with Developmental Disabilities

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*Report of a Symposium Sponsored by  
the Camphill Association of North America*

at Triform Camphill Community  
Hudson, New York

April 3-4, 2001

*by Kay E. Sherwood*



*Celebrating 40 Years of Camphill  
in North America*



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## INTRODUCTION

On April 3 and 4, 2001, 33 people who are deeply committed to helping people with developmental disabilities participate fully in life gathered in a community intentionally designed for this purpose. This place, Triform Camphill Community, near Hudson, New York, is one of eight Camphill communities in North America and over 100 in the world, all of which pursue therapeutic and developmental goals primarily through a way of life in which people with disabilities and others live together in communities where everyone contributes in some way to the community and has meaningful work or education; where nature and natural rhythms are important; and the life is rich in spiritual, cultural, and artistic experiences.

The Camphill way of caring for people with disabilities represents a small proportion of the services and care provided for such people in the U.S. and worldwide and is based on a philosophy that is distinctly different from the mainstream thought in the field of developmental disabilities. This difference was the impetus for the gathering in Triform Camphill Community. The purpose of the symposium was to explore the issues facing people with disabilities and, in that context, the present and potential contributions of the Camphill Communities to the field.

The agenda for the symposium was divided into two parts. First, there were presentations by several people, some from the mainstream service delivery system for people with developmental disabilities and some from Camphill. Second, there were plenary and small-group discussions of the ideas and perspectives presented. Opening remarks from the co-chairs of the symposium were followed by a panel of three Camphill people who discussed the essentials of the Camphill approach. After an evening performance by the students and apprentices of the Triform Camphill Community, the symposium participants reconvened to hear a lecture by a prominent researcher, educator and policy advisor in the field of disabilities about the challenges and goals in the field of disabilities in the next twenty years. On the second day of the symposium, the agenda began with reactions to the lecture, followed by continuing dialogue in groups, each of which addressed a different challenge or goal. After the groups reconvened and reported their discussions and conclusions, the closing session of the meeting addressed partnerships between Camphill and other service providers as well as joint field-building and community-building activities. *(A copy of the written agenda is included at the end of this report.)*

## The Symposium Participants

The symposium was designed to bring together colleagues with diverse perspectives on how the issues facing people with developmental disabilities can best be engaged. The symposium was co-chaired by Deborah Spitalnik, Director of the Elizabeth M. Boggs Center on Developmental Disabilities/University Affiliated Program at the Robert Wood Johnson Medical School of the University of Medicine and Dentistry of New Jersey, and Bernard Murphy, President of the Camphill Association of North America (CANA) and President of Triform Camphill Community. Participants came from across the country, from state and county government, service provider organizations, self-advocacy organizations, and academia, as well as from the Camphill communities, including managers, co-workers (the Camphill equivalent of direct care staff), and residents with disabilities, and from the non-residents who play a role in Camphill - members of community Boards of Trustees and of CANA. The common characteristic of the individuals who participated was an openness to the possibility of productive exchange and, as Deborah Spitalnik expressed it, a passion for the work, whether the work is considered a job, a career, or a way of life.

### Camphill Symposium Attendee List

Guy Alma <i>Camphill Village Special Schools</i>	Michael Green <i>Asset-Based Community Development Institute</i>	Regis Obijiski <i>New Horizons Resources, Inc.</i>
Thomas J. Articola <i>New York State OMRDD</i>	Diedra Heitzman <i>Camphill Village Kimberton Hills</i>	Dr. Michael O'Leary <i>Columbia County Community Services Board</i>
Ansley Bacon <i>Westchester Institute for Human Development</i>	Lawrence Hunt <i>Camphill Village USA</i>	Asse Righter
Beth Barol	Kevin Keane <i>Astronics Corporation</i>	Elias Rives <i>Camphill Village USA</i>
Jim Cashen, Esq.	Chuck Kyd <i>Camphill Communities Ontario</i>	Kay Sherwood
Zelene Cooper <i>Soltane Communities</i>	K. Charlie Lakin, PhD. <i>Rehab/Research Institute of University of Minnesota</i>	Deborah Spitalnik, PhD. <i>The Boggs Center, UMDNJ</i>
Gregg Davis <i>Soltane Communities</i>	Jeanne Leonard <i>Triform Camphill Community</i>	Claus Sproll <i>Camphill Special Schools</i>
Kathryn duPree <i>Connecticut Dept. of Mental Retardation</i>	Bobbi Miller-Rosenow <i>Camphill Village Minnesota</i>	Nick Stanton <i>Cadmus Life-Sharing Association</i>
Pat Fratangelo <i>Onondaga Community Living</i>	Bernard Murphy <i>Camphill Association of North America</i>	Stephen Steen <i>Triform Camphill Community</i>
Joni Fritz	Richard Neal <i>Camphill Village USA</i>	Marcia Tewell <i>Colorado Developmental Disabilities Planning Council</i>
William Furse		Sonja Thormeyer <i>Camphill Special Schools</i>
Bill Gaventa <i>The Boggs Center, UMDNJ</i>		

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## PART I : PRESENTATIONS

### **Camphill's Goals for the Dialogue**

**Bernard Murphy**, in his welcoming remarks, noted that the symposium helped to mark 40th anniversary of Camphill in North America and the 60th anniversary of Camphill as a world movement. It also marked the passing of 15 years since the first such dialogue, which was initiated with the leadership of the late Elizabeth Boggs, who was instrumental in bringing the ideas and reality of Camphill to the wider field of developmental disabilities in North America. Bernard introduced the theme of reflection by observing that “anytime there is a birthday or an anniversary, one is presented with an opportunity to review, to look back, to look forward, to try to determine what one has accomplished.” He underlined the importance of reflection and feedback from colleagues outside the Camphill movement because critical years are ahead for Camphill. “Camphill as a way of life is being challenged and to a certain degree is failing to meet the challenges throughout the world,” Bernard reported. The evidence is, that within the last few years, places in Scotland have closed down and are no longer Camphill communities and a number of other Camphill places, including those in Great Britain, are experiencing shortages of committed co-workers so that they may not be able to go forward in the way that Camphill communities have traditionally defined their essential practices. Bernard observed, “These are challenges that we know that if we don’t address now on this continent will be just around the corner for us.”

The people of the Camphill movement brought to the symposium a distinct conception of the nature of the challenges and sought from colleagues in the larger disabilities community their perspectives on these challenges. Bernard stated the goals Camphill had for the symposium in the following way:

*We want to reach out in a way that we can learn from each other. We would like to hear back from our friends and partners and colleagues: When you look at Camphill, what do you see? How do you perceive what we do? What is your experience of us as we present ourselves to the world? What is there for us to learn? Where do you think that we’re being blind. Where have we not managed to see something that is painfully obvious to you, but as friends or interested parties you have not been able to tell us is there before us? What can you see that we have that we can offer? What are the gifts or capacities that we don’t see we have, that we don’t see how others can benefit from having access to it.*

Before turning to the others in the developmental disabilities field to begin to discuss their perceptions, Bernard summarized the origin and history of the Camphill movement, which helps to explain why Camphill’s approach to caring for people with developmental disabilities is different from the approach of “mainstream” professionals in the field.

## Camphill's Origin and Contribution as an Alternative Approach to Care for People with Developmental Disabilities

Camphill started in 1939 in Europe as a movement of refugees from the Second World War who wanted consciously to live their ideals for a social alternative. It was clearly recognized that the social alternative needed to have at its center a task that everyone in the community would commonly work on. The original intention was not to become a service provider for children with developmental disabilities. The motive for beginning Camphill was to establish a community of spiritual striving. The child with special needs was the task that was recognized by the first community members of Camphill as one that they could work with and that they would be able to place in the center - primarily because Camphill's founder, Dr. Karl Koenig, was a pediatrician who was experienced in working with special needs children, primarily children with developmental disabilities.

As the children grew up, there was a need to find places for them as they became adults and so the work spread, always holding the child and the young adult with special needs at the center. Camphill expanded and grew, not primarily out of a motivation to provide care for more people with special needs, but because more and more people were coming toward Camphill who, with Camphill people, wanted to continue developing an alternative social system that was essentially a communal way of living with spiritual development and service as its purpose.

### KARL KOENIG

Born in Vienna in 1902, Karl Koenig began his medical career at the Institute of Embryology in the University of Vienna. He later became house physician at the Clinical and Therapeutic Institute at Arresheim, near Basel, Switzerland. His life work for the handicapped person began with his co-founding of the Pilgrimshain Home in Silesia. In 1939, fleeing the Nazi's with his family and a group of friends, he founded the Camphill Rudolf Steiner Schools for children in need of special care in Scotland. This work grew to encompass caring for adolescents and adults with special needs, including the establishment of schools, colleges, and village communities in many countries. Dr. Koenig died in 1966.

## The Conundrum of Camphill: Original Purpose *versus* Present Perception

One of the challenges that Camphill faces decades later is that Camphill has become synonymous with a care delivery system. Most people when they think of Camphill think primarily of providers of care for people with special needs. The reality from the Camphill perspective is different in subtle but important ways. Camphill's perception of its purposes and realities is of intentional community that shares life with people with special needs. While Camphill places have a primary responsibility to care for the people with special needs, that is not the only reason that Camphill places were created.

A second major challenge for Camphill is in relation to the norms of the field of developmental disabilities, which emphasizes the needs of disabled individuals. Camphill began focused on community needs in a very difficult time. In its early years, community residents sacrificed some individual development, individual growth, and individual needs for the benefit of the whole community. This is a legacy that lives in Camphill communities worldwide. However, “as a third generation movement, we now have to look at being able to recognize how the community can serve the needs of the individual,” Bernard observed.

This evolution from the primacy of the community to recognition of the individual is not distinctive to Camphill. Society as a whole has moved through the dominance of tribes to the organizational primacy of families, which elevated the importance of blood relations and established the extended family as the fabric of society. Bernard noted:

*We are no longer living in a society where the extended family holds down the roots. We are now living in a society where individuals have to stand on their own two feet and will leave the families. That presents a challenge in old age, for example, because families used to take care of their elderly. Today that situation is completely different, but we recognize in our work with people who have developmental disabilities that we have also moved from groups - institutions and then group homes - into individualized planning. Personalized planning in the last few years has rightfully been in the forefront. Now, the question is: How do we recognize the needs of the individual and then together work to allow those needs to be fulfilled?*

Camphill is in a similar situation. “Walking side-by-side with the person with special needs” means that the community as a whole has to be able to place the needs of the individual in the forefront without sacrificing the community values that make Camphill what it is. One of the challenges, therefore, is that in order for community to serve the individual, it is very important that the individual understands how to serve the community. “It’s a two-way street.”

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BERNARD MURPHY  
*President, Triform Camphill Community*

The origins of Camphill as an intentional community caring for children with special needs as its focus, the passage of time in the lives of the children and the life of the Camphill movement, and the elevation of individual needs are the elements of the present conundrum. Recognizing these, Bernard put forward a question for the Camphill movement that will shape the future of caring for people with disabilities in communities:



*As we go forward, we must now not only care for the person with special needs and provide an environment for the person with special needs, but now the question facing us as an intentional community is: How can we together with the person with special needs do something that is actually a task that we both take on together? How can we make that task a central part of our work as we move forward into the future, particularly with our older individuals?*

The people attending the symposium were invited, in part, in order to help Camphill people find out what the barriers are to envisioning and living a life in common with adults with developmental disabilities. Specific questions about the barriers Bernard identified included:

- ◆ How can we break out of the image that we have created for Camphill of being a service provider in a service delivery system?
- ◆ How can we move into a reality where we are together with the person with special needs accomplishing and taking on a common task?
- ◆ Having become largely dependent upon the public and private financing that comes from being a service provider, how can we find ways through that dependency to create greater alignment between our mission and our revenue?

The conundrum of being perceived and recognized as a service provider by people outside Camphill, and deriving income for providing services, while striving to care for people with disabilities in the context of a community established for multiple reasons - reasons that are often antithetical to the relationships that arise out of service delivery - became a dominant theme of the symposium.

## **A View of Camphill from the Larger Disability Community**

**Deborah Spitalnik**, co-chair and co-facilitator with Bernard of the symposium, having been introduced by Bernard as a “trusted friend,” welcomed the participants and described her perspective: “I come from the perspective of someone who works in the larger disability service community who is intrigued, moved, nurtured by the community elements of Camphill, but I come at it from the commitment to service delivery with people with disabilities.” Deborah explained that this community/service delivery difference in perspectives was central to the design in bringing people together for the symposium.

Deborah spoke of having been connected to Camphill by Elizabeth Boggs, whose would have been 88 years old on the second day of the symposium - a “propitious” sign because Elizabeth was, in her lifetime, powerfully present to the complexity of life and moral choice. Elements of Camphill spoke to Elizabeth’s broad range of interests and her intellectual curiosity - how things work, how they grow, color, texture, fabric of both cloth and of life, interests to which she could give voice at Camphill even as she played an important role in the creation of public policy for people with disabilities.

Elizabeth Boggs' appreciation of Camphill, according to Deborah, was "largely in terms of the very direct connection between co-workers and villagers, volunteers and companions, and the way that people change through the encounters with each other." This has been described by Patrick Lydon, a senior co-worker in Ballytobin, a Camphill community in the Republic of Ireland. In his writing about the Camphill movement in Ireland, he calls it a *culture of human recognition*. Deborah contrasted this culture to the ways that people with disabilities are devalued and unrecognized.

*In a Camphill community, there is someone who knows one's history, one's story, why one came, what one's life course has been. If we think about the fabric of our own lives, this is the essence of relationship, be it brother, sister, aunt, uncle, spouse, physician, whomever that we encounter. We all want someone who knows truly who we are, with all our flaws, all our history.*

#### **ELIZABETH M. BOGGS**

Trained for a life of scientific scholarship in an era when this was unusual for women, Elizabeth Boggs' life plans were changed by the birth of a son, David, in 1945, who experienced a major illness in infancy that led to severe developmental disability. She became a leader of advocacy for people with disabilities in the U.S., participating in the founding of the national Association for Retarded Citizens, advising national policymakers, drafting landmark legislation, and creating the model for state Developmental Disabilities Councils over a 40-year career as a volunteer, "Washington insider," and adviser to a host of groups seeking to improve the services to and prospects of people with disabilities.

Elizabeth served on the Boards of Camphill Village Copake and Kimberton Hills and was instrumental in creating the Camphill Association of North America, serving as its second President. The first symposium on developmental disabilities, held 25 years ago in 1976, was spearheaded by Elizabeth Boggs. CANA recognizes her contribution by awarding in her name annual acknowledgments of significant contributions of others to the Camphill movement in North America.

This community experience in Camphill is in very dramatic contrast to the instability, the turnover, and the transitory nature of relationships that exist in most service systems, Deborah reported. There, people can become fictions of case records that are abstracted over and over and there is no one who knows what the experience of any person with disabilities has been like. Deborah reiterated Bernard's concern about the fate of people who are aging in a world where community is less important than individuality. "We all are aging and as people have fewer family members available to them, it is more likely that people will not be known to anyone. That's one of the elements of the Camphill community that I so value."

For the remainder of her introductory remarks, Deborah proposed to explore the ideas of intentionality, stability, connection, and history and to share her impressions of “the ways that Camphill resonates with me and the ways that I hope that we in the larger community can figure out how to achieve some of the fabric of life that gives people stability and place in the world.” She also addressed Bernard’s description of the Camphill origins, saying, “It’s very important that we recognize Camphill as a movement, not as a service, not as a business, but as a movement and a set of social commitments.”

*It’s very important that we recognize Camphill as a movement, not as a service, not as a business, but as a movement and a set of social commitments.*

DEBORAH SPITALNIK  
*Elizabeth M. Boggs Center on  
Developmental Disabilities*

## **Lessons from Camphill for the Mainstream Service Delivery System**

Deborah used a recent professional experience to illustrate her view of an important way in which Camphill is different from the mainstream service delivery system. In a training workshop, the director of the Council on Quality for Services for People with Disabilities did an exercise with a group of New Jersey service providers and state workers using two flip charts, placed very far apart from each other. On one of these charts were recorded the group’s descriptions of what they did, what their work was about, and on the other chart, the group listed what was important to them.

*The tragedy and the enlightenment of this exercise was the complete discrepancy between that which we valued for ourselves as individuals and what we did as actors in a service system. That gulf, no matter what our intentions were, was very dramatic. It is my experience in relating to Camphill that if that gulf exists, it is much smaller and that is it is a gulf that is both qualitatively and quantitatively different.*

Probing further into the differences between what happens in Camphill communities for people with developmental disabilities and what happens in the mainstream service delivery system, Deborah referred to “qualities of connection and embeddedness,” which seemed to her the hallmarks of intentional community and shared living. She also noted that these qualities are not the traditional ways that mainstream service providers think about services for people with disabilities, nor are they the indicators used to measure services. “We know that they create a richness in our own lives and we intend to support people with disabilities in achieving a richness in their lives - yet I see a tremendous discrepancy.” She provided an example of these qualities:

*Camphill is the first place I ever heard classical music along with people with disabilities and played by people with disabilities. That’s not a social indicator we’d find in many accreditation systems.*

In the larger disability community, people who are involved in public policy are trying to create a world in which the fabric of community could be addressed, but Deborah worries “that we are trying to create structures that make that possible but that the fabric itself is missing.” She explained further:

*I worry that [in the mainstream service delivery system for people with disabilities] there is a lack of meaningful work and task, a lack of real life choices. We put tremendous responsibility on direct support professionals who are basically disadvantaged, disenfranchised, where there is tremendous turnover, where people don't have a chance to do meaningful work in their jobs, that there is a lack of meaningful relationships and even a lack of aesthetics that enrich all our lives.*

On the other hand, in the larger disability community, there has been a positive and potent move to look at person-centered planning and person-centered supports, and also self-determination - people making decisions about how they want their supports delivered, what they want their life to look like. These are approaches to services that “we assume and we hope and we work toward that create dignity and the mutual respect that come from participation, contribution and relationship.” This represents, in the larger field, a move away from the goal of service as being developmental, Deborah observed, “employing, in effect, almost an industrial approach to make the person with disabilities as independent as possible or to have the person achieve his or her maximum development. We are beginning in the disability field to recognize the human life goal of interdependence and the importance of community life.”

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DEBORAH SPITALNIK

Noting that interdependence and community are central to the Camphill vision of care for people with disabilities, Deborah drew from the 10th anniversary book of the Soltane Camphill community a quote by Rudolf Steiner:

*The healthy social life is found when in the mirror of each human soul the whole community finds its reflection and when in the community the strength of each one is living.*

In contrast to the Camphill vision, in the larger disabilities world, this is a novelty and, Deborah reported, “we struggle to find ways to make it a reality.” In Camphill, by definition, everyone contributes to the demands of being part of an intentional community and as people in the mainstream service delivery system are trying to create community through facilitating opportunities for work or friendship, “we find that there isn't an abundance of community.” Deborah's conclusions about these issues were:

*We ask untrained staff working at minimum wage with little support in their own lives to work contrary to typical community norms and to create more reciprocity. And we do very little of addressing the inner life of both the people we serve and the people we ask to serve and that leads us to a lot of dilemmas. We have just begun to learn to recognize the spiritual life of people with disabilities. There is much that Camphill has to teach the larger disabilities community [in this area].*

## Challenges for Shared Exploration

Deborah suggested that there are challenges for both Camphill and the mainstream service delivery system that are worth exploring together. One of these is aging - the aging of people with disabilities, the aging of families who provide support, and the aging of people who are co-workers in Camphill. Camphill faces special challenges in this respect because, as a community that values all its members and was created with the intention of providing for the needs of all its members, Camphill has never made payments into a social security system that would provide people with Medicare and other benefits as they age. Currently, Camphill communities provide for the care of elderly co-workers out of their operating budgets and local and regional “human concerns” funds, although self-financed retirement and leaving security funds are being established in several North American communities. Deborah indicated that others would benefit from Camphill’s experience with the issues of aging in place, aging within the context of the community.

The issues of “calling” - including people being attracted to living and working in an intentional community and people being attracted to direct support and other caregiving roles - are of common interest and importance to Camphill and the larger disabilities community. The fundamental question is: What is the nature of meaningful work in a society that’s becoming increasingly technical and technological? There are issues involved in answering this question that are about dependence on public systems and independence from public systems, and about values and philosophy. Deborah reported that, in the larger community, “we talk a lot about services being value-driven.” Camphill derives from a philosophy and a set of beliefs, so the question arises: Is Camphill a faith-based initiative, in the terms of present parlance? Deborah asked, “If so, what does that mean and what does that teach us about the richness of community life available here, in Camphill?”

### RUDOLF STEINER

Originally a student of theosophy, Rudolf Steiner (b. 1861) developed anthroposophy, which he defined as “the consciousness of one’s humanity,” out of his experiences as a clairvoyant with direct cognition of the spiritual world. A phenomenological approach to the spirit, anthroposophy encompassed ideas about the evolution of the world and humanity and methods of personal development. Intended to be a universal science of the spirit, anthroposophy was neither religious nor sectarian but focused on how each individual can improve his or her understanding. Steiner’s writings, ultimately including 30 books and over 6,000 lectures, addressed education — both general and special — agriculture, medicine, economics, architecture, science, philosophy, religion, and the arts. Steiner founded the General Anthroposophical Society in 1924 (a year before he died). Steiner’s ideas were a major source of inspiration for the work of Dr. Karl Koenig, the founder of Camphill, as well as for the Waldorf School movement, biodynamic agriculture, and other forms of curative education, care and medicine.

## The Background and Foundations for Camphill's Work: A Panel Presentation

**Gregg Davis**, Executive Director of the Soltane Camphill Community, presented “seven things that you would want to know if you wanted to understand what Camphill is doing and where it is coming from.”

- 1) Camphill co-workers self-identify as members of an intentional community and anything else is connected, complementary, but a subheading to that self-experience as a member of an intentional community.

A concrete manifestation of this is how co-workers answer the frequently asked question: “What is your vocation?” Gregg reported that “the answer you get most often is ‘I’m doing community-building. I’m a community-builder.’” What that means is in the nature of aspiration.

*The motive in each of us, as individuals, to extend ourselves to the need - and to the being - of others ... [is a fragile impulse]. This is a personal resolve to answer Cain's great question: "Am I my brother's keeper?" with a resounding "Yes!", and to let that Yes shape our lives.*

PATRICK LYDON

Senior Co-Worker, Ballytobin Community, Southern Ireland  
Lecture given at the Fifth Camphill Dialogue — International Board  
Members' Meeting, April 6-10, 1999, Camphill Community Glencraig

As Gregg put it, “It’s not something that we’ve got all the answers to and we know exactly what it is, but it’s definitely what we’re aspiring towards even if we’re not quite sure what it is.”

Gregg posed the question: Is “community-builder” a profession that hasn’t been recognized yet? He noted that “We have community development people, we have organizational development, we have consultants, we have community services, community supports.” Is community builder a new profession “that we need in creating this social fabric that Deborah was speaking to?”

- 2) Camphill is trying to create an alternative context of meaning within which to operate because Camphill co-workers generally do not consider the goals, the values, the cultural icons, and the lifestyle practices of 21st century mainstream America to be *their* goals and their values and the lifestyle practices that they would chose, nor even necessarily ones that they would want to imitate.

It is difficult to communicate about this essential aspect of Camphill practice without seeming to be judgmental. However, “a lot of the goals, norms, and lifestyle practices of contemporary America are not the things that are striven for in Camphill places.” Camphill recognizes that we all need a context of meaning in which to operate and, at the founding of Camphill so many years ago, there was a clear intention, which is still there, to create a *different* context of meaning than the one that is the most

prevalent in our society. Part of that context for Camphill is a value system that is spiritually-based, that recognizes something higher than ourselves. Operating from a spiritually-based value system is not in itself unique. In fact, the current attention to faith-based social programs highlights that there are plenty of people, mainstream or otherwise, for whom, the faith-based concept is important.

- 3) Within the Camphill-created alternative context of meaning there is a recognition that individual growth and personal development happens at hand of others and in and through relationships (whether or not people are living with disabilities), relationships over the course of time and sometimes in the human encounter in the moment.

There is in Camphill an attempt to cherish and sanctify the human relationship and the human encounter out of the recognition that “we don’t grow, live and develop in a vacuum. The social fabric that surrounds us, however poverty-stricken or rich it might be, is really the fabric within which growth and development can happen,” Gregg said.

Another element in the alternative context of meaning for Camphill that Gregg identified is “a respect for and a wish to engage with nature, with the earth, with the natural cycles.” From the beginning of Camphill, the work with organic and biodynamic agriculture has been an essential part of creating that context of meaning. As a result, many of the Camphill communities are rural - not because the community members want to be isolated but because they are looking to create experiences and an environment where it’s possible to connect with nature and natural cycles.

- 4) Camphill people have a perspective that beauty, art and culture actually matter.

Beauty, art and culture are not seen as ancillary, complementary, leisure pursuits - attended to and engaged in “if you have time.” Camphill people consider these things part and parcel of a full human experience and the fullest possible expression of humanness to engage in those kind of activities. In Camphill, “we tend to try to create a lot of these experiences over the whole course of a lifespan.”

- 5) In Camphill, we have not enthroned independence and individual and personal choice in the same way that is experienced elsewhere and if we had a throne, probably interdependence would be there along with independence.

This comes from the notion that as human beings we develop through and with each other and that the social fabric is what provides the opportunities for all of us to grow and change and become better. In practical life, there is a lot of work on independence in Camphill communities. Specifically, Greg said: “In the school for children, of course, what you’re doing all the time is trying to create as much independence as possible for the children through their education. But it isn’t the one and only goal for us because the interdependence aspect is so critical.”

Interdependent reality also presents challenges at times for co-workers and for people with disabilities because it implies limitations on personal choice for *everybody* in the community. That perspective is at odds with the current thinking in the disabilities field, but it comes out of the Camphill goal of creating an alternative context of meaning and the recognition of interdependence and mutuality in a life-sharing situation.

- 6) In Camphill and in anthroposophy, which is the philosophy and spiritual basis of Camphill's work, there is a recognition that it is meaningful for growth and development to continue to happen through the entire life cycle from birth to death - that continuing growth experiences are of lasting value for the soul.

Key things needed for ongoing growth and development are human relationships and a connection to nature and the cycles of nature. "It's a philosophy of engagement," Gregg said. One result is that Camphill people do not value passive entertainment. "There isn't a lot of access to TV in Camphill." Another result is that Camphill people have an experience that "we don't feel 'grown-up' at age 21 or 35 because all along the lifespan new possibilities for enrichment, for growth and development can happen. At 20, 30, 40, or 50, we're continually seeking those possibilities for the development of the individual."

- 7) The practice in Camphill communities that co-workers do not take salaries has nothing to do with financial arrangements. It is not about finances, creating a positive bottom line, or saving money. It is meant to be an expression of the idea of mutual service and mutual help offered freely.

Gregg explained the idea in this way: "I work so that you can live and grow and you work so that I can live and grow; I work and your needs can be met and you work and my needs can be met." This gets complicated because Camphill has become very identified with the services that are provided and because most communities depend on income either from private tuition and fees or from state funding for providing services for people with disabilities. This creates the conundrum, "but the reality we are trying to recognize is that of interdependence."

**Diedra Heitzman**, the Executive Director and Village Coordinator of Camphill Village Kimberton Hills, began her discussion of the essentials of Camphill taking up the principle of lifelong learning. In Camphill Kimberton Hills, "we all do a lot of adjusting, and adjusting to each other." Diedra related to the symposium participants stories from the lives of two people with disabilities to illustrate the adjusting and the continuous learning through relationships. (Names of people in these anecdotes have been changed.)



## **Ivy**

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*Ivy has lived in Camphill Village Kimberton Hills for twenty-some years. A few years ago, she moved into a new house and in that house was a relatively new householder. Ivy moved into the house where Carrie was and she began to have upsetting moments, often at mealtime. Carrie was new and wasn't sure what to do about it but what she did was some really smart things. She tried to empathize with where Ivy was and she did some biography work to try to understand who Ivy had been previous to coming to the house where Carrie lived. Carrie asked Ivy what she needed. In the course of all that, Ivy said that she wanted was to learn to read. Carrie said, "Well, I could help you do that" and proceeded to set up some reading lessons at a local library about 20 minutes drive away.*

*Some people thought that was a pretty good idea, saying thing like "it's self-determination, this makes sense, she wants to learn." Some other people said, "I don't know, maybe it would be better to do something else that wouldn't take so much time and driving. It was a decision that could have gone either way. What were the possible outcomes? Ivy would start learning to read, develop a new lease on life, get excited...or at least she has tried something out. If it doesn't work so well, she's gotten some reality-based thinking and she can go back into her life in a different way.*

*It went differently from that. Ivy took the lessons and the very experienced reading teacher threw up her hands after a year and a half of the lessons and she said, "This is the first person I've met who I don't think will ever learn to read."*

*Before that happened, the difficulties in the house had not stopped and it was clear there was a lot of tension. Then, someone else in the community offered Ivy a place in a different house, she accepted, and the problems went away.*

One of Diedra's reasons for bringing this story was to illustrate that not everybody in Camphill has been there for the last forty years and knows all the things that Gregg talked about. "We're all learning as we go, even those of us who have been there longer." In the story of Ivy, Carrie - the person who said, "I want to help Ivy, something is not going well here" - was more affected by what happened than anyone else because her view of how it is to accompany someone changed. In fact, even though she worked hard to set up the reading lessons and the transportation and the rescheduling and the rest, what Ivy probably needed most from her was a certain kind of solid centering. What was helpful was not doing something that was theoretically justified, but rather that Ivy began living with people able to interact with her in centered and accepting ways. (Ivy is doing very well now and has taken up singing.)

## **Clara**

*There was another woman in Camphill Village Kimberton Hills, Clara, who had not asked to learn to read, but if she had thought to ask she might have. Between age thirty and forty, she did a lot of copying. She had lots of notebooks and she would copy words and poems. She couldn't read them, but she really worked at the copying. She had a diary that someone helped her write. When she was moving through life and had something special happen, people would sit with her and help write down her experiences, but she really hadn't ever been able to learn to read.*

*Around her forty-first birthday, someone noticed that when Clara sat looking at a book, she was saying a few words. That was the moment when she could begin to learn to read and the person who noticed said to her, "How about if I help you with some reading lessons?" "Absolutely!" Clara replied. They started the reading lessons and she's now reading, doing very well.*

There are many lessons one could take from Ivy's and Clara's stories. Diedra summarized one lesson in this way: "We all work with theories and we're all excited about the ideas that come toward us - self-determination and person-centered planning, for example - and yet it really takes knowing somebody well to make interventions that are effective, to really assist somebody helpfully." One of the things we experience over and over is that accompanying somebody through life is an art. In order to do that well, we have to be open to the moment, as the person who noticed Clara's incipient reading efforts was.

*We all work with theories and we're all excited about the ideas that come toward us - self-determination and person-centered planning, for example - and yet it really takes knowing somebody well to make interventions that are effective, to really assist somebody helpfully.*

DIEDRA HEITZMAN  
Executive Director and Village Coordinator,  
Camphill Village Kimberton Hills

Diedra placed the two stories in the context of Camphill philosophy and principles. "There is a big idea that pervades Camphill's idealism, which is sometimes referred to as the image of a human being. Within the idea of the image of a human being is another - that there is an archetypal possibility for each one of us that we can develop toward but are not there yet. The how of developing becomes a matter of interaction with each other and interaction with the world." Lifelong learning is not a goal but a means by which we embrace life on earth in order to promote development toward the archetypal possibilities. "We do it in a variety of ways and we enable each other to do it. Generally, Camphill communities have been good at creating environments where lifelong learning can take place, which I appreciate. Yet even those of us who have been in Camphill for 15 or 20 or more years, know that we're aspiring to something, we're not there yet."

Diedra offered additional examples of lifelong learning in action. One she drew from reports on the quality of care in Camphill communities prepared by Kay Sherwood. “Kay wrote about being surprised that she had been in Camphill for awhile and had not heard anybody mention the word ‘reincarnation’ as one of the basic ideas upon which our work is based. We’re interested in so many things and we probably don’t talk about reincarnation any more than we talk about pruning or a whole lot of other things.” People in Camphill are learning about all kinds of things all the time.

Finally, Diedra told about village events of great meaning and effect.

*In January, we christened a baby in a hall similar to this one and then in February a woman in our village died. She was 58 years old and she had lived with us for a lot of years. At her funeral, the priest, who lives outside the community, gave the eulogy. He told about her biography, including her parents, and he said that her parents had been told early on that she would probably live to be twenty if she was lucky. His own experience was that Camphill Village had created a home for this woman, whose body was so inhospitable for her to live in. Because she had a place that was really a home for her, she was able to stay on earth as long as she did.*

*In that moment we all just sat awed by the fact that we all have a home in the place where we are living and in that place live people whom we know really, really well. We rub off on each other a lot and learn by our difficulties often. It’s not easy but we are at home there. Those of us who live in Camphill share in a wonderful way.*

**Kevin Keane** spoke about the Camphill experience from two perspectives - the perspective of a parent of a Camphill resident who is disabled and a member of the Board of Directors of Triform Camphill community. Kevin is the parent of a son, David, who came to Triform in 1988. Kevin told a story about David that illustrates much of what he and David’s mother initially responded to in Camphill.

*Within the first week of David’s life in Triform, he was in the car with his houseparent, Claus, when they had an accident. They drove down a road and got up to a corner not too far from here and two cars ran into each other. They ended up going to the hospital. Claus was in a hospital bed adjacent to David’s and the first thing that one or the other of them recognized when he started to focus on “Where am I and what am I doing here?” is that they were holding each other’s hands. We understood that first experience to reflect a focus in Camphill on “How is the other?” “Are you O.K.?” In effect, the touch was meant to say, “How can I help you?” It personified for us as a family the first magical thought of what this community could be like.*

Kevin elaborated on his experience as a parent, describing what it was like to discover a community that was structured and organized to help the community members “become what they could become.” He observed that this “is an amazing contrast to the normal world, much of the Western world, where you are grown from birth to achieve, to compete, to win, to do things that, perhaps, create society in many ways but do not foster principles of ‘What can I do for you and what can we do together to make a better

world.” These underpinnings of Camphill become apparent when “you watch the families, you watch the other parents, you watch the co-workers” and, most telling, “when you observe the children and young people with disabilities who have become the masters of this community and who are the most assured, the most able to live their lives in a way that we all throughout the world struggle to achieve. They are achieving it, not because they themselves have just flowered but because of the community of effort that is creating this amazing experience.”

Kevin’s parental experience of Camphill has not only been reinforced over the years but it continues to intensify. He observed that as parents become involved in a Camphill community, “they become first attuned to and then obsessed with the lost art, the secret to true life, the reality of what it is all about” because they see their sons and daughters living in a way that seems to offer satisfactions and inner peace that are mostly absent from the world outside Camphill. Specifically, he said, “what you glimpse in a Camphill community, when you are looking at your own flesh and blood and worrying about your own mortality, is a process that is an inspiration and a learning source for the wider culture.”

*As parents become involved in a Camphill community, they become first attuned to and then obsessed with the reality of what it is all about because they see their sons and daughters living in a way that seems to offer satisfactions and inner peace that are mostly absent from the world outside Camphill.*

*The reality of a Triform or a Camphill community is in the experience that exudes to the outside world — in the way that a young person with disabilities takes command of his or her own body and soul and lives a life that you just don’t see very often in communities that are working with the disabled.*

KEVIN KEANE

Parent of David, a resident of Triform Camphill Community, and former chair of the Triform Board of Directors

After talking about his experience as a parent, Kevin turned to his experience as a Board member. (He has been a member of the Triform Board of Directors since 1989, and chaired the Board until recently.) “Being a Board member is a combination of this fascination with community, a recognition that there is need, a dream that you can give to a community and help, and a process of learning constantly.” Kevin’s experience is that the Triform community exemplifies a mix of the dreams from inside the community and the perceptions - not necessarily the reality - and the eagerness to help from the outside. And “that blend is different in every Camphill community.” Although Camphill communities each have a different personality and each has a different structure in order to do what they need to do to achieve their goals, the common denominator of “giving and sensing is all there.”

As a Board member, Kevin has come to understand that “the wonderment of a community like this and why it exists this way and what is different in a community like this” are explained by the philosophy of the community, which Kevin called “the underpinnings” or “the principles by which the community is brought together.” He elaborated:

*It's the anthroposophical underpinnings that bring together the Camphill communities. It could be another philosophy, and it is in other cultures, but anthroposophy is the common denominator for Camphill, it's rationale - a philosophy that can be studied and mentored and nurtured. Through the wisdom of this knowledge comes the inspiration for a community of effort and that is what generates the success of the people in it. The proof of the pudding is in the tasting. We can spend much time searching for the rationale - and we need to do that - and what the lessons are to be learned - and we have to reach for that - but, in reality, there is something here, it permeates Camphill, and it is enduring.*

## ANTHROPOSOPHY

...is a philosophy that embraces a spiritual view of the human being and the cosmos, but emphasizes knowledge rather than faith. Anthroposophy (meaning the wisdom of man, from the Greek) is a spiritual path that involves the heart, the hand, and the mind — a three-fold way of living and striving for spiritual development that begins with the individual and humanity as a whole and then extends to the physical environment and the universe. Anthroposophy offers a specific view of the nature and place of human life in the earthly sphere and the cosmos that is based on the idea of reincarnation and posits an eternal spirit for each human incarnation and an animate nature for the earth itself.

Anthroposophy prescribes practices that enhance spiritual awareness and development of the people who choose the anthroposophic path — such as study, contemplation, movement, and the production of spirit-infused goods from the hand, the heart, and the mind, based on an understanding of the earth as a vital sustaining element of the human spirit. Practices that preserve and enhance the quality of our physical environment, some of which are the foundation of biodynamic agriculture and anthroposophic herb-based medicine, are central to anthroposophy in action in practice.

Like all comprehensive human philosophies/cosmologies, anthroposophy seeks to explain why we are what we are and how we fit into the physical world and the cosmos. Anthroposophy differs from many other explanations in that it offers to humans the possibility before death of understanding and apprehending “supersensible” beings and their knowledge. The effect of anthroposophy on people with disabilities is that Camphill communities, rooted in anthroposophic beliefs, recognize and “speak to” humanity-wide sensibilities and the individual spiritual nature of each person. Further, Camphill co-workers assume, in their education and therapies, that people with disabilities can learn about and relate to human-wide experiences and feelings, and have something important to teach people who do not have disabilities.

## Challenges to Camphill from the Perspective of a Public Policy Advocate

**K. Charles Lakin**, the invited speaker, is the Director of the Rehabilitation Research and Training Center on Community Living, a component of the University of Minnesota's Institute on Community Integration (UAP). Over 25 years of working in the field of services to individuals with developmental disabilities, Dr. Lakin has been a teacher, researcher, and advocate and he has consulted with numerous state, federal and international agencies on policy, research and evaluation. He was appointed to President Clinton's Committee on Mental Retardation. Dr. Lakin's subject was "The Next Twenty Years: Challenges and Goals, Working Together." Among his key challenges to Camphill were:

- ◆ Reach out, communicate who you are, become more visible.
- ◆ Help bring new technologies to people with developmental disabilities.
- ◆ Participate more actively in the policy process.
- ◆ Consider whether and to what extent Camphill responds to what people with developmental disabilities say they want for themselves.
- ◆ Help the field understand care as service and help bring service back into the system of care.

Dr. Lakin began his talk describing his connections to Camphill, with the broader purpose of sketching Camphill's influence on the disabilities field. He called his participation in the symposium "a coming home because Camphill has been very much a part of my life even though I have never been to a village" until visiting the Triform and Copake Camphill communities in connection with the symposium. He also described his personal connection to the Camphill idea of accompanying people with disabilities. He and his family decided more than 20 years ago to commit themselves to being with children with disabilities and their families.

*We decided to walk with three families as they tried to raise three infants who were very severely disabled. This was before there was "family support" and so we were the family support that included taking the children on weekends and, on a couple of occasions foster parenting the children for a year or longer. The commitment to do that came out of my learning about Camphill. Camphill showed me a commitment that people extended that went beyond what they were paid to do in their lives but that made their lives more than they were ever or could ever be paid to do. So I feel real indebtedness to Camphill as I reflect back on that experience that made my family's life so much richer and my children much better people and, in a small way, contributed to the lives of three families and three children who are now women.*

## Camphill's Influence on the Wider Disabilities Community

Dr. Lakin suggested that Camphill's influence is profound for the few who are able to connect, but limited by the Camphill culture that not only does not promote the philosophy and way of life, but is relatively uncommunicative to people in the mainstream of service delivery for people with disabilities. He likened the culture of Camphill to that of the Navaho people, among whom he lived and worked some years ago. He discovered that the Navaho people have an extremely "low need to talk. When I think about that culture and the culture of Camphill, I see those characteristics as shared." Dr. Lakin went on to suggest that this should change.

*I know you talk a lot in the village, probably with great passion, but outside the community not many people know what goes on inside Camphill and even less is known about what Camphill has meant to those of us who have not been inside. I think in some ways it is important that we come to understand what Camphill is to the larger world of services to people with disabilities or - from the perspective that others take - as an intentional community.*

Dr. Lakin cited statistics underlining Camphill's influence. "It is so remarkable when you think that 99.8 percent of the people with developmental disabilities in the United States have never been part of the Camphill experience and yet the experience of that .2 percent has had such an impact on so many people."

*It is so remarkable when you think that 99.8 percent of the people with developmental disabilities in the United States have never been part of the Camphill experience and yet the experience of that .2 percent has had such an impact on so many people.*

K. CHARLES LAKIN  
Director of the Rehabilitation Research and  
Training Center on Community Living, University of  
Minnesota Institute on Community Integration

He then identified some of the people who were influenced. “I know the incredible impact that had on the experience of Burton Blatt and how Burton from those experiences of Camphill began to think of the moral imperatives that we all have to share lives with people with disabilities and he taught that in powerful ways to people all over the country.” Dr. Lakin also sees Camphill’s influence “in the transformation of Wolf Wolfensberger from somebody focused on typicality and physical arrangements to the value of people’s roles within communities.” He reported that “those experiences really

permeate our society and we really need to think about ways that we can communicate those more broadly.” In contrast, Dr. Lakin noted a generational divide in familiarity with Camphill.

## PIONEERS IN DISABILITY RIGHTS

Two important figures in the reform of public policy and services for people with developmental disabilities were influenced in their thinking and writing by Camphill. **Burton Blatt**, whose 1966 book with Fred Kaplan, titled *Christmas in Purgatory*, exposed the degrading conditions of people with disabilities living in state institutions. Blatt visited Camphill Village Copake in the late 1970’s, spoke about Camphill often as a model, and, before his untimely death in 1985, wanted to retire there. **Wolf Wolfensberger**, the progenitor of the movement in the U.S. to community-based care, drawing on the principle of “normalization,” engaged in continuous conversation with Camphill leaders and friends over his long career and ultimately shifted from his emphasis on the geography of living arrangements — which he felt had been transformed into inflexible policy — to program approaches built on the quality of a person’s whole experience of living.

*When you think about the impact that Camphill has had on Burton Blatt’s generation and on my generation, we really need to be concerned about how we can sustain that influence into future generations. Part of that is my challenge as an educator, but it is one that I hope Camphill will take seriously as well.*

## A View of the Next Twenty Years for People with Developmental Disabilities

Dr. Lakin asked the symposium participants to consider the world that technological innovation has created and **the effect of technology on the lives of people with developmental disabilities.**

*People describe a quite amazing world where we will carry in our pockets the equivalent of a computer, a television, a telephone, a CD player, we’ll be able to access the whole library from a machine that we carry in our pockets and if we want, we can sit on a park bench and take a class in mathematics from the best professor that MIT has to offer.*



Dr. Lakin acknowledged that these capabilities are frightening for some people, but he urged the audience to recognize the reality, including that “they are very, very attractive, not only to people without disabilities but very attractive to people with disabilities, too.” Further, he urged the audience to “look at this new world with enthusiasm and embrace the opportunities it provides.” But he also pointed out the risks of the new world.

*One by-product of all these tools is certainly the risk that we are all going to become more isolated - that's inevitable - and the risk is greatest for people who have intellectual limitations. There is a growing expectation in our society that people are going to have these tools available and they're going to know how to use them. If we don't help people with intellectual and other developmental disabilities have access to the tools, they're going to be more isolated from the freedom that these things are going to provide to people who do have access to them. So in a very profound way, I don't think it's moral for us to let that happen. We can't ignore that world.*

Dr. Lakin then contrasted the real changes taking place in people's lives as a result of technological innovations with the **continuing problems of social policy and the recurring nature of public policy debate**. He described recent cycles of Medicaid reform as an example, predicting that this issue would rise again soon.

*The amazing capabilities of technology are going to be there and they are very, very attractive, not only to people without disabilities but very attractive to people with disabilities, too.*

K. CHARLES LAKIN  
Director of the Rehabilitation Research Center on  
Community Living  
University of Minnesota

*In the mid-1990's, there was a great concern that Medicaid costs were going up very rapidly and Congress had to do something. What Congress was going to do was create block grants that would go to the states, the states would in turn create some sort of managed care program for people with disabilities and what many of us were concerned about was that states would revert to the best managed care system, the purest managed care system that's ever been created for people with developmental disabilities - the state institution. Lo and behold, welfare reform came, people were either placed in work or found work, Medicaid costs began to come down, everybody forgot about the concern about Medicaid costs for people with developmental disabilities. But, those costs keep going up and they're going to be rediscovered again.*

Dr. Lakin predicted that the battles fought in the mid-1990's by advocates of people with developmental disabilities to stave off the institutional managed care solution to Medicaid cost increases would have to be fought again. But, he said, “these are just the ebbs and flows of public policy. They come and they go

and we need to be ready to fight and we need to be able to relax in the periods when the threats don't exist." He speculated that if Elizabeth Boggs were at the symposium, she would advise "Don't worry, just be ready."

Describing "**incredible inequities**" in the system of services for people with developmental disabilities, Dr. Lakin encouraged Camphill to be more actively engaged in the broader issues, saying that, "It's so important for us to attend to [the inequities], particularly for people who come at this from a moral framework." He provided these examples of the inequities:

- ◆ In 12 states, \$5 for every \$1,000 of personal income is spent for services for people with developmental disabilities, whereas in 9 other states, the amount spent is less than half that.
- ◆ The rates at which people have been moved out of state institutions varies widely as well. In the 17 states that decreased their state institution populations the fastest, about three-quarters of the people who were in state institutions in 1990 were gone by the year 2000. In the 17 states with medium rates of reduction, about 43 percent of the people who started the decade in state institutions were gone by the end of the decade. In the slowest states, only 23 percent of the population of 1990 was gone by the end of the decade. Fifty-seven percent of all the people in state institutions in the United States live in those slowest states.
- ◆ The waiting list circumstances also vary around the country. There are about 10 states that would have to increase their total amount of residential services by 30 percent or more in order to meet the people who are waiting for services whereas in another 12 states, a 5 percent increase in residential services would cover everyone waiting.

Dr. Lakin concluded about these statistics, "People are being resigned to state institutions in this country simply based on where they live." On the other hand, there are very active court cases going on to challenge the right of states that participate in Medicaid to deny people access to services within what Medicaid law calls "reasonable promptness" and to fund services adequately so that people who are authorized actually receive them. Dr. Lakin's message to Camphill was: "All through this country, people are challenging the inequities that exist within the system and the Camphill movement as a moral movement needs to be participating in that."

## What People with Developmental Disabilities Want for Their Lives

At a conference that Dr. Lakin attended, along with other researchers, state directors of services, state and national advocates, parents of children with disabilities and people with disabilities, the participants were asked to identify “What is it that people ought to be getting out of service?” and “What is it that people with disabilities want, with our support to help you accomplish?” Dr. Lakin reported to the symposium audience what people said, and noted the contrast between these statements and the symposium discussions of interdependence and community:

- ◆ People with developmental disabilities want homes of their own. They want other people to respect that their homes are *their* homes. They want to be the ones who control their own front door, their refrigerator and all their own stuff. They want to select their own homes.
- ◆ People want to live with people with whom they chose to live. Most particularly, they want to be free to not to live with people they do not like, people who hurt, intimidate, and otherwise prevent them from feeling at ease at home. They want help in being able to find homes they like that they can afford.
- ◆ People want to be able to choose and have help to participate in activities that they like and that they feel good about. They want to have more choices. They want to have more variety in what they can do. They want jobs with pay. They want to work more hours and earn more money than they currently do.
- ◆ People want to contribute to their community. They want to feel acceptance and personal value from what they do. They want people in their lives who think it is important to help them do what they want to do in life.
- ◆ People want direct support when, where, how they need it. When they do need direct support, they want it from people they like and who they feel like them. They want to be able to select the people who support them. They want to be able to get rid of people they don't like.
- ◆ People want to be listened to. They want to be listened to when things are being planned for them. They want to be asked how things are going in their lives. People want to be asked if they like their services.
- ◆ If people's lives are not going well, if they are not getting needed services, they want things to change. They want people in their lives who see themselves as friends and who will help them have better lives.

- ◆ People want to live in communities where their neighbors and community service providers (like doctors, dentists, bus drivers, sales persons, community park directors) respect them, have time for them and want to include them.

Dr. Lakin added to this list what the parents of people with disabilities particularly want, which is for them to be healthy and safe. He then raised the challenges of knowing what people with disabilities want, and providing it over time, as expectations change.

*These are elegantly simple ideas, ideas not much different from what any of us would no doubt list, but they present standards that we need always to use to test what we're doing. That's part of the Camphill philosophy. Dr. Koenig said that Camphill villages never cease to readjust their social structure, to remodel it as times require.*

*In some ways, times now require change because people have different expectations today, people are expecting different things out of the world, and they're causing all of us to readjust and remodel. It doesn't matter whether we're in Camphill or in "Acme Group Home" downtown, what people are asking for are things that we have no right to ever deny - respect, control over the most intimate parts of their life, opportunities and choice, assistance in living lives that feel good to them and a chance to communicate how they really feel about their lives and what they want to do in them.*

Turning back to the earlier discussions by Camphill presenters of interdependence and community, Dr. Lakin told the symposium audience that in spite of the dread everyone has of isolation and the feeling of protection that interdependence gives us, *people with disabilities tell us how deeply they crave privacy*. A sense of privacy is one of the most missing things in their lives, and a sense of being treated as an individual. We always need to attend to that need.

Dr. Lakin brought the experience of Clarence to illustrate "how we so often get in a mold of looking at the world through one lens, and fail to attend to the fact that we're all very different and everyone has a right to expect that we will respect the possibility that their view of life is very different than ours." Dr. Lakin met Clarence in Vermont, where Clarence had just moved to a farm that, to Dr. Lakin's eyes, looked "pretty run down, but Clarence was delighted."

## **Clarence**

*Clarence had lived in town, had his own house, his own name on the lease. A lot of money had been spent to fix up his house. He lived with some caring people who really took care of him and yet he was miserable. The people around him recognized that he was miserable and spent some time trying to figure out what was the problem.*

*Just before he had moved into that house in town, Clarence had lived with his own family on a farm. He had grown up on a farm with his family for years and eventually somebody said, "Maybe Clarence craves a farm and a family" and, indeed, that's what was discovered. Clarence wanted to live with a family on a farm.*

Clarence's experience suggests that the people trying to help him "had to deconstruct their idea of what was ideal for him." Clarence had everything by the standards of contemporary services - a home of his own and direct support staff person who lived in the house as a companion with him. "Everything was ideal except that Clarence was miserable."

## **Bringing the Sense of Service into the Service Delivery System**

"If Camphill understands anything, it's service." That is how Dr. Lakin summarized his reasons for Camphill to interact more with the larger disabilities community. In a discussion of the **challenges of recruiting, hiring, and training direct support staff**, Dr. Lakin noted that the "huge problems with direct support these days have not changed much in 20 years." While the turnover rates are the same, 20 years ago when direct support staff left replacements were easily found. "Now people are leaving and we are wondering where these new people are going to come from." Because the proportion of people between 18 and 30 in the U.S. is the lowest it has been since the Depression, many industries are competing for service employees, and wages in direct support jobs are low, "we're going to have to struggle."

Dr. Lakin reported that there are several state initiatives to increase wages, but "somehow we've got to transform our system into one where service is brought back into the understanding of what the direct care role is." He suggested that working toward national service programs is one approach, taking note of the fact that the Camphill recruitment office has tapped into the AmeriCorps model.

*If Camphill understands anything, it's service.*

C. CHARLES LAKIN

*AmeriCorps is not going to solve all of Camphill's problems or America's problems by any means but we need to begin to look at programs like tuition voucher programs for direct support staff that really touch the tens and hundreds of thousands of people that we need to draw into this field.*

*They're the kinds of people we want, too. We want young people, we want vigorous people, we want people who have excitement about their work. That's a kind of initiative in which Camphill can really be important.*

In his remarks about **quality assurance**, Dr. Lakin presented another challenge to Camphill, particularly to the idea presented in symposium discussions about interdependence and community.

*By quality assurance, I mean what we do within our organizations to make sure that we're doing what we're all about. Every organization needs to figure out what it's all about, but in our field, there's no justification for anything but making people's lives as much like they want them to be as is possible. I don't think Camphill was put here in service to people with disabilities to provide enlightenment for co-workers. If that happens, that's fine, but the mission that has been taken on is to be of service to people with disabilities and that can only be understood from the perspective of the individual. As I read through the [Camphill] literature in which I hear what co-worker after co-worker thinks about their experience, I want to say, "What do people with disabilities think?"*

Dr. Lakin urged Camphill to attend to the challenge of learning what it is that people with disabilities want out of their lives and what Camphill - or any organization involved with people with developmental disabilities - is doing to provide those things that they want.

*People can articulate what they want in life, they can tell us, even if they can't speak, what they want in life. Our job is to provide that and in that we will find the enrichment as non-disabled people that we need.*

**Self-advocacy** was the final topic of Dr. Lakin's presentation. A 22-minute documentary film called "Disability Culture Rap" constituted the main part of this presentation. It was written and produced by Jerry Smith, a colleague of Dr. Lakin's at the University of Minnesota, and sponsored by a grassroots organization of persons with developmental and other disabilities called Advocating Change Together, based in St. Paul. Dr. Lakin introduced the film with these words:

*Self-advocacy is a chance for people to find pride in themselves as a group and as individuals participating in a group, that simply can't be replicated in any other form. The video captures what the self-advocacy movement is about. It's a little edgy. They're not saying thank you for all the help you've given over the years, but it communicates a lot about what we need to help people achieve.*

Dr. Lakin contrasted the sense of pride evident in the people filmed to conditions for people with developmental disabilities in the early 1970's, when people were trying hard to shed the identity of mental retardation because it was so stigmatizing that it made life not worth living. "Thirty years later, they're some people here [in the video] saying there's a lot of living, even if people want to apply a label like that to you."

## **DISABILITY CULTURE RAP: A FILM**

Featuring Cheryl Marie Wade, the Queen Mother of Gnarly herself, also writer and co-producer of the film, we take a fresh look at what it means to be disabled in America. Through hundreds of images and a high-energy delivery, this is disability in our own words: who we say we are. Not the usual anthropological study of disabled people as specimens, we uncover the issues that set our souls on fire: freedom of choice, disability pride, independent living, the power of language and images, sexuality, community, and the right to live with dignity. Here we assume that, Yes, Virginia, there is a disability culture, and at the core of this culture is empowerment, pride, and flat-out, no apologies celebration of difference.

From a catalogue of “Tools for Change,” a video-based curriculum building skills and knowledge in self-advocacy and disability rights.

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## PART 2. THE DIALOGUE

Starting off the dialogue, symposium participants shared their reactions to Dr. Lakin's talk and to the film. A major theme of the responses was Camphill's intention, effort and achievements with regard to learning what each person with developmental disabilities in its care wants and assisting that person to live the life that he or she wants — i.e., the extent to which the people with disabilities living in Camphill communities are able to exercise self-determination. A related theme of the responses was the distinction between providing services *to* people with developmental disabilities and living *with* them in a way that is intended to both be therapeutic and *mutually* developmental. Some Camphill people found one statement on this subject by Dr. Lakin particularly relevant and provocative: "Camphill was not put here in service to people with disabilities to provide enlightenment for co-workers." Selected comments of participants follow.

**Beth Barol**, an independent consultant who provides training to direct care staff both in Camphill communities and in the mainstream service system, offered observations about Camphill practice stimulated by Dr. Lakin's presentation.

*Camphill brings into the dialogue a spiritual way of thinking about service, an investigation of self in terms of the necessity of helping others. Also, while the wider culture puts all artistic expression into the hands of a few "artists," Camphill is particularly good at sharing the artistic experience and engaging the whole person.*

*With regard to Dr. Lakin's statement that the people with disabilities are not here in Camphill for the enlightenment of the co-workers, there is a tender balance needed between using one's will to create different opportunities for the person with disabilities and using one's will to improve oneself. Camphill ideals and the living experience in the moment do not always match, in part, because the demands of the community mean that co-workers cannot always take the time someone with disabilities needs for individual difficulties.*

*In practice, the Camphill priority seems to be the relationship between co-workers and persons with disabilities - the dyad - as opposed to the development of the person with disabilities in the three-fold way of anthroposophical thought that encompasses body, soul and spirit. The separateness of the body from being, the equality of souls, and the freedom of spirit - the triad way of thinking - was expressed by the people with disabilities in the film, "Disability Culture Rap."*



**Guy Alma**, a senior co-worker, housefather, teacher and administrator, at the Camphill Special School in Beaver Run, Pennsylvania, described the experience of “self-determination” in his own life and its implication for caring for people with disabilities.

*An exercise in thinking about the limits of self-determination for anyone is to consider the rhythm of a day in the life of a Camphill co-worker like myself. My self-determination is high at a very early hour of the morning before anyone else is awake. It declines as other people with needs rise. As human beings, we have to be able to expect things of each other. Work not only goes to the meaning of life, work is where society has the most expectations. We don't necessarily choose the things that are expected of us.*

**Marcia Tewell**, the Executive Director of the Colorado Developmental Disabilities Planning Council, appreciated Dr. Lakin's story about Clarence.

*It is useful to bring the issues down to the individual level [as in the report of Clarence's experience]. When you peel away the disability layers, you can find the person's vocation - where he wanted to live and what he wanted to do. When we look at community or group living, it is important to get under the layers.*

**Joni Fritz**, a former Executive Director of the American Network of Community Options and Resources (ANCOR) and a long-time friend of Camphill who is now living in Sedona, Arizona, related her own experiences with family members who are disabled.

*So many of us [in or close to Camphill] have difficulty understanding that there are other places that people with disabilities might want to live. It is necessary to expose people with developmental disabilities to options so that they can choose for themselves. Where we live and who we live with are the most important choices that people make.*

**William Furse**, a self-advocate who now works with people with disabilities throughout the Hudson River region and was once a resident of Triform Camphill Community, highlighted the ways in which Camphill could be of service to the self-advocacy movement.

*Camphill already helps people with disabilities become more independent. A next step is to prepare people with developmental disabilities for self-determination and to connect to the self-advocacy movement.*

## Camphill in the World

The dialogue continued in a discussion among all the symposium participants, who were asked to comment on questions about why and how Camphill should engage with the broader disabilities community. Participants commented on four main issues: (1) What Camphill contributes; (2) The issues for Camphill of receiving pay for service; (3) Camphill's relation to the mainstream service delivery system; and (4) Camphill's relation to the government, which finances most of the paid service.

### CAMPHILL'S CONTRIBUTIONS

**Bill Gaventa**, who is based at the Elizabeth M. Boggs Center of the University of Medicine and Dentistry of New Jersey and works with people in the disabilities community on issues of spirituality, morality, ethics, and expressions of these in service delivery, offered a list of areas in which Camphill has a unique contribution to make:

**1. What it means to know and listen to someone so that his/her preferences become a driving force in what happens for him/her.**

*In a world driven by tests and formal assessment, Camphill has an advantage because "intimacy is needed to know someone" well enough to understand their aspirations.*

**2. Helping people build lives.**

*Self-determination is not just about independence and autonomy, but it also requires the development of responsibility under conditions of freedom. Camphill offers the paradoxical experience of shared freedom and responsibility that promotes choice and competence.*

**3. What community means and what calling and commitment mean.**

*Camphill offers a living example that can serve as a touchstone or point of departure for the mainstream social services delivery system and the world in general.*

**Deborah Spitalnik**, co-chair of the symposium, suggested that Camphill might help the service providers in the mainstream system with their difficulties in finding people to do direct caregiving and support.

*Are there meaningful ways of encouraging commitment in Camphill that can be shared? Although the standard of living and quality of life for Camphill co-workers is much higher than for people in direct caregiving and support, if we have people who are going to be paid [in the mainstream service delivery system], are there ways of treating people who are paid to give service so that they develop intrinsic motivation more like Camphill?*

**Mike Green**, Training Director of the Asset-Based Community Development Institute (ABCD) is engaged in trying to start a Camphill community in Colorado. He reported his experience with community initiatives that ended up being service systems - and the importance of recognizing the boundary between community and service. ABCD is dedicated to an approach to community-building that differs from traditional community planning based on needs and deficiencies

## THE PAID SERVICE ISSUES

**Diedra Heitzman**, from Camphill Village Kimberton Hills, who presented on the previous day, explored some of the Camphill thinking about being paid to provide service and what Camphill can learn about this from people in the mainstream service delivery system. She noted that “Often, the things that are off-putting to us are the areas of greatest learning.” Then, she related the story of a man considering joining a Camphill community after 17 years working as a driver for Federal Express. This man took the FedEx job, instead of becoming the history teacher that he wanted to be, because he “wanted opportunities for his children.”

*His choice [illustrates] important questions about paid service because, in effect, he chose the vocation of provider of his children’s opportunities. Are we [in Camphill and in the mainstream service delivery system] choosing the vocation we really want to be in? This relates to self-determination. Receiving payment does not stop love or giving service.*

**Nick Stanton**, a member of the Cadmus intentional communities in Great Barrington, Massachusetts, and a former Camphill co-worker, took up the questions about paid service as well.

*Dr. Karl Koenig did say that “paid help is no help” and we “should not get paid in the usual sense” of compensation because the value of service is negated in the concept of “exchange.” However, there is a view of payment as a means to stay alive in order to render service.*

Nick also quoted John McKnight, a well-known thinker about service and community whose ideas are the inspiration for the work of the ABCD Institute: “If I am rendering a service that is compensated, then I am rendering the ‘service recipient’ in a dependent role.” Echoing Gregg Davis’ remarks on the opening day of the symposium, Nick proposed that the solution to this dilemma is in the “third corner of the triangle” - i.e., that co-workers and people with disabilities need a role outside their relationship in order to conduct their relationship and foster mutual development.

**Beth Barol**, who spoke on the first day of the symposium about Camphill’s contribution of a spiritual model and the primacy of the dyad relationship in practice, addressed the issues of paid service.

*When Camphill people talk about relationships with people with disabilities, there is the implication that money does not come into Camphill on behalf of the people with disabilities. But, in fact, the community thrives on the income the disabled bring, which drives the relationship. Can we say that service is secondary to another mission when we survive on the money that the people with disabilities bring?*

With regard to regulation and government funding, Beth observed that regulation sharpens the awareness of safety issues among service providers, including Camphill, and that the Camphill communities particularly need to look at restraint policy and practice, which has developed a great deal recently. She also asked,

*What does the change in getting funding [in Camphill Village Copake, for example, where there is a substantial new state contract] and increased funding mean to “taking people as they are?” When Camphill is getting paid to meet people’s needs, there is not a choice not to meet their needs.*

## **CAMPHILL’S RELATION TO THE MAINSTREAM SERVICE DELIVERY SYSTEM**

**Michael O’Leary**, the Director of the Columbia County Community Services Board (within whose jurisdiction the Triform Camphill community is located) urged Camphill to broaden its idea of community and not to create an unnecessary separation between the pursuit of community and the performance of service, or between Camphill and the mainstream service delivery system.

*People select careers because they want a unity of their work and personal lives. Service providers for people with developmental disabilities are committed to creating the best possible circumstances for people with disabilities to live the lives that people say they want. And, there is a “community” of service providers.*

*A common language is important because there are at least two sets of metaphors about services - “the dance” and “numbers.” The people in government have gotten used to living in the world of numbers, what they would call fact. Service providers, on the other hand, recognize things that we know but can’t convey in numbers or in language that can be understood by someone accustomed to a different metaphor. We need to encourage others to listen in a different way and speak in a different way. Perhaps the language is in the doing - i.e., the process of meeting, conveying and sharing locally.*

**Aasa Richter**, a former Camphill co-worker who also worked as Assistant Executive Director of ANCOR (with Joni Fritz) and now works in the Camphill recruitment office (sponsored as a cross-community effort by the Camphill Association of North America), reported that the recruiters needed to be able to answer questions from inquirers about “What will I have after my Camphill experience?” One of the potential answers is that when young people learn the Camphill way of living with people with developmental disabilities, service delivery agencies in the broader community acknowledge this learning, which has a special value. Exchanges between the staff at Camphill communities and organizations like New Horizons Resources, Inc. (a service provider based in Poughkeepsie, New York) would be useful to increase understanding of how experience in Camphill translated into other services work.

## **CAMPHILL’S RELATION TO THE GOVERNMENT**

**Jim Cashen**, attorney, former Deputy Commissioner of the New York State Commission on Quality of Care, and advocate for people with disabilities, addressed the question of Camphill’s relation to state regulatory agencies.

*The dialogue between Camphill and state officials regarding accountability, oversight and funding has been “How can Camphill fit into the existing system” that presumes paid service. Can we move the dialogue to a higher level [as in earlier state administrations] when the state tried to accommodate Camphill by creating special regulations? Now, how do state officials think about the possibility of concrete regulatory modifications that are accountability-focused but more appropriate to Camphill and other alternative community-oriented services for people with disabilities. Perhaps there is a wider umbrella under which to approach state regulatory issues.*

**Thomas Articola**, the Regional Director in the Mid-Hudson area of New York State’s Office of Mental Health and Developmental Disabilities, responded to Jim Cashen’s comments by noting that the state agency is in the position of being both a regulator, driven primarily by the federal government, and a service provider.

**Kathryn duPree**, Deputy Commissioner of the Connecticut Department of Mental Retardation, reported that the relevant federal regulatory agency, the Health Care Financing Administration, is currently looking at how to make services more of an individual and provider responsibility but still fit the accountability and quality assurance systems. **Bill Gaventa** noted that a person with individualized services funding in New Jersey cannot buy a slot in a group home.

*Regulatory investigation in the future will be much more focused on the things that people with disabilities say they want.*

K. CHARLES LAKIN

**Regis Obijiski**, Executive Director of New Horizons Resources, Inc., in Poughkeepsie, New York (near Triform Camphill Community), reported a new, unfriendly regulatory context at the federal government level that uses a medical model of re-habilitation rather than the habilitation model that reflects customary thinking in the developmental disabilities community.

**Claus Sproll**, an administrator of the Camphill Special Schools - Beaver Run (Glenmoore, Pennsylvania), taking note of the conjunction in the Camphill model of “no pay” and, nevertheless, a higher standard of living and quality of life, suggested that a research experiment to apply the financial principles of Camphill to some mainstream service providers might be enlightening.

**Jeanne Leonard**, staff to the Camphill Association of North America (CANA) for the last two years (who will be transferring to the Triform Camphill Community administration to shepherd that organization through the state licensing process), posed the question,

*What do we need to know about the regulatory environment now and why do we need to know it? In order to achieve our ideal of supporting a person with disabilities, and sustaining the moral imperative to do it, we need to link with like-minded people. This linking should be a CANA role. [As we get closer to mainstream service delivery and government regulation] we should make sure to do better in the area of physical limitations. It is hard and expensive to assure that every barrier is removed and that every person can visit every building and workshop.*

**Charlie Lakin** introduced his concluding remarks for this symposium session by noting that the contributions of William Furse (a self-advocate and former resident of Triform Camphill Community) to the meeting stood as a testament to what people with developmental disabilities can achieve. He then reflected on the symposium discussion noting that there was one strand of discussion about whether Camphill is actually a service provider and another strand [in the context of Camphill’s relation to government] about whether Camphill can get more public funding to provide services. His view is that:

*More public funding for Camphill entails a primary obligation to service delivery and to people with disabilities - as opposed to the original Camphill mission of living in community as a social alternative with a secondary mission of helping people with disabilities.*

Dr. Lakin also predicted that regulatory investigation in the future will be much more focused on the things that people with disabilities say they want.

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## PART III: KEY CHALLENGES: DISCUSSION AND RECOMMENDATIONS

Symposium participants gathered in four groups to discuss and offer recommendations for Camphill to meet key challenges. The topics for the groups were:

- 1) Quality and self-determination in the Camphill context.
- 2) Creating a culture of service.
- 3) Community and community-building.
- 4) Exchange between Camphill and the mainstream service delivery system: ways of connecting.

The group reports are summarized below.

### **Quality and Self-Determination in the Camphill Context**

Quality and self-determination intersect, but they are not the same; self-determination is a means to get quality. With regard to self-determination, there are existing processes in Camphill communities by which people with disabilities are enabled to express what they want. In Camphill Village Copake, for example, a state-funded group of lawyer-advocates visits the Village every year and meets individually with each resident who is disabled to ask about how the resident's life is and whether he or she desires any changes. From these meetings come requests to which the Village must respond. In Triform Camphill Community, there is a "Birthday Meeting" for each resident with disabilities. Family, friends, co-workers and others who know the birthday celebrant well join him or her to talk together about how the past year has been and what should happen in the coming year for him or her.

Challenges to self-determination in the Camphill context include: Having the ability and making the effort to expose the people with disabilities to other ways of living and activities that are not available in the Camphill communities; the resources to

*Quality and self-determination intersect, but they are not the same. Self-determination is a means to get quality.*

broaden the options of the residents with disabilities; and the philosophical questions about the tradeoff between individual aspirations and intentional community. An important question about self-determination in the Camphill context is: Who gets to decide that the tradeoff is fair? An essential step for Camphill with regard to self-determination and quality is to include people with disabilities in the governance structures (the Boards, both the individual community boards and the trustees of the Camphill Association of North America).



*An important question about self-determination in the Camphill context is who gets to decide whether the tradeoff between individual aspirations and the purpose of intentional community is fair?*

With regard to quality, which extends beyond self-determination, the family-style living in Camphill communities contributes to knowing each other and the development of real relationships in a way that the shift work organization of the mainstream service

delivery system cannot replicate. However, to improve and sustain quality in Camphill care and service, independent monitoring is helpful. Some Camphill communities have invited teams to come into the communities for a week and share their observations, which was seen as helpful. In one example, the Pennsylvania state agency that oversees services for people with developmental disabilities has a process of independent monitoring (not connected to funding) that involves consumers in asking others how their lives are, and the annual visits to Camphill Village Copake by the New York Mental Health Legal Services organization is another example.

Continuity and depth of relationships are Camphill's strength in providing high-quality service and a high quality of life for people with disabilities. However, the Camphill model can be limiting. Camphill could provide a wider range of options for residents with disabilities and expand into the outer world by connecting with local people, encouraging them to come into the communities and residents to go out to stay with them for short or long periods, helping people who have moved out of a community to maintain a connection, and connecting with the local self-advocacy efforts.

## **Creating a Culture of Service**

A culture of service has to be for everybody — people with disabilities, direct care staff, therapists, administrators. It has to start with the interests and values of the other person and work from strengths. In order to help direct care workers achieve mastery, their development needs to be considered and worked on as much as the development of people with disabilities. The administrative relationship to direct care workers is mirrored in the caregiver relationship with people with disabilities.

In the mainstream service delivery system, direct care workers are disenfranchised and at the bottom of a social/economic hierarchy, which often results in low self-esteem and poor care. In Camphill communities, there are good relationships between care providers and people with disabilities. An important question for Camphill's culture of service is: What are the ways to identify and train young people to do human interaction and achieve mastery of self so that co-workers don't get in the way of the development of people with disabilities? There may be a common interest between Camphill and people in the field of management and organizational behavior who study organizations that successfully empower their "frontline" workers to define and deliver service that fulfills the organizational mission and promotes employee satisfaction.

One example of success in creating a culture of service comes from Camphill Village Kimberton Hills, where the concept of a “third corner of the triangle” was used. Specifically, an Environmental Initiative of the village brings together volunteers from outside the village (AmeriCorps, students, and others) and people with disabilities from in the village to work on projects to improve the local watershed — in the process, developing and deepening their relationships and fostering mutual development.

*A culture of service has to be for everybody - people with disabilities, direct care staff, therapists, administrators.*

When the issue of recruiting young co-workers to Camphill communities is addressed from this perspective of relationship and mutual development - as opposed to “service” — a new recruitment message emerges. For example, recruitment advertisements for Camphill might say: “Would you like to enter a relationship with people with disabilities and *move* through them?” In this message, who has power in a relationship is turned around to ask how young co-workers can develop powerful relationships. Another recruitment message, one that emphasizes that opportunity for the young person to develop mastery, might say: “You will be mentored into a career that will enable you to work with people with special needs and all kinds of people in community living situations.”

*We must learn to recognize ourselves as curative teachers in such a way that we are not only the guides, but simultaneously also the guided ones; not only the teachers, but at the same moment also the pupils.*

DR. KARL KOENIG

Exchange programs for Camphill co-workers and mainstream service delivery staff might reinforce the sense that there is a kind of work and career that spans both settings and that people in each setting can learn from the people in the other about the culture of service and development of everybody.

## **Community and Community-Building**

Essential elements of community and community-building are: (1) They do not entail hierarchical structures; (2) Community is constant reinvention - similar events have different outcomes in different moments; (3) Community has an identity and boundaries so that it is possible to know what is part of the community and what is not. Also, in intentional communities, the “third corner of the triangle” represents a purpose, function and goal that the communities have for their existence, such as taking care of someone with AIDS.

A service community taking care of people does not necessarily diminish the value of the people cared for when they are obviously in need. But it is important to avoid the pitfall in service of making the “recipients” dependent. The purpose and value of a “third-corner task” is that it enables people with disabilities to participate on an equal footing in something of importance to the community. In addition to a third-corner task, communities need capacities for social art to allow people to enter into relationships.

*Community is constant reinvention - similar events have different outcomes in different moments.*

Clear identity and boundaries around a community have advantages and disadvantages. Clear boundaries are an advantage for sustaining purpose, vision and commitment over time and for this, a guardian for the community to know its boundaries is important. Boundaries around a community create a greater or lesser ability for a community to be joined and to attract new members. Learning how to give away community members so that they can belong to other places is one of the challenges for communities with a clearly defined identity and boundaries. Camphill has experience with all these issues and could serve as a resource for service agencies trying to “get more communal.”

### **Exchange Between Camphill and the “Mainstream” System and Ways of Connecting**

Connections for Camphill begin with recognizing natural and needed allies. One definition of these allies is “People who want to learn, teach, sustain, and expand ways of assisting people to live lives of choice in communities in which they receive love, respect, and opportunities to grow as human beings.” Within this large circle of potential allies, there are concentric rings, beginning inside with local government, local providers, the local community and local self-advocacy groups and moving outward to state government, the state provider community, and statewide advocacy and self-advocacy groups. Outward still farther are national political connections, including the national government and national organizations with values similar to Camphill’s, international organizations with similar values, and theme-related communities, which may be local, state, national or international in scope. Related communities might be focused on co-housing, intentional community living and organic farming.

*Camphill’s natural and needed allies are people who want to learn, teach, sustain, and expand ways of assisting people to live lives of choice in communities in which they receive love, respect, and opportunities to grow as human beings.*

Camphill alliances have two different purposes: (1) To work together in learning, teaching and advocacy and (2) To extend the opportunities available to the residents of Camphill communities who are disabled. Methods of promoting alliances and working together include:

- ◆ Exchange visits of Camphill co-workers and mainstream service providers;
- ◆ Camphill communication to others about Camphill via video, websites, and written materials;
- ◆ Camphill acting as host of meeting of groups within the circle of allies and potential allies, including state and national gathering of ARC's (formerly Associations of Retarded Children/Citizens), state government quality assurance people and experts on developmental disabilities;
- ◆ Development of training and education material for direct care workers and their supervisors in the mainstream service delivery system that draw from Camphill's learning and strengths;
- ◆ Camphill participation in meetings that affect the ability of the whole circle to realize a shared mission;
- ◆ Camphill openness to being studied, written about, and filmed by others;
- ◆ Opening Camphill village events and activities to others in the circle of allies and reaching out to invite their participation;
- ◆ Sharing resources, space and expertise with individuals and organizations from the communities surrounding Camphill communities in ways that bring people into the villages to establish relationships with the residents who are disabled (e.g., providing garden space and assistance);
- ◆ Bringing outside consultants and reviewers into Camphill communities and offering the assistance of Camphill co-workers to review and consult with mainstream service providers.

These are only some of the possible ways for Camphill to connect with its potential allies. Camphill needs to brainstorm others and, more important, to invest in exchange efforts financially by committing people to the work of exchange as well as physical and other resources. Recognizing that the group of experienced Camphill people who are best able to undertake exchange efforts is small, and that they already have multiple responsibilities and commitments, Camphill should call on "friends" to go places to listen and communicate about Camphill.

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## PART IV: NEXT STEPS

In the concluding session of the symposium, the recommendations of the four groups that discussed quality and self-determination, creating a culture of service, community and community-building, and exchange between Camphill and the mainstream service delivery system were combined, producing a set of recommendations for Camphill's next steps. These included:

1. **Report** on the symposium dialogue.
2. **Disseminate** the lessons from Camphill to the people working in the field of developmental disabilities and the lessons of the broader field among the Camphill places.
3. **Connect locally** - activities for Camphill and local service system people to undertake jointly.
4. **Self-advocacy groups:** Re-evaluate Camphill's commitment to self-determination; connect with self-advocacy groups; and invite people with disabilities onto the governing boards of the Camphill communities and the Board of the Camphill Association of North America.
5. **Use Camphill friends and Board members** to make connections and be a Camphill presence in meetings and other events for the field of developmental disabilities when Camphill people cannot participate.
6. **Invite visits** to Camphill places by people from the broader field, including for peer reviews, and visits to "mainstream" service delivery sites by Camphill people for the same purpose.
7. **Develop research projects** that would test the application of Camphill knowledge and practices to "mainstream" service delivery.
8. **Sponsor a conference or symposium** in a Camphill place that would bring mainstream and Camphill people together and increase Camphill's visibility in the broader field; host meetings of mainstream people; and/or simply provide meeting space to mainstream groups. Suggested purposes/topics include:

- ◆ a gathering of “young fellows” in the field (a generation not as aware of or knowledgeable about Camphill as the now-middle-aged generation);
  - ◆ community-building;
  - ◆ the developments in the field of organizational behavior and management that can inform Camphill’s structure, governance, accountability, and ways of making the organizations “flatter” and the essential work of direct care more rewarding/developmentally enhancing; and
  - ◆ a retreat for the New York State “quality assurance people.”
9. **Develop a symposium on empowering direct care staff** in cooperation with experts on management and organizational behavior in service organizations.
  10. **Offer internships** in Camphill places to people from “faith-based” organizations - such as college chaplains - to enable them to study and learn from the Camphill ways of supporting working with vocation or calling;
  11. **Inform the symposium participants** about achievements in the future that have been encouraged by the symposium or inspired by similar ideas.

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## The Camphill Communities Of North America

### **Camphill Special School ~ Beaver Run (Children)**

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### **Camphill Village, U.S.A., Inc. ~ Copake (Adults)**

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Phone: 610-935-0300  
Fax: 610-935-8896  
E-Mail: [information@camphillkimberton.org](mailto:information@camphillkimberton.org)  
Website: [www.camphillkimberton.org](http://www.camphillkimberton.org)

### **Camphill Village Minnesota (Adults)**

15136 Celtic Drive  
Sauk Centre, MN 56378  
Phone: 320-732-6365  
Fax: 320-732-3204  
E-Mail: [cvmn@rea-alp.com](mailto:cvmn@rea-alp.com)  
Website: [www.camphillvillage-minnesota.org](http://www.camphillvillage-minnesota.org)

### **Camphill Communities Ontario (Adults)**

7841 4<sup>th</sup> Line  
Angus, Ontario L0M 1B1 Canada  
Phone: 705-424-5363  
Fax: 705-424-1854  
E-Mail: [info@camphill.on.ca](mailto:info@camphill.on.ca)  
Website: [www.camphill.on.ca](http://www.camphill.on.ca)

### **Camphill Soltane (Young Adults)**

224 Nantmeal Road  
Glenmoore, PA 19343  
Phone: 610-469-0933  
Fax: 610-469-1054  
E-Mail: [info@camphillsoltane.org](mailto:info@camphillsoltane.org)  
Website: [www.camphillsoltane.org](http://www.camphillsoltane.org)

### **Triform Camphill Community (Young Adults)**

20 Triform Road  
Hudson, NY 12534  
Phone: 518-851-9320  
Fax: 518-851-2864  
E-Mail: [info@triformcamphill.org](mailto:info@triformcamphill.org)  
Website: [www.triformcamphill.org](http://www.triformcamphill.org)

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## Supporting Camphill in North America

### **Camphill Association of North America**

c/o Triform Camphill Community  
20 Triform Road  
Hudson, NY 12534  
Phone: 518-851-3260 Fax: 518-851-3257  
E-Mail: [info@camphill.org](mailto:info@camphill.org)  
Website: [www.camphill.org](http://www.camphill.org)

### **Camphill Foundation**

P. O. Box 290 ~ Pughtown Road  
Kimberton, PA 19422  
Phone: 610-935-0200  
Fax: 610-935-4985  
E-Mail: [Hfitz@camphillfdn.org](mailto:Hfitz@camphillfdn.org)  
Website: [www.camphill.org](http://www.camphill.org)

### **Camphill Recruitment Office**

c/o Triform Camphill Community  
20 Triform Road  
Hudson, NY 12534  
Phone: 518-851-3260 Fax: 518-851-3257  
E-Mail: [recruitcamphill@taconic.net](mailto:recruitcamphill@taconic.net)  
Website: [www.coworker@camphill.org](http://www.coworker@camphill.org)

### **Camphill Residents Trust**

P. O. Box 222 ~ Pughtown Road  
Kimberton, PA 19422  
Phone: 610-935-0200  
Fax: 610-935-4985  
E-Mail: [camphilltrust@aol.com](mailto:camphilltrust@aol.com)

The official registration and financial information of the Camphill Foundation may be obtained from the PA Dept. of State by calling, toll free (in PA), 1-800-732-0999. Registration does not imply endorsement.

DeenDayal Disabled Rehabilitation Scheme: Under the scheme financial assistance is provided to NGOs for providing various services to Persons with Disabilities, like special schools, vocational training centres, community based rehabilitation, pre-school and early intervention etc. Assistance to Disabled Persons for Purchase / fitting of Aids and Appliances (ADIP): The Scheme aims at helping the disabled persons by bringing suitable, durable, scientifically-manufactured, modern, standard aids and appliances within their reach. National Fellowship for Students with Disabilities (RGMF). The major issues with collection of data and measuring disability are: Difficult to define disability. Coverage: Different purposes require different disability data. Developmental disability is a diverse group of chronic conditions that are due to mental or physical impairments that arise before adulthood. Developmental disabilities cause individuals living with them many difficulties in certain areas of life, especially in "language, mobility, learning, self-help, and independent living". Developmental disabilities can be detected early on and persist throughout an individual's lifespan. Developmental disability that affects all areas of a child's development is People with intellectual disabilities usually have very limited health literacy, and health providers have a responsibility to find ways to help them make appropriate use of services (Reference Michael Michael 2008; Reference Raynor and Theo Raynor 2012). Reference Raynor and Theo Raynor & Theo (2012) have suggested that there are three aspects to health literacy. Introductions are important. Clinicians normally begin by introducing themselves to the patient with a welcoming handshake and making eye contact. The way the patient responds to this is the beginning of an assessment of their confidence, communication skills and mental state.