

1993 TASH COMMUNITY LIVING GATHERING

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This Community
honors our learning
and the living memory
of

Cory Moore

whose gentle outrage
and
unwavering conviction
gave us
leadership
inspiration
and
direction
as we continue our struggle for
Diverse
Inclusive
Community Living
for all.

Welcome to the Community Living Gathering at the TASH Conference November, 1993!!!!

by Judith A. Snow & Margie Diekmann

Right after an exciting presentation from Jonathan Kozol, a curious group of 150 people gathered in the Williford C room to begin the Community Living Gathering. Many looked puzzled while others looked intrigued as each participant was encouraged to pick up a rock from the beaches of Oregon to symbolize their membership in this community, to decorate their name tag with stars and other stickers, to pick up a trinket such as a dried leaf from New Hampshire or a plastic hot dog from Wisconson, and to take a seat under a balloon or a blown up hammer, saxophone, crayon etc.—Whatever could be about to happen here???!

Soon the Gathering was opened with an energetic welcome from Marsha Forest, a brief history of how we got here by Jay Klein and Judith Snow, co-chairpersons of the Community Living Committee, and - at long last - an explanation of the unfolding process from Jack Pearpoint. (A written explanation of Open Space Technology is included in this book.) Soon the participants were milling about creatively setting their own agendas for two and a half days of intensive shared learning and teaching about inclusive community living. People with every different interest in the subject were soon organized into intensive discussion groups —— some located under the balloons, and some taking advantage of other spaces and events in the TASH Conference.

In this book you will find the shared record of the discussions and learnings that took place at our Community Living Gathering. For those of us who were there its a reminder of what we learned and of the friendship that we shared. For others who may read this book we hope that you find it both informative and an invitation to join us in 94.

Happy Reading!!

ADAPT/Activism/Self-Advocacy

Free Our Brothers! Free Our Sisters! Free our People Now!!!

Chanting fills the halls of congress, the doorways blocked by wheelchairs, and the streets of cities across America. People formerly incarcerated in nursing homes and state schools, people historically relegated to segregated settings and denied power over their own lives have come together to <u>demand</u> their civil, legal, and human rights. To <u>demand</u> an end to institutional incarceration, to <u>demand</u> the right to live in community with their families and friends.

In partnership with family members, friends and other allies, persons with disabilities are increasingly joining ADAPT (American Disabled for Attendant Programs Today) to create a powerful presence and a strong unified voice for change. this Disability rights activism, coming for people with disabilities themselves, is a complement to the inclusion efforts that are occurring will around the world on a person by person basis. While an individual circle assists someone to establish a home and life and connections in the community, ADAPT works to accomplish the social justice that results in more accessible communities and the supports to assist individuals.

Not only is ADAPT the epitome of self-advocacy, but it is a model for inclusion. In fact, while other human service and advice groups struggle with attracting and retaining multicultural members, ADAPT is visibly diverse in terms of age, disability, gender, race and ethnic heritage. This diversity, in strong numbers, is testimony to the empowerment people feel as ADAPT members and that ADAPT is responsive to their needs and successful in its actions.

Even so, as a growing organization with minimal structure and maximum sharing of power, there are still lots of "growth opportunities" left. In some locales state ADAPT groups are still learning to be as inclusive as the national actions are where persons with developmental disabilities are concerned. While current focus on adequate personal assistance includes the availability of assistance for cognitive needs, it is not a well publicized concept. "Cognitive accessibility" is still an emerging issue which continues to require advocacy and increased understanding. because Adept's focus prior to the Americans with Disabilities Act was accessible transportation, a few people within and many outside the movement still associate it with only physical disabilities. Personal Assistance has been the issue to clearly establish that ADAPT is for everyone.

Since ADAPT is completely run by persons with disabilities, persons with no (discernible) disabilities wonder if they can be included --- if they have a place? The answer is a resounding <u>YES!</u> They can learn, assist, provide input, get

arrested and cheer ADAPT efforts toward the goal of one community accessible and welcoming of us all.

For any of us and all of us who consider ourselves disability activists, we now need to look at building bridges with other activist groups who also are fighting discrimination of one sort or another. Working with groups in the civil rights, feminist, gay and lesbian, older, racial, and multicultural arenas, we can all learn from one another and assist each other as allies with a common agenda - an end to discrimination and an accepting, hospitable community.

There are still many more places where people are segregated than included. Group homes, workshops, special education centers and self-contained classes are only a step away from institutions and nursing homes. Those of us still connected to or working in systems as well as in advocacy can and should do whatever we are able to help all persons learn their rights, that they have choices, that they can always say NO, and where to go to connect with others of a like mind. Those of us who are paid to assist persons with disabilities can not "empower" them - we can only assist, guide, support and share knowledge with them as they risk, act and take power for themselves.

ADAPT is one of the vehicles open to persons with disabilities where they can choose to experience the dignity of risk, where they can choose to act on their own agenda and where they have an undeniable opportunity to experience their own power. Can you imagine the feeling of power a woman in a sip-and-puff controlled wheelchair who isn't able to move any part of her body voluntarily, who needs personal assistance nearly twenty-four hours a day, and who suddenly realizes that when she stops her chair in a doorway, she stops traffic? Her mere breath becomes the sole factor controlling the comings and goings of the multitudes who would otherwise seem to hurriedly pass her by or ignore her altogether. Self-advocacy? Maybe. Activism?

Yes. Empowerment? Definitely!

Assuring Quality

Present: Rebecca Shuman, Jan Lampman, Judith Gran, Virginia Chancelleire, Carol Reckard, Robert Holland

From 2:00 pm-3:00 pm on Friday, November 4, 1993 we posed the following questions and made the following observations.

Questions:

There are people who are living in their own homes, living with people that they chose to live with. They chose people who support them. What is our role in assuring that that person is OK. In the absence of system licensing, inspection, etc. does that leave a void in terms of assuring that people are being served?

As we organize the way that people are supported, how do we assure that we are serving people in the way that they want to be supported?

How do the people we serve learn what quality is and how can they be supported in obtaining quality?

If "we" are responsible for assuring quality, how do we do that without compromising peoples ability to receive services in a variety of ways?

What happens when people refuse needed services, i.e. medical services?

How do you hold a system accountable for people who do not have a voice or someone who cares about them with a voice?

Solutions

Monitoring: Relationship with the person being served is important when monitoring for quality P

Without choices people can not be assured quality. "If you can't walk away, how can you be sure that you can get what you want."

There is no substitute for having people who truly care about you making sure that you get what you need and want.

Organizational values need to change to a point where the people served are valued and listened to.

When people can't speak, we look to people who know them i.e. family, friends, neighbors.

Topic: Building Attitudes for Inclusion

Participants: Nancy Sullivan, Becky Johnson, Cindy Alberding, Sue Marshall, Jan Holmes, Stacey Holmes

Main Points:

- * Our values and attitudes evolve from a lifetime of unique and powerful experiences. In the quest to impact attitudes, one must first understand the experiences and values that shaped the belief.
- The intolerance of differences underpins all of the beliefs and attitudes that interfere with the achievement of inclusion, not only for people with disabilities but for any individual or group who is different. This intolerance is molded from ignorance which breeds fear and prejudice.
- * As long as people are segregated, ignorance, fear and prejudice will abound. The first step to exploding this intolerance is to establish opportunities in which people can interact with those who are different in their everyday lives. Therefore integration of people with disabilities into the world is critical in changing attitudes.
- * Integration is a necessary precursor to inclusion; however, the achievement of integration does not equate inclusion.
- * Our values and attitudes are shaped from our experiences from the time we are born--they are well grounded in our minds and hearts at a very early age. Those we ran with as kids are those we value as adults. As integration occurs at a young age--i.e. in day care programs and early school years, kids are growing up learning that people with disabilities are friends and neighbors, not people to be feared and shunned. There is great hope that, in communities where integration exists, there will be no need for this discussion in future generations.

- One of the keys to changing attitudes in the future is for integration. While federal laws and an energetic movement has brought us a new wave of integration and inclusion, there are still many, many communities in which these concepts are not embraced. Our challenge in changing attitudes is to work for inclusion throughout the country, because inclusion will lead to changing attitudes.
- We can learn from Mr. Kozol. We must "go down to where people are." That means getting to know people who embrace attitudes of fear and prejudice. We are much more apt to be influenced in our attitudes and beliefs by people who value us rather than be those who find us obnoxious because of the way we believe. Perhaps one of the roles for people without families, friends and advocates of people with disabilities is to get to know those who are intolerant, to strive to understand why they feel that way, to show that we value others, regardless of their differences in attitude and to work to change those attitudes of intolerance from a base of love and understanding rather than anger and outrage.
- Sometimes, even when an intolerant person does have a positive personal interaction with a person with disabilities it does not break down the stereotypes--individuals may be seen as exceptions to the rule. One experience doesn't necessarily get to the core of the prejudice.
- * Embracing the basic value of freedom is a consistent characteristic of people who value others--not just personal freedom, but freedom for everyone. Another common theme is a sense of outrage at injustice. People who grew up together can be very different in relation to these values. Perhaps if we can identify why some people embrace these values, it will help us to understand why others don't.
- Just as in programming, our tendency in life is to correct negative behavior rather than praise positive behavior. We don't do a very good job praising people who value others. Why can't we say, "I really appreciate the way you interact with me," or "it's great to meet someone who values people so much," or "thanks for caring!" Positive responses can shape societal values.

- No one can change attitudes about people with disabilities better than people with disabilities.
- * We can change attitudes by how we respond to people that think that we're special for working with "those people." We tend to smile and go on about our business. We should say, it isn't a special talent—it's all in whether you look at the person or at the disability.
- If we really value diversity, then we have to value those who are bigoted too, don't we? We can't expect others to value us unless we value them. There is an Indian saying that Lee Graber tells that talks about the importance of our attitudes: I went out early in the morning looking for enemies, that day I found no friends. I went early in the morning looking for friends, that day I found no enemies.
- * While we do need to value those with attitudes foreign to ours, there are lines that are not okay to cross--we cannot tolerate people hurting others or denying them rights and opportunities.
- * People with disabilities don't always value each other. There seems to be a cast system within the disability community with people who have developmental disabilities often being step children when involved with those whose disabilities are only physical. How do we build attitudes of valuing people with disabilities in Everyone?
- * We must ask ourselves if we really walk the walk or merely talk the talk. Do we in our personal lives have friends and acquaintances with disabilities. Are there people we value and with whom we interact that are not our clients or family members? A powerful way of changing attitudes is by modeling friendship. People in a neighborhood pub will view a person with disabilities very differently when they are sitting with a staff person helping them learn to order than when they are sitting with friends having a beer.
- * When we see prejudice, our typical response is to walk away. Perhaps we feel guilty later, but we believe it isn't socially acceptable to correct others. It is! It's okay to say that what you are saying isn't right. It's not okay for you to hurt that person. If we aren't part of the solution, we are part of the problem. If we remain silent because we are afraid of how others will view

- us, we are part of the problem. We have a responsibility to stop injustice and must recognize that there is also a price. Are we willing to risk?
- * We create the image of how others see us. There are many ways we can change our image—ways to act, ways to dress—most people don't understand the importance of the image that we create.
- We have taught people to be afraid of people with disabilities by trying to group integrate. Taking people for outings in groups of 4 or 5 or more says a lot to the public--these people can't be by themselves, I shouldn't talk to them, they need a staff person to control them, there must be reason they need to be grouped together, they are happier together. We have created attitudes and must take responsibility for that.
- * Labels change. Many young parents won't use the label mental retardation, they use cognitively disabled. All it is just another way to do smoke and mirrors. The point is to be able to identify and have pride in yourself.
- * Labels we use for people send messages that it's okay for others to categorize people too. Why not use labels like Jim, Sally, and Todd rather than MR, CP and autistic.
- * We shouldn't get angry when people don't take the big leaps we want them to take. It's good when people make any movement toward acceptance regardless of how small it is. We must learn to celebrate even small steps in the right direction.
- * We must grow in numbers and build our strength—when we are stronger than those who do not value others, we will change attitudes. When it is socially acceptable to value others, peer pressure will change attitudes.
- * We must also work on changing attitudes of families who fear community or inclusive services. Families of people in institutions have safety as their primary concern. People must come to understand that no one can guarantee safety for anyone. People certainly aren't safe in the institution. We can't assure our own safety much less the safety of people with disabilities. We can work to minimize risk. But we need to address the fallacy that people are safe in institutions.

Building Circles

The Waldorf room was packed with people interested in circle building. Marsha Forest, Judith Snow and Jack Pearpoint each presented a personal view of their thoughts on circle building. Judith spoke of the dream she had as a child of being a truck driver. Is this unrealistic for a person who uses a wheelchair and has mobility only in her thumb or is this dream the seed of Judith's search for a life of travel, adventure, bringing the goods to places all over the globe and seeking meaning.

Marsha spoke of the need for people to make time to build circles. This is not a gimmick or trick but a lifelong commitment to one's friends. All three of the presenters agreed that you start in the third circle — i.e. the circle where people do things together and work together towards the outcome of a real and true circle of friends.

The question arose of should we say Circle of Friends or Circles of Support. Judith favored circles of support while Marsha and Jack have found in their work with children that children prefer the term circle of friends as they have said, "circles of support is too sophisticated for us kids."

Jack walked the group through the four circle exercise and then showed a series of overheads sent to him by a family in Ohio who had attended a TASH session on circle building a few years ago. Their discovery was that their own adult circles were fairly scarce and that they needed to rebuild their own lives as well as building new circles for their son.

Many in the group found the ideas practical and useful especially

- build from the outside in
- circles of support lead to a circle of friends
- ask for what you really want not for what you think you can get
- circles are a journey not a destination

We asked for a kaleidoscope of words that summed up what people had learned or felt about the session. Just a few words that sum up the spirit.

- passion
- like a light bulb going off
- hope
- practical ideas
- hard work
- love.....

Opening To The Participation Of People Who Do Not Speak

Judith Snow and Jay Klein - facilitators 11/5/93

All participants went around the room and discussed their views and listened to each other express their ideas on how to open the doors for all people, even those who do not have spoken communication. People need to be heard and ways need to be figured out to invite people who do not have a spoken means of communication to become involved in issues such as TASH committees, TASH boards other boards that effect their homes and communities, such as agency boards etc.

These are some of the statements that were expressed by the participants: Judith-we are clearly ignoring the communication that is already there.

Mark-Ontario- I work with people who don't speak and I find that these people are much more vulnerable than others. An example is a lady I know who is not verbal whose husband is making decisions for her and these are not always good decisions. People who are not speaking are falling through the cracks all the time.

Joan - Denver/ I am a parent. I have had a daughter in the school system for 15 years and being in the school system. People make decisions for her all the time and then they wonder why they get bit when they don't listen to what she is saying. People don't listen to her. Why is it that people say to individuals that cannot speak, "if you cant tell me what you want then I know what you want",

Susan - Colorado - how do we teach people to have patient to give people the opportunity to speak. How do we begin to build a value base for people .We have to change our behavior!

Parent - Colorado. My son is 21 years old - Alex is assertive, and a leader, yet because he does not have conversational speech it has been perceived by others that he does not understand, which leads to behaviors. We have learned to pay a lot closer attention to his speech. He should be in leadership roles ,but because he does not have conversational speech he is not allowed these opportunities.

Patty - Denver/ I have examined human rights abuses. I am listening very closely and want to learn from others, I want to listen to those that cannot speak.

Amy - WI - I think we need to be bringing more people into conferences etc. And a lot of time it is hard for people to participate. We need to get more imput from people, those who do not have spoken language.

Chuck - MA - I serve people who are verbal and who do not have spoken communication and through f/c they have shown much more than they did and I am working with the staff on choices, listening etc., Typically people who are less verbal are perceived to be less capable

Missouri- director of program / I work with people who are mostly non verbal. There is a lack of information

Available for people.

Jay - New Hampshire part of reason Judith and I have been having this conversation around this topics that we have a five year grant to address issues of communication by all people and we have struggled with this as we have seen groups or agencies which say "lets include all people who don't speak and yet people never get to be fully included. It is tokenism. We want to figure out how can it not be tokenism anymore, such as having that token person on boards etc. Included in group is people with labels. What we are looking at is finding people to build circles of support around these issues of communication. We have thought about having someone in circles in support and find someone interested and have them go out as a team.

Vicki - AK - I want to help people with communication through advocacy with others. I have started a support group at the agency that I get services from.

Pam - AK - working with an agency in which assisting people to determine

their communication modes is very important..

Chuck - MA - I am having a hard time of making a leap from the everyday issues to an organization response. Even when we put people being in roles as consultants, we still feel that we make the informed choice. In terms of TASH and its role we can look at it in respect of the whole role. This community living consultation role lends itself to becoming a model.

Example of a young man who learned to write found out about past abuse and now we have established trust. All the things that he is relating is now communicating.

We have to be able to listen effectively so that we end up having "happy accidents".

All behavior plans in our agency are tied to our support plans. It is interesting to me "how important the history is". It is important to know the history and to explore and find out and figure that part out.

The general discussion was the participants work in supporting people who were not using words in and/or examining the lack of their control or unavailability of them to be heard. Because of this concern, Jay and Judith have written a grant which has been awarded, that will develop a resource of consultants to assist in assuring that people are heard.

Some of the questions that brought about this process are:

Why aren't people using communication as a form of listening to people.

And there is the ongoing question of why should we bother?

There must be people out there who are not using words which effects the whole issue is of diversity and at this point we are not allowing people to participate based on the fact that they do not have verbal communication. We say such things as come sit on our board, etc. Then don't examine a way for them to communicate on that board.

Judith wants to experiment over the next couple of years in figuring out the link that will enable people to participate. Fully, there will be at the TASH board meeting the community living tract bringing up the issues of fostering communication for all people.

Things will change when we have people control their lives.

The grant will establish a mentor ship to get consumer participation. We have to get past the point of saying ____ is not capable. Because he does not have spoken communication.

Judith stated three ideas that she wanted to work on throughout the grant process.

- 1 We have to turn the question concerning spoken communication and have to listen.
- 2. We have to get ourselves to the point to be prepared to effectively communicate to those people that are being abused and we have to effectively communicate to the person that has experienced abuse to effectively use this. Process. Until then we are not ready to do anything meaningful.

3 Give people control of their lives

What can we do right now?

We have to start at the community level.

How do people get involved? When I look at the young man I am dealing with its like he doesn't trust us. Even those who can communicate aren't being heard. It is learning to listen. It is still a much bigger issue of control.

I would like to have said to staff if you are attempting to exert your extra control on a person then you are not listening.

What Jay and Judith would like for this grant is people who would like to be mentioned or be a mentor. Through TASH to develop a list of people who would like to be in a consulting role to assist in determining that all people communicate.

Write Jay a letter if you are interested in following or in being a part of this process.

Below Is A List Of People Who Want To Be Involved In This Process As A Consultant, Host, Etc.,

Vicki Oxford 900 North Levertt-Apart. 102 Fayetteville AR. 72701 Pam Biesiot 3 Valley View Bentonville Ar. 72712

Penny Ford 4200 E>Liff Denver Colorado 80222

Mark Mccormick > 196 Dufferin Avenue London Ontario..N6A 1K8

Carol Kraus 2917 Ding Street-Suite C-Jonesboro, AR.72401

Rainee Courtnage Joel Broszat Susie Walton All In Colorado - Send Information To This Address -U155 East Jewell Avenue #916 - Denver CO 80222

Chuck Howard - 110 Pleasant Street Malden. MA. 02148

Amy Lutzke Options In Community Living 22 North 2nd Street Madison WI. 53704

COMMITTEE LIVING COMMITTEE MEETING

Facilitators - Jay Klein & Judith Snow.

The group discussed how they felt about the process used this year in the Community Living Series tract. Ideas were generated by people who were present about looking at some other ways of devising the session, such as;

Bringing the who tract back together at the beginning and the end of the day

- Jack and Marsha doing a Path session
- Using the agency part of the Path process
- Using a newsletter format
- People commit to an open session at the beginning of the session
- Using a map so that agencies can talk to other agencies
- Pizza party

1. Introductions

People present See the sign-in list

- 2. Review Other Issues Add To The Agenda None Given
- 3. Discussion On Community Living Session As It Is Unfolding Several suggestions were given from the group such as
 - 1. Have four or five issues of Community Living Services tract
 - 2. Have Jack and Judith do a simple PATH process at the beginning
 - 3. Have the newsletter explain more about the opening session
- 4. On Friday AM have a gathering where people share they come from and where they are going (map)
 - 5. Could we have a gathering during this conference
 - Put information on message board
 - get word out to do a gathering for Saturday morning
 - 6. have people replace trinkets for trinkets
- 4. Judith discussed That TASH is listening and responding to the Community Living committee. Example; last year committee asked Jay and Judith to write a letter concerning the name of TASH. It was addressed by the board. It was addressed by the board. There are some forces that are working to move forward.
- 5. Brainstorming possible future projects including an evaluation of last years projects the
 - On behalf of the organization tie together with the organization
- The committee identify individuals who have an interest in something like TASH and ask them to work with tash and have TASH support these individuals in the ongoing activities of TASH.

- Have a computer bulletin board that expands for 12 months a year. Have a space for the community living section and to open it up for people. Have TASH assist with the long-distance phone calls to provide a means of giving people a way to communicate to TASH.

The committeé needs to offer assistance and technical assistance. We can influence this now. There doesn't seem to be as much information on community living as on education.

 Make certain that there is more information in the media on community living

 Get stories out about people living in the community/ people who are getting supported

 Develop a project to get people in newsletter, letter in local papers and to pushing and implementing more information

Things That Need To Be Done:

We need to write an article about this community living committee - Judith will do this.

Identifying

This group will be the core group of the committee
Judith will be the new chairperson with Jay Co-chair person
A teleconference will be held with group to finish discussion of the issues.
Pictures were taken to identify committee members

Sharing of information: by a committee member The world as it is needs those who will love it long enough to change it with what they have, where they are and you're dammed right that's idealistic, no apology. When idealism goes into the trash as junk mail we are finished.

Community Supported Living Arrangements (CSLA)

Participants: Carol Beatty - Columbia, Maryland

Margie Diekmann - Edgewater, Maryland Janice Lampman - Midland, Michigan

Myrna Bartlett
Nancy Krumel
Rebecca Shuman
"

Deborah Siegel - Pontiac, Michigan

Douglas Riggs - New Jersey

Main Points: What is CSLA? CSLA is a federally funded pilot project, through Medicaid, that is currently being tried in eight states including Michigan and Maryland. It provides funds to help people with developmental disabilities live in the community with whatever supports they need to do so. The intention is that the decisions regarding what supports are provided will be made by the individual receiving services, not the service system.

How are Michigan and Maryland implementing the grants?
Michigan has a state governing board that has made decisions regarding how monies will be expended. Michigan funnels the money through its community mental health boards, each of which has it own local CSLA governing board. Maryland also has a state governing board, but does not funnel money through local governmental agencies.

How do we avoid Medicaid bureaucracy and keep the spirit of the grant? Discussion was centered around fears that when you receive federal money you eventually have to prostitute yourself. Is it worth it to serve a greater number of people with money that may eventually have too many regulations attached to it? Some people feel that we must live with the bureaucracy but effect the regulatory

process as much as possible. Currently in New Jersey new standards are being written and "right thinkers" are being invited to participate in the development of these standards.

Other discussion took place regarding how each state is providing quality assurance, how support and choice are assured, and fears about how the size of the program might jeopardize its integrity.

Home Ownership

Participants:

Kim turner, Jan Lampman, Julie McGill, Tara Asai, Jennifer Auletta, Janet Holmes, Bonnie, Shultz, Russ Spearman, Joe Wykowski, Virginia Harmon, Jay Klein

Resources:

Brookfield, WI - Residential Clearinghouse Waukesha County 1201 Pearol St. Waukesha Wi 53186 (Has information regarding housing options for people with developmental disabilities)

David Reece Fund 220 W. Main Midland MI 48640 (Non Profit Housing Corp.) Purchases homes for people with disabilities. People choose their own home and live there as long as they like.

Virginia Harmon, Michigan Dept. of Mental Health, 320 S. Walnut, Lansing, MI 48913

Is a great contact person in Michigan regarding housing for people with disabilities, also knows about HUD

Jay Klein, Institute on Disability, Heidelberg-Harris Building, 125 Technology Dr., Durham, NH 03824

HUD, State Housing Authorities, Local Community government programs, Community Development Block Grant (HUD), Section 8 (HUD), National Affordable Housing Act

Issue:

When people own the home do they lose services i.e. Medicaid, For many programs people need to be homeless. Federal programs often are too cumbersome.

Strategies:

Need to look at what you want your outcome to be and then make yourself system savvy.

Look for a friendly Housing Authority and work with them.

Community reinvestment Act(every bank must have a plan for community reinvestment)

Federal Home Loan Bank loans to non profits who focus on people with very low income.

MI started a revolving fund for repairs, etc.

Federal Register - NOFA

Habitat for Humanity.

Comprehensive Housing Affordability Strategy is a document that each housing authority must write for the Feds. It is important that we have input into that CHAS.

Idaho is working on getting waivers and is working with ICF/MR to convert to supporting people in their home

In Michigan DMH has worked with Housing authority to develop programs that can be used by people or non-profits

In the past we have taught Housing authorities that people with disabilities want and need to live in congregate housing (ICF/MR). We now have to go back and try to re-teach. The issue is poverty and isolation not disability.

There is a federal regulation which allows people on SSI to hold accounts for special purposes without losing their benefits. New Hampshire P and A is looking at this regulation and will issue a legal opinion.

If Medicaid money really goes to the individual, then it should be considered as part of income for purposes of getting a home loan. This has been done successfully in some places.

Develop non-profits or look for existing non-profits that wish to purchase housing for people or help people purchase housing for themselves.

Become involved in the policy making - get on boards, work with current housing corporations, work with local housing development authority, develop relationships with the people who can help figure out the issues.

Topic: HOMOPHOBIA

Main Points: There appear to be many issues surrounding gays, lesbians, bisexuals and transgender (GLBT) individuals who work with people who need support. Some of these issues pertain to personal sexuality, others' perceptions about sexuality, and others' perceptions about a GLBT individual's legitimacy when working with people who need personal care/support. Some GLBT individuals literally feel compelled to have "witnesses" when doing personal/private care.

Much of the conservative element in our culture believe that GLBT individuals are "recruiters," again projecting there own personal tendency to recruit.

Being an "out" individual can have consequences. Co-workers and family members, who use community supports, may not want GLBT individuals to work with children or individuals perceived as being vulnerable to abuse.

Coming out is a process, not a single event. Individuals have different comfort levels pertaining to being "out." Homophobia breeds fear among GLBT individuals surrounding how far to "come out."

There are a lot of parallels between GLBT rights and the rights of persons with disabilities. These are civil rights issues. TASH talks about social justice. GLBT individuals closely "relate" to these same issues pertaining discrimination. TASH works closely with school issues, yet schools appear to be a source of a significant amount of homophobia.

Fear is directly related to ignorance. As our culture looks at the disabled and can't see past their disability, our culture looks at GLBT individuals and can't see past sexuality. As persons with disabilities must not be defined by their disability, GLBT individuals must not be defined by this single aspect of their personality.

The pink triangle was used in a Circle of Friends session as a symbol of segregation. GLBT individuals often use this as a symbol of community, understanding that in many ways we are segregated, and not always by choice. We grow up in a "straight" world lacking GLBT individuals role models. We ban together as a group for protection. and a sense of community. Being GLBT is not about sex.

There are also GLBT individuals who come to life with disabilities. There are many issues surrounding finding community supports for these people who want social contact.

Suggestions/Recommendations

One clear issue is the lack, at this conference, for educational and support opportunities specifically tailored to increase awareness about GLBT issues. We strongly recommend that TASH committees talk with Karen who address human rights in a manner. that "includes" every group. We ask that TASH acknowledge the legitimacy of our civil rights. Clearly we, as a group, need to propose sessions. Possible topics:

Confronting homophobia/perceptions
Issues relating to care giving and sexuality
Supporting GLBT students in schools
Finding community supports for GLBT individuals disabled
Civil rights is civil rights: How disability rights relate to racism, sexism, homophobia etc..

Ethics

Service Delivery

Sexuality for persons with disabilities

**** There was not a GLBT individual with a disability as a part of this group. It is essential to include these individuals in our planning.

TOPIC: L'ARCHE AND OTHER FORMS OF INTENTIONAL COMMUNITY

PARTICIPANTS:

MARK MCCORMICK, MAURA NAGLE, KAREN GUTSHALL, KATHIE BOYLE, DENNIS MILLER, PETER BAZUR-LEIDY, DOUG RIGGS, AMY LUTSKE, DEBORAH SEIGEL, and JUDITH VOSS

MAIN POINTS:

- * THE CALL TO COMMUNITY
- * WHAT WE BELIEVE COMMUNITY TO BE
- * WHAT EXAMPLES ARE AVAILABLE

THE CALL TO COMMUNITY

We have lost that feeling of being a member of a village. The challenge of connecting others to community life has called us to examine our own personal relationship to community. We have concerns for our future and the future of our children.

Many of us have experienced some event or events in our lives which has challenged our connection to and understanding of community. These events have also sparked a deep desire to belong, to be a part of a community of people committed to sharing life with and caring for one another.

We feel that choice is essential for everyone. What is right for one person is not necessarily right for another at that time and possibly never. Also, how one person approaches the process of making decisions in their life will greatly differ from another person. Either way, individual's choices to participate or not participate in community must be respected.

WHAT WE BELIEVE COMMUNITY TO BE

Sharing, caring, and living close to others.

Open and available to all its members regardless of race, income or disability.

Inclusive, diverse, fluid, alive, loving, and supportive.

We have the ability to generate an emergent community.

Community is not social service systems which ironically tend to isolate people from their social life.

It can be intentionally established, or emerge from a group who share something in common like a neighborhood or church.

Community is sometimes seen as the place we live and/or the people we choose to share our lives with.

Community is celebrating together and finding hospitality and reciprocity..

Community is sharing your life with others, and still maintaining your own autonomy.

Community is the interdependence of people who are somehow committed to being present in each others lives. Many of us feel the need to have a more people in our life who are not transient.

Community is unconditionally being loved.

WHAT EXAMPLES ARE AVAILABLE

Camphill communities based on the philosophy of Rudolf Steiner.

Many intentional religious communities based on Christianity, Sufism, Judaism etc.

There was a gathering this summer in Olympia, WA of people from many different Intentional Communities throughout the world. In Israel there are Kibbutz.

This Community Living Gathering is a microcosmic intentional community.

Circles of Support are intentional communities built up around a single individual.

L"ARCHE

L'Arche was started in France through the efforts of Jean Vanier. The philosophy of L'Arche originally was based on the beatitudes of Christ from the gospel of Matthew. L'Arche was developed in response to the alienation and indignity society imposes upon people who have mental and physical disabilities.

There exist a network of L'Arche communities throughout the United States, Canada, and Europe.

A member of our group, Mark McCormick, has been working toward developing a L'Arche community in Canada. During the past two years, Mark has been part of a Faith and Light group set up to develop a L'Arche community which works with a regional L'Arche advisory board. Mark shared some of his observations regarding L'Arche.

Some of Mark's observations included: L'Arche grew out of a spiritual center. Not all members of the L'Arche communities have religious affiliations. L'Arche is open to including those who are vulnerable. All L'Arche community members are committed to supporting one another and helping each other to feel loved and included. Those feelings of healing and trust do not spring up over night, but take time and committment. L'Arche invites people to visit and if a person is inclined to become more involved, L'Arche usually asks that people make a five (5) year commitment. L'Arche communities receive government funding. In a town of Stratford, Canada there is an established L'Arche community living in 5 homes. Each home has 3-4 people with disabilities living in them. L'Arche is open to individuals or married couples. L'Arche involves sharing life, meals, celebrations with others. L'Arche is based on the idea of people making committment to share their life and stand with people who have being marginalized by society. L'Arche is people choosing to be together.

Moving From Group Homes to Community

Present: Patti Scott, Margie Dickmann, Christine Nardi Mack, Julie McGill, Kathie Boyle, Karen Gutshall, Dennis Miller, Tara Asai, Jan Lampman, Peter Bazur-Leidy, Kathleen DeGenaro, Katherine Lesnick, Susan Dickson, Carol Kraus, Chuck Howard

Issues: When people have intense needs it is often easier for people who are concerned about money to think about group living as opposed to each person making individual housing choices.

Often is takes more time than we would prefer. It is essential, however, that it happen one person at a time.

We need to be prepared to allow people to experiment with where and how they will live. How many of us still live in the same house and with the same person that we lived in when we first left our parents home.

We often assume that people need more paid support than they recieve. Often very important support can be unpaid and is not the only important aspect to living in the community, relationships are also very important. Should community connections come first or should the place come first Regardless of which comes first, it is essential that we support people in developing relationships with neighbors, church, community.

How the process can work: The first step is for the person to indicate a desire to live in their own home. Sometimes the process moves quickly and sometimes it can take a number of years. Flexibility with regard to funding and support is essential. It is important to have the support and assistance of people who know and care about the person. It is important to ensure that people know what the options really are. It is also important that we listen to people and help them discover what they really want.

It is important to explore the generic resources in your community. Often there are ways to access affordable housing, help people find house mates, access social and recreational opportunities, etc.

A good story: Kathie and Dennis were introduced and for three years went out to movies, hiking, etc. Along the way they became friends and eventually decided to move in to an apartment together. Dennis lived in a group home during the development of their friendship. During those years he occasionally dropped little hints like "you really could use a man around here" After three years, Kathie decided that Dennis was right. Now they share a house.

Out of System Experience

Participants: Patricia McBee, Rainee Courtnege, Gayle Brankin, Linda Ransom, Jocelyn Jones Walker, Connie Peterson, Tammy Franklin, Maura Nagle, Karen Zimbrich, Nancy Krumel, Cheryl Whiting Wright, Mark McCormick, Joel Broszat.

Issue: Being and doing in one's own community without State, Federal, Local dollars paying for and directing or providing a service. Assume there is no funding from any system and you have been isolated from others. How does one access community members and locate individuals who wish to make a personal commitment to support one particular person on a daily basis? What attracts someone to "person to person" involvement? How and where does one find these individuals?

Points:

- issue of test to enter college which exclude people from access to higher education.
- no test needed for continuing education.
- setting up mentors.
- not taking on the battle alone.
- idea of combining state and private funds to support a person.
- gathering of grass roots/parent groups attacking the problem.
- presently, the system rewards the squeaky wheel.
- this defeats the efforts to join together.
- who will we access to help and support people when there is no more money/churches.
- developing community outside the system.
- real people, real lives, struggle toward fulfilling dreams.
- dealing with the issue of being physically distant from those we support.
- people first-joining together to be heard-boycotting.
- mentors/advocates/citizen advocates.
- communities working for everyone.
- getting the services which people need.
- brick walls/concerns about agencies facilitating person centered planning.
- what is working?
- parents having the say in supports being provided.
- peers for children in school.
- communication between agencies.
- what if we wake up and there is no funding??!!!

Path - An Introduction

PATH is an exciting a colorful futures planning tool developed by Jack Pearpoint, John O'Brien and Marsha Forest for building inclusive communities, school, families. It is a creative problem solving tool that looks at possible positive futures.

A packed room watched Jack and Marsha set up for a PATH session. Jack put up the large white sheets of paper with the PATH arrow. People were welcomed and an ending time was negotiated. Marsha and Jack explained that if people are running in and out during a PATH session it just doesn't work.

A welcoming atmosphere was set. The group had short buzz sessions - meeting and greeting one another and figuring out the key elements of PATH

- Personal
- Team facilitation
- Graphic recording
- A willing team to solve a problem

PATH is a journey. The group saw two videos to set the vision -- Kids Belong Together and Greg's High School Celebration. They then saw a brand new shown for the first time 5 minute PATH video that is a preview of a longer training tape available late Nov.

Marsha and Jack walked the group through the 8 steps of PATH as described in the book.

- Touching the Dream The North Star
- Sensing the Goal
- Grounding in the NOW.
- Identifying People to Enroll
- Recognizing ways to build Strength.
- Charting Action for the Next Few Months
- Planning the next month's work
- Committing to the First Step

Marsha and Jack stressed the power and potency of PATH to solve complex and messy issues and that facilitation of PATH takes vision, values and skills. It was a lively session that ended with the kaleidoscope wheel evaluation. These five words summed up the session.

- excellent
- awesome
- scary
- colorful
- powerful

Real Jobs: Converting Sheltered Workshops to Community Employment

Participants:

Tara Asai Margie Diekmann Chuck Howard Julie Racino Carolyn Shelton

Main Points Projects to Close Workshops

Carolyn Shelton shared the McKinney, Texas Project This project is a four year project to close the sheltered workshop that is currently serving 45 people. They have a DD Council Grant, \$140,000 per year to do systems change and find individuals jobs they want.

In the first year of the project they identified people across the nation, who have done best practices They called these people together to learn from them. It was sort of like a think tank. Michael Callahan facilitated this think tank meeting.

Other interesting things they're doing is they interviewed the individuals in the workshop as to what their dreams for jobs were. The dreams were recorded on video for future reference. They are also setting the project up for information replication.

Margie Diekmann shared The Arc of Prince George's County in Maryland project to close their sheltered workshop. This project is a two year DD Council funded project (\$60,000 per year) to find individuals jobs, and/or interesting things they want to do during the day, and eliminate the need for the workshop.

Tara Asai shared how they are working towards closing their workshop which has been in existence for 30 years.

We also identified some strategies.

- Develop contacts and relationships with the business community.
- Create business advisory board, invite business people to sit on your board or significant committee
- Hire individuals that are employed in the workshop to do other jobs in the organization..data entry was a suggestion. Idea is to learn what it is like employ individuals as an employer and to show business community that your business does this too.

Job sharing

-Accepted practice in many businesses - Find a variation that fits the individual needs, ex. maybe 2 individuals and a job coach "share" a job.

Hook up with Entrepreneurs who may need new employees

Talk with bank loan officers to get them to refer entrepreneurs to your organization

DEED (Department of Economic Development) which makes small business loans to refer them to you

Other agencies that make small business loans

Listen to individuals, ask them what kind of job they want Utilize individual planning tools, Futures Planning, Career Vision Planning or variations that work **PREFACE**: In the never ending, always renewing search for community, five adventurers set out. This is our story.

TOPIC: <u>RETRIEVING DEBORAH'S LUGGAGE OR CREATING CULTURAL INCLUSION THROUGH COMMUNITY</u>

PARTICIPANTS: Deborah Siegel, Gabriel Siegel, Maura Nagle, Judith Voss, and Doug Riggs

THE JOURNEY:

Ultimately, the bottom line always ends up: To be or not to be. We decided not two bes, but four bees. They were bagels, breadsticks, binkys and brothers. It all began around 6:30 Friday night. I had arrived to the meeting a bit late, but was attempting to make up for my tardiness with a bagel, cream cheese, and lox, as well as some breadsticks I had stuffed into my coat pocket. I soon discovered that although food was high on everyone's attention list, it was not at the top. Apparently, Deborah's husband wasn't going to make it to Chicago tonight, and as a result, she needed to retrieve her luggage from the Holiday Inn cross town. We conferred on this issue briefly and decided that accompanying her to pick up the luggage was the best solution.

On the way to the Holiday Inn, our cabby, Yan, assisted us with finding a wonderful Indian restaurant to eat in. We sat down to vegetarian thali and mattar panier. We talked of the big picture, the macrocosm. We spoke to one another of the global village and how social consciousness is raised. Maybe I haven't been focusing our energy in the right place, (one of our team said). Maybe the real focus needs to be social activism. Or maybe we should be focusing on assisting one another through rites of passage, like 40th birthdays.

Each of us sat their eating and enjoying some very fine Indian food, yet mildly anxious of the strong calling we were feeling inside. We started to share some of our more personal experiences of multi-cultural and sub-cultural communities. One person shared an experience she had when she was thirteen. She had spent time living on a commune in the early seventies near Santa Barbara as part of a school project. Two other members of our group had attended gatherings of the Rainbow Tribe. But nothing more complemented the evening as did the realization that Maura and Deborah had both lived on a kibbutz, near the Golan Heights, in 1975.

Awed in the synchronicity of the night, our sinuses swimming in a sea of spices, we moved on to the last and most exciting tale of the evening. One member had lived in an intentional community for many years. She has always had this thing about not excluding people. At the birth of her first son 14 members of her community attended the birthing. Along with the OB nurse, labor coach, and an osteopath, she had extended an invitation to her women's group. Her women's group, feeling quite compelled decided to invite the other women from their community. These women, not wishing to be perceived as "sexist" invited the men of the community as well, assuming that they would refuse. Alas, they showed up as well...... and sat by her side on the bed.

We got Gabriel into his snowsuit and headed out into the winter storm. Lawrence, our cabby, and Doug sat up front discussing the various ways to clear the oily film off of the windshield. The Holiday Inn knight in shining armor brought the luggage to the trunk of the cab. On the way back to our hotel, Gabriel lost his binky, but fortunately we recovered it. Lawrence, hit a slick spot in the road. Shaken by images of bald tires and icy roads, Judith started to sing the first song she could think of. I Yi Yi. Yes, it was the frito bandito song, just perfect for the occasion.

Back at the hotel, we got Deborah and Gabriel and their luggage settled into a room with a fold down bed and worked on how Deborah and Gabriel were going to get home to Michigan. Remember that this journey all started with Deborah's husband not making it to Chicago. We thought of asking everyone at the conference if they could offer a ride to Michigan, but without a car seat for Gabriel, (he's very short), well it just wouldn't work out. Deborah felt much more comfortable with the train idea. It was pretty much settled. All except for finding a train schedule.

Then Deborah's mom called. Her brother was passing through Chicago the next day and wanted to see her and Gabriel. We had walked with Deborah far enough that night, she was going to have to tackle this one on her own. We left her knowing somehow that God, in all Her wisdom would take good care of our companions.

When parents look like a "problem" to us.

(Editor's Notes: I listened and typed so this was our discussion. I didn't catch everyone's names for which I apologize; but I have left in your comments. Chuck)

Barb Mck - struggles with issues of independence and inclusion - and attitudes of parents who see their disabled child differently from their other children

A person-experiencing issues with parents who have adopted children with disabilities who

Virginia - lives with a family

Janet - ""parent from hell"" - looking for another "parent from hell"

Judy - Philadelphia lawyer - represents parents in inclusion cases with school districts - and represents people who live or have lived in institutions but who do not have active family. This puts her in the role of being an "advocate from hell" - helped start a community collaborative that was intended to develop a plan to create more inclusive services; but ran into holy alliance of providers, parents and administrators have put parents on pedestal in opposition to supported employment rather that sheltered workshops

A parent - there are parents who have seen their children hurt and want to prevent future pain through obstruction to inclusion and thinks that it is the job of parents who believe in inclusion to help those other parents to move on

Carolyn - professional and parent of three children with mental retardation (15 - 27 yrs) - has trouble keeping roles separate - has trouble letting go to allow for greater independence for children - each has different aspirations

Mark - from Minnesota - half of board that start an agency that developed group homes that they are currently trying to disband so that they can shift to an individualized approach - experiencing conflict with parents fearful of change - sees parents as important some Quality Assurance protection is provided even if parents are from hell, but it is necessary to identify whose interests are being served

Beth - parent of 2 kids - does not want to move to Philly - helps parents of kids with disabilities- also a "parent from hell" - wants to see what others want to do about parents from hell

Ann - parent - wants to look at issues now before her daughter gets there so that she can be a better parent - would like to viewed as parent not from hell

Brenda - parent from Illinois - son is 19 - struggling to see his choices as his and be supportive but has to deal with consequences of her son's choices

Rhonda - from Illinois - liked title - parent of 12 yr. old daughter with disabilities - not sure about how she will deal with choices in the future - empowerment used as way of not delivering services -

Gail - from Ill. - professional who has met families through their efforts for inclusive education but their success has brought acceptance - feels that she has contributed to a new struggle arising to achieve acceptance

Michael - works on transition projects in Mich. - has trouble getting families involved

Antonia- came to room because it looked fun

Jay - frustrated by belief that most parents want what is best fro their kids but since parents have been forced to be case managers they are left without opportunity to just be parents - frustrated by not knowing how to help parents

Amy - from Mich. - sometimes wants to strangle parents - sees them as barriers - dependency on disabilities checks for family is obstacle for person to move to own home - looking for way to facilitate without interfering

Mike - from NY state - agency is developing bridge building component - works with people whose families are not active through exclusion across time - afraid to put parents together - concerned

Pam - has 8 yr. old daughter - works with self-advocacy group - wants best for her daughter - but not sure about how to promote independence

Pam - Arkansas - provides family support services - wants to learn from families

John - CA provides supported living services - finds paradox of parents challenging

Judith - frustration in context that belief that parent/child relationship is bottom line but does not believe that parent always wants what's best - allows situations to be created that are not always best - grew up occasionally disagreeing with parents

and needing to creatively take chances - but since she needs personal supports her opportunities to make mistakes are rare

Question: How do you convince an 80 yr. old parent that it is time to let child move from home? Many parents do not want children to move from institutions regardless of evidence to contrary - Why should parent have to be convinced that change is good?

Barb - Problems with labels being thrown around - thinks focus should be on individual - how do we facilitate change for people - tired of being at the mercy of the system

Anecdote: about parent who considered guardianship when daughter wanted home of her own but never pursued it daughter now has own apartment with beeper - mother thinks that it is the most wonderful thing to happen in either of their lives -

How do we let parents be parents without pushing them into or out of role case manager - fine line to let relationship with each child be special

If parent is forced into making decision or allowing child to make decision they are punished by having to deal with unfortunate consequences without support so when parent balks at future decisions the child begins to object to intrusion in his/her life -

Why do parents move beyond the issues of their own children? why are parents punished for having continued to care for their children so they work to maintain the status quo rather than gamble on change - guilt - brainwashing -

JK frustration: spends time with parents who work for progressive inclusive experiences and spends time with parents whose children are still in institutions anecdote: about parent who wanted to buy house that daughter lived in (a group home) you are telling me that I have to stop thinking about others and now can think about only her daughter - When any one is speaking for anyone else it is suspect

V - lived in institution for 13 yrs then moved to group home then wanted to have his own home his own life - group home staff told him he was crazy - Whose choice is it?

Trust - reputation — with it comes freedom - important to establish trust with at least one person in child's life

Frustration - impatience - things take time - some things have to be left behind rather than blocking the doing of things in the present - friends are those who enable you to do things even in the face of parent opposition -

Lack of information - having to own what seemed like the right decision in the context of the values of an earlier generation -

Nightmare - what will happen in the future when I am not here to protect - maybe circle is an answer - acknowledgment of nightmares is critical -

Systems don't tolerate mistakes - errors in judgment as learning tools - there has to be recognition of rights -

We need a farm team that has recognized the value of nightmares.

In Closing ...

We opened with balloons and trinkets and curiosity—— and closed with cake and music and friendship and learning.

Next year's Community Living Gathering will be better because we have learned how to use the potential of Open Space Technology in even more powerful ways than we used it this year. But nothing will ever take away from the experience of being the first group of people to bring this creative learning and relating to the TASH Conference. We hope that all who read this collection can share in all that we have learned and catch the flavor of our relaxed and energetic community.

See you at TASH in 1994.

the real end...

The computer gods worked well - and at 12:30 on Saturday a.m.

We headed to Jay's room to toast our success as our laser printer produced the master for the 6:00 a.m. printer deadline. The technology gods wrecked havoc - or took the weekend off.

Printer failed.

Kinko's with a great cabbie.

3:45 a.m. - master done..

And we outclassed Oprah...???

Jack Pearpoint Joe Wykowski Jay Klein the exhausted final editors



The COMMUNITY LIVING GATHERING TASH Nov. 4-6, 1993

The Learning Marketplace

Our Learning Marketplace is a tool to maximize talent and diversity of a community. The idea is built on the work of many - but most recently, Harrison Owen, and his new book, *Open Space Technology* (Abbott Publishing, 7808 River Falls Drive, Potomac, MD 20854). The concept is simple and operates quickly and efficiently to create an agenda for a diverse group - to meet the priority needs of each participant - as far as is possible.

It truly empowers the participants. They create the agenda. They decide

what they want to do - and then do it.

There are four Principles and one law of open space technology:

* Whoever comes is the right people.

* Whatever happens is the only thing that could have.

* Whenever it starts is the right time.

* When it is over it is over.

There is one additional guideline: The Law of Two Feet (or Four Wheels). Put simply, if a session is not meeting your needs, use your feet/wheels and find a place that does. Move on with respect - but meet YOUR needs.

The proceedings begin with a huge blank wall chart. A second sheet has post-it notes on a simple matrix with possible meeting places and time slots.

The group gathers in front of the blank chart. An invitation will be announced. Anyone who feels passion for an issue and is willing to take some responsibility, will be asked to "convene" a session. Each convenor posts a short title on a piece of paper, signs it, picks a post-it note with a time a place - then announces and posts their session on the large wall chart. (Convenors could have a question they would like to discuss or simply want to share stories. They are NOT required to make a "presentation". Convenors merely arrange the group discussion.) In 15 minutes, the former blank wall will brim with your community's interests.

Next we will open the **Learning Marketplace**. Everyone is invited to "sign up" for whatever they like. In cases of overlap or time conflict, individuals are encouraged to negotiate for mergers, time changes, etc.

In about 30 minutes, the hubbub of the marketplace will dwindle. Individuals will join their first choice groups and go to work.

The Community gathers each morning and evening to review, adjust and continue their selected learning choices.

One additional guideline. Each group will provide a brief report of their discussions to share with the whole community in a new book we will publish on the last day of the Gathering.

Jack Pearpoint



The Community Living Gathering Chicago TASH Nov. 4-6, 1993 The Learning Marketplace

To: Convenors in the Community Living Gathering

Nov. 4, 1993

We want everyone in our learning community to benefit from your group's thinking and learning. Our plan is to bring together the proceedings of our work in a publication entitled *The Community Gathering, TASH 1993* which will be printed on Saturday for distribution Saturday at 2:00 p.m. (if the technology gods cooperate).

Please insure that a report of your group's learning gets typed on a computer disk and handed to Jack or Jay by 4:00 PM Friday latest (the earlier the better). You can produce the report yourself, or get someone from your group to do it.

Please make your report clear, specific & informative. Include these headings:

Topic:

Participants:

Main Points:

(try not to exceed 3 pages)

Discussion (optional):

Write to be informative and useful to people who were not at your meeting. Imagine reading a report on a discussion of an important topic and ask yourself: what would I want to know? Recognize that you would be very frustrated by vague generalities and grateful for a concrete, concise summary of what a group learned.

Past experience suggests that the whole community will benefit if we use the computer to prepare our text. [Typing beyond hunt and peck is not required. You don't need any familiarity with a computer. Jack and Jay will provide whatever computer help you need if others can't.]

Options for computer use:

* Use your own computer with <u>our</u> disk. Make sure the program you use can be "translated" easily before you begin.

* Mac Powerbooks will be available from participants - days and most evenings.

Please use our disks. Sign them in & out so we can anticipate "chapters".

Please use simple formatting. Whatever word processing program you use, unless it is Microsoft word for the Mac, save it as a "text only" file or an "ASCI II" file. (If this makes no sense, have someone explain it as you are introduced to the computer.)

Hand made graphics, on a 8.5" x 11" page, will enhance your reports. People who were not at the meeting will almost always need some text to refer to if graphics are to communicate to them. (If you think yours is a stand alone graphic, test by showing it to at least two people who weren't at your meeting and asking them to "read" the graphic aloud.) Additionally, please test the *readability* of your graphic by Xeroxing a copy (some colors show up poorly).

Please hand in your disk as soon as possible - by 4:00 p.m. Friday latest. If you are NOT submitting a report, please inform Jack so we do not hold the press for your contribution.



GUIDELINES FOR GROUPS for Convenors

- 1. Before you start, negotiate a time to finish so that your meeting comes to a recognized conclusion where everyone leaves together (not in dribs and drabs).
- 2. It's a good idea to start by brainstorming your subject, recording ALL contributions and then deciding which of these that you want to cover.
- 3. Remember to give everyone a chance to contribute. Some people do not find it as easy as others to speak up and may need to be asked if they want to make any particular points.
- 4. Some variation on the "talking stick" theme (whoever has the stick is the speaker) can be a very useful way of guarding against everyone trying to speak at the same time and ensuring that no one person hogs your session.
- 5. Never allow anyone to leave your group with unresolved anger or hurt. People can agree to differ without a sustained feeling of ill will.
- 6. Writing up your discussion should not be delegated entirely to one person. Every individual member of your group has a responsibility to take some ownership in recording what has taken place. It is therefore a good idea to allow for some time at the end of your session, when everyone jots down three or four points which they feel were important and want included in your group's final document. These can be collected by a scribe or scribes who will take on the role of writing a paper. This way it is more likely to be a reflection of your group's thinking and not of just one or two people. Suggested report length 2-3 pages.
- 7. If you particularly liked someone's contribution during your meeting, make a point of approaching them afterwards to let them know.
- 8. Remember, if you discover that this particular group meeting turns out to be of no real interest to you after all, don't stay all through it and complain afterwards, just apply the law of two feet or four wheels.
- 9. Disks must be returned to Jack or Jay. Please give it to them directly to ensure your report is included in the final book.