

PLANNING TOGETHER

**A Handbook For People Who Want
To Improve Home and Family Supports**

prepared for

**The Governor's Council for the Handicapped and Gifted
Fairbanks, Alaska**

by

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Without the help and concern of many people, the process that is described in PLANNING TOGETHER would never have happened. Dot Truran and Laurie Goggin began work in January 1980 laying the ground work that has continued until the present. Laurie spent many hours and days working on the logistical arrangements for both the Phase I process and the Search Conference. David Sibbet brought his boundless energy, thirst for learning about new things and his wonderful graphics to the Search Conference and helped us all "SEE what we mean" as we worked together to better understand home and family support. Although we will not acknowledge them all by name, we owe the greatest thanks to those people who participated in the evaluation phase of this process and in the search conference. This includes the people who came from all across the Doyon region and those people from other parts of Alaska. We thank you for the things you taught us.

INTRODUCTION

Improving home and family supports offers the promise of better quality community life and poses major challenges in planning and implementation. This handbook defines a point of view on home and family support and describes the way citizens of Alaska's Doyon region laid a foundation for improvement. It is a guide for people who want to take constructive action on this important theme.

This handbook describes the theory and procedures behind what people in the Doyon region did between September and December 1982. It explains the how and why of beginning to make improvements in support to the people of a region. As a case study, it presents what we did as outsiders asked to design and implement a planning process. We don't claim that this is the only way to plan for improved home and family support. You will want to think about how to modify this process to fit your own circumstances.

The two stages we describe here are only the beginning of what we believe must be an ongoing process. Home and family support can't be improved once and for all by a package of written recommendations. Real improvement will take many people, learning together from a complex of related small and large constructive actions.

The handbook has two parts: description and commentary on the Doyon region process, and copies of the project's forms, procedures and reports. A companion volume, Thinking About Home and Family Support, includes a guide to the literature and some selected readings.

If you are most interested in what people in the Doyon region discovered and decided, the handbook will be less interesting to you than the records of the first two phases of their work (see Appendix A and Appendix B).

Plans can only be effective if there is a good fit between the way they are made, the set of problems they are intended to address, and the environment which surrounds them. Making purposeful choices of how to go about planning is the first step in improving support to people and their families. We hope you will read this handbook critically. See whether your experience and ideas fit with ours. Where things are different for you, you may want to make different choices than we did.

WHAT CAME BEFORE

Since its founding, the Governor's Council for the Handicapped and Gifted (GCHG) has promoted approaches to meeting the needs of people with handicaps which "...maximize individual potential, minimize institutionalization, and [are] provided in the least restrictive setting."* The Council has expanded this legislative intent into a set of service principles:**

- To the maximum extent possible, services should be directed at helping persons with disabilities develop their full potentials;
- To the maximum extent possible, persons should be able to remain in their own homes, in their own communities, avoiding costly and often emotionally painful institutionalization;
- Services provided should be specialized or adapted versions of services available to the general public.
- Services should be provided in the least restrictive environments, enabling persons with disabilities to live as normally as possible.

As GCHG notes in its 1982 Priorities for Legislation, these principles direct attention to the extent and quality of supports available to people and their families in their own homes.

Recognizing the priority of home and family support and realizing the importance of developing strategies that will work on a local and regional basis, in 1981 GCHG undertook a study of home support services focused on the

* Alaska Statutes 47.80.110.

** GCHG. 1982 Priorities for Legislation, p.1.

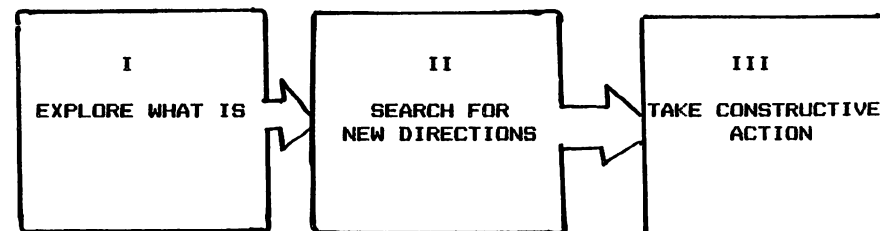
Doyon region. This study estimated the number and characteristics of people with handicaps in the region, collected consumer opinions about service needs, defined a range of support services, and identified gaps in service delivery. Based on this 1981 study,* GCHG decided to invest in the development of a plan to improve home support services focused, for purposes of demonstration, on the Doyon region.

As originally defined, this project called for the evaluation of home support services in the region by an outside team who would use a standard evaluation method to identify problems and, based on expert knowledge of the state of the art, write a plan for improving home and family support. Based on our sense of the problem, we negotiated with GCHG to shift the focus and style of the project to emphasize mutual learning among people who have a personal interest in improving the Doyon Region's home and family supports. GCHG's acceptance of this redefinition of the project led to the process described here.

 * GCHG. Home Support Services Study for Interior Alaska (Doyon Region). Phase I Report. Fairbanks! GCHG, August, 1982.

AN OVERVIEW OF THE PROCESS

This planning process is designed to provide people who have an interest in improving home and family support in the Doyon region with opportunities to learn together from one another's understanding of current realities and desirable futures. The process has three phases:



Each phase promotes five outcomes:

- Building a network of people from diverse backgrounds, organizational affiliations, and roles around the theme of improving home and family support.
- Developing a shared appreciation of the present state of home and family support and the trends that define the context for its future development.
- Creating shared images of desirable futures for home and family support.
- Defining and building support for a wide variety of constructive actions, large and small, which network members can undertake in their own situations to increase the chances of a desirable future for home and family support.
- Testing methods for learning and planning together that could be useful to people in other regions.

As designers and assistants in the process, we worked from an image that organized our effort. Our image was of developing patterns of relationships between people and

connections between experiences that would build a flexible intelligence focused on the theme of improving support to people and their families at home.

This image contains a distinction between data, information, and intelligence.* Data are bits of facts and ideas about a situation. Information happens when someone asks a question that organizes data into a pattern. Information is what-was and what-is. Intelligence is the capacity to ask questions that lead people to imagine and make changes in a situation based on the information that results. Intelligence is what-to-do and how-to-do-it; it grows from reflection on experience. Developing an intelligence network involves creating opportunities for people to have new experiences, reflect together on their meaning, and resolve to change their future experience together.

This image may seem abstract or farfetched but it contains the seed of what we attempted: to bring together a group of people with a common interest but no history of collaboration and provide them with chances to make new personal relationships, ask new questions, and discover new opportunities for action.

The first phase, in September, involved twenty two people interested in home and family support. Some live in the region; some live in other parts of Alaska. Some are service providers; some are state officials; some are consumers. They worked in five small teams to explore what-was and what-is in the region. GCHB staff identified agencies providing home support services. Each team worked for five days, visited several agencies and interviewed providers and consumers of home support services. Each day team members talked with one another and logged their impressions. At the end of the week the whole group prepared individual and group summaries of what they learned about the present status of home and family support in the region. On the basis of their summaries, they identified issues and opportunities for improvement.

* The information/intelligence distinction comes from Michel Chevalier, Position Statement, York Insurance Project, January 1982.

The second phase focused on a search for new directions. Thirty eight people, twelve of whom were involved in Phase I, met for two and a half days in December. They worked through a structured planning process to consider the present and future trends influencing home and family support, create images of more desirable futures, define strategies for improving home and family support, and decide on next steps for action.

The group in the Doyon region is beginning Phase III as this handbook is being written. As one outcome of Phase II, the GCHB is discussing ways to support the network developed in the first two phases.

Each phase of the process is linked to the next in two ways. The most important source of continuity is personal. About half of the people who worked together intensively in Phase I were active in Phase II, and a number of Phase II participants agreed to maintain contact with one another as they moved into Phase III. As a secondary link, Phase I and Phase II produced documents which were shared with participants and interested others. Phase I produced The Future of Home and Family Support in Alaska's Doyon Region (Appendix A) and Phase II resulted in Improving Home and Family Support in the Doyon Region (Appendix B).

Connections between the Doyon region's efforts and other parts of Alaska were made by including Alaskans from outside the region in the activities of each phase. This handbook provides another link.

Given the size of the region and the diversity of participants, scheduling and travel arrangements were complex and represent a major cost of this approach. Laurie Goggin, the GCHB staff person who managed this critical part of the project, describes her part in the process in Appendix C.

A POINT OF VIEW

Like anyone who wants to improve things by making a plan, we had to choose a design for planning. What we decided was based on our ideas about the nature of home and family support, our model of the kind of planning that would be likely to fit the problem of improving home and family support in the Doyon region, and what we took as given. These notions define the point of view from which we designed and assisted the process.

GIVENS

The Doyon planning process was designed in response to these constraints:

- We are outsiders. We have experience working with Alaska's developmental services and good relationships with some key people in the state. But we don't live in the Doyon region. This limits our knowledge of the varied patterns of everyday life for families and people with handicaps in the region, our ability to provide follow through, and thus our credibility as experts on the specifics of improving home and family support in the region.

- As of the beginning of the project there is no organized constituency within the region focused on improving home and family support. However, many people have this concern somewhere on their personal agenda. There are also people in the region and in the state who operate effective home and family supports and who are familiar with much of the "state of the art" outside Alaska.

- Taking a regional perspective on improving home and family support means dealing with a number of significant differences among the people who will need to be involved. Among these differences are those between people who live in Fairbanks and people who live in the bush, native people and non-native people, professional providers and consumers, contract providers and state officials, and representatives of different agencies and sponsoring organizations.

- The high cost of travel severely limits opportunities to meet face to face with the variety of people who have an important interest in improving home and family support. It's much easier for any planning process to involve people from Fairbanks than people from other parts of the region.

To manage these constraints, we decided to provide occasions for people to form a network around the theme of improving home and family support. We encouraged people to explore their own experience with others in the region. This meant using project resources to develop personal contacts among people who represent diverse interests in the theme. We designed project work settings and procedures with three questions in mind:

- Will this support people in actively sharing their ideas and interests around the theme?

- Will this confirm people as having important knowledge and skills?

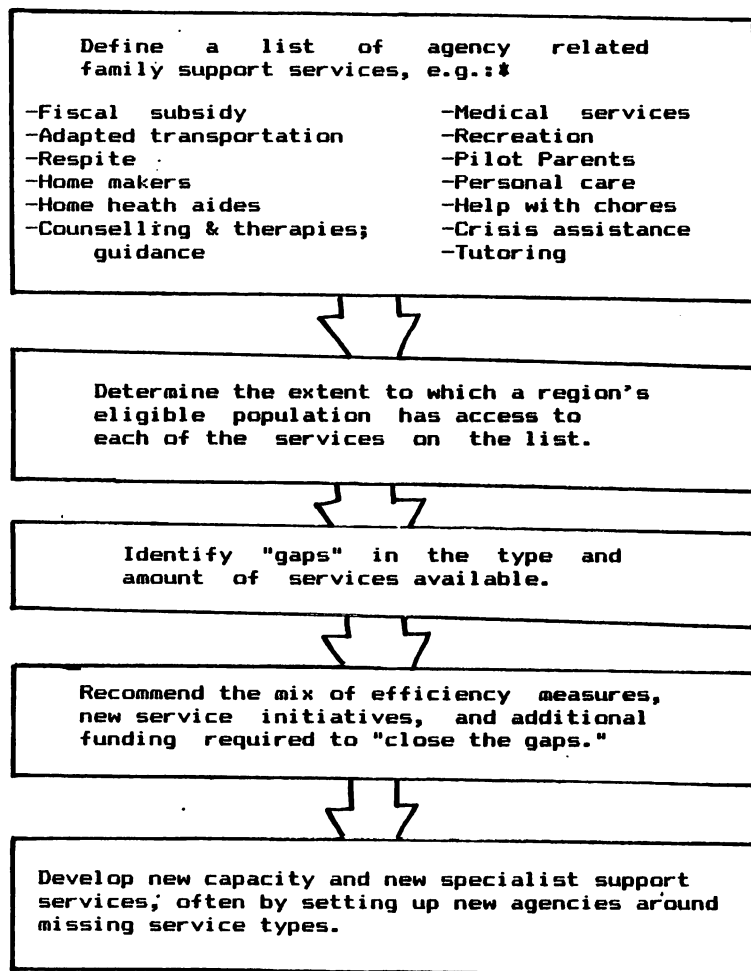
- Will this call on people to collaborate with one another?

We deemphasized our role as experts on what-to-do and how-to-do-it and offered ourselves as designers and managers of a learning process. We committed ourselves to learn along with interested people from the region and to share what we learned as we went.

To insure that several parts of the region were represented, GCHG staff worked long and hard to arrange visits to villages far from Fairbanks during Phase I and to bring people who live outside of Fairbanks to participate in Phase II. This was costly both in travel funds and in GCHG staff time, but all participants agree that the results justified the expenditure.

IDEAS ABOUT HOME & FAMILY SUPPORT

One common way to approach the problem of planning better home and family support looks like this:



* This list comes from M. Hogan & A. MacEachron, PEG: Plan Evaluation Guide. Toronto:NIMR, 1980, p.53.

This shopping list approach makes one kind of common sense: take inventory, decide what you need, then go and buy it. It has worked tolerably well in guiding the expansion of well defined service programs in times of economic growth for the human service sector. But its effectiveness depends on how much supporting a person at home is like going to buy groceries. If home support comes in well defined packages that can be bought for a good price, and if it is easy to get money into the correct budget categories, then a shopping list is plan enough, especially when there is money enough to put providers into business to offer the supports no one is presently selling.

We think there are four important features of effective home and family support that make the shopping list approach a poor choice as the first step in planning.

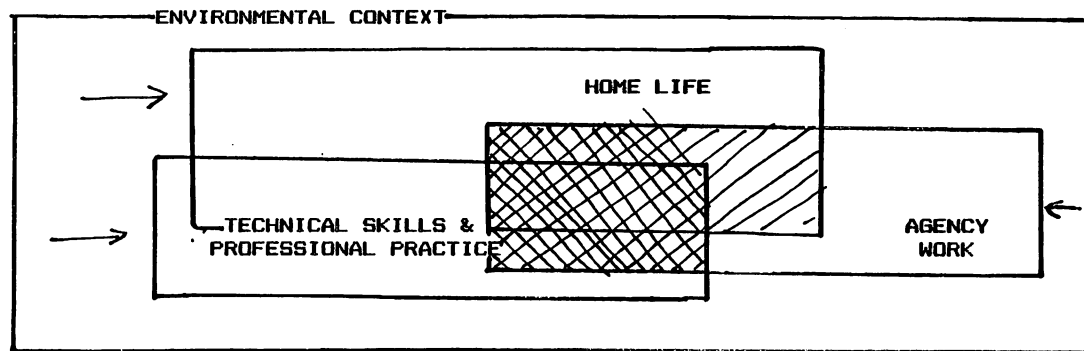
- It makes sense to us to define support from the point of view of the people being supported. As a person experiences it at home, support includes but is not the same as receiving a specialist support service.

- Many people speak of the effects of day or residential service practices as major influences on their ability to cope at home. Agency policies need to be set with an awareness of potential impact on home and family life. Changes in the hours and days a program is available can create or lessen strain on families; so can the extent to which agency practices influence a person's sense of power over her own life.

- Some parents of people with severe handicaps identify their estimate of the future capacity of the service system as central to their feeling of security and support. As one older mother said, "The recreation is good, and the respite program has been a blessing, but what eats me up inside is not knowing where my daughter would live if something happened to me."

- Investment of public funds in home and family support services is appropriate and cost beneficial. But there is a fundamental tension between the range of responses demanded by the changing needs of different home and family cultures and circumstances and the bureaucratic principle of organizing in terms of discrete, standardized, interchangeable parts. Home and family support services happen at the intersection of the personal world, world of technical/professional skills and knowledge, and

(because most support service workers are agency employees) the world of bureaucratic work. Each of these worlds is changing in response to the logic of its own development, changes in its immediate environment, and changes in the set of systems that make up the context for all three worlds. Family needs change as children are born, grow and leave home. Support workers have new options as research and practice develop new tools and techniques. Agency management feels the pressures of changing cultural values and economic circumstances just as a family does.



Spanning these boundaries effectively way takes ongoing action learning by the people who receive support, the people who give support, and the people who set working conditions for support providers. This complex situation imposes two conditions for efforts to improve home and family support:

- Planning should actively promote partnership among people who receive support, support workers, and managers at each level of the system. Partnership is, for obvious reasons, much easier to talk about than to achieve. For a beginning, the planning process itself should provide real opportunities to experience and negotiate the boundaries among these three diverse groups.

- Planning should recognize the need for the partners to continuously invent new ways to provide support. This implies planning on the basis of partial ignorance about how home and family support is best done. The shopping list of service packages creates a false sense of certainty.

- Home and family support isn't the province of any one organization. Many different agencies provide some support services. In fact, some individual families rely on more than one home support agency. And much home and family support comes from outside the organized service system. Extended family members, friends, some neighbors, church congregations, community organizations, and many other formal and informal groups provide support that cannot be purchased, even if it were affordable in dollars.

- Home and family support services and make major improvements if they can...

- ...increase ability to recognize informal support,

- ...assist informal helpers rather than supplanting them, and

- ...help people recognize the possibilities in informal support networks and organize them.

- The notion of coordinating home and family supports on a regional basis through an hierarchical system of controls can't fit the real situation. It makes much more sense to work on home and family support services as an inter-organizational domain.*

- Home and family support is broadly and inventively practiced throughout the region. People's folk knowledge contains much valuable intelligence. The stories of these efforts are not widely shared, so they are easily overlooked as a foundation for making improvements.

From this point of view, the shopping list approach has several important disadvantages:

- It frames the problem primarily in terms of improving agency related services, and emphasizes increasing the quantity of resources expended as the measure of progress. ("We need 2,321 more units of home health services at \$27.50 per unit.")

- It can lead people to assume that accidents of program implementation are givens. For example, the distinction between homemaker and home health aide services has far more to do with federal funding patterns of the 1960's and '70's than with sharply distinct family needs.

- It isolates the home and family support mission and assigns responsibility for this part of a family's need to specialist parts of a service system. ("We have a family support unit; they look after the parent's complaints.")

- It encourages people to see home and family support as a professional enterprise which may invite some degree of consumer participation on agency terms, but does not offer people with handicaps and their families a genuine partnership. ("Mrs. Smith, we're pleased to tell you that, according to accepted professional standards, your family is totally supported.")

- Because eligibility for service is established on the basis of statements about individual deficiency, this approach tends to narrow the focus of thinking about support to the remediation of defects in a person or, occasionally, a family. Strengths and potential resources in families or among kith and kin are hard to think about.

- It offers incentives for the development of distinct, specialist agencies. This may increase overhead costs and decrease options for managing stable or declining resources.

We wanted a way to plan improvements in home and family support that avoids some of the problems of the shopping list approach. So instead of accepting the narrowing down that goes with a predefined list of services, we decided to open up home and family support as a theme. And, instead of trying to design a hierarchical system that would provide rational overall coordination, we decided to begin development of an interorganizational domain through people's experience of project related activities.

THEME FOCUS

Instead of emphasizing "services", we asked people in the Doyon region to explore the broader theme of improving home and family support. This shift makes the planning process more ambiguous by reopening questions that are closed by a standard list of services. It puts a new frame around the "problem as given" and asks people to exchange experiences, questions, and ideals. Theme focus turns the definition of home and family support services from a given into a problem.

Theme focus makes room for new questions which allow anyone with an interest to learn from anyone else. Questions like these blur the distinction between experts and clients. Their answers are a rich source of ideas about what-to-do and how to do it.

- What range of experiences do people with handicaps and their families identify as supportive from their point of view? This question can be especially helpful if the answers aren't limited to what service workers do for them. Many useful supports have been invented by other family members or neighbors.

- Which service practices create strain for families? Are different families strained by different service activities?

- How do needs, preferences, and opportunities for informal support change with culture and geographic location?

- What are the bases for partnership between service providers and people with handicaps and their families? What are the alternatives to "clienthood"?

- How can service resources assist extended family members, neighborhood helping people, fellow church members, and other natural helpers to support people with handicaps and their immediate families?

Opening up these and other new questions creates opportunities for learning. It allows renegotiation of boundaries between providers and consumers and among providers. It can also cause anxiety among people who see an advantage in present boundaries and habitual patterns of thinking. Accordingly, the planning process needs to encourage the exchange of divergent perceptions and values without pressing for premature agreement and support collaborative efforts without demanding major reallocations of resources or subordination to external coordination authorities.

DEVELOPING A DOMAIN

The concept of a domain arises from the recognition that organizations as separate as a church congregation, a group residence, and a homemaker service are commonly concerned about the set of social problems which we have put under the theme of improved home and family support. Each organization in a domain is engaged with a common set of problems, each has an important perspective on the situation, each can contribute to a positive response, and each can create problems for the others. But no one organization has the ability to solve the whole set of problems because of their complexity and interdependence. In fact, some attempts to make things better end up making things worse.

Common interest in complex problems defines an inter-organizational field. There is a strong inclination to try managing the field by creating a hierarchy (remember the enthusiasm for human service super-agencies and all powerful case managers who "make it work, or else"). The complexity of the problem set and the fact that the field relates organizations that have necessarily distinct identities makes bureaucratic control unlikely to work. One reasonable alternative is to invest in the formation of an interorganizational domain.

We drew on Eric Trist's* ideas about domain formation to design this planning process. He says a domain grows when organizations engaged with a set of problems develop a shared appreciation of their common interests and make decisions within their own organizations which correlate their distinct directions with each other. He identifies five aspects of domain formation:

- Making a shared appreciation of the set of problems that creates interdependence.
- Recognizing that the domain exists and acquiring an acceptable identity for it.

* Eric Trist. Referent Organizations and The Development of Interorganizational Domains. Address to the academy of Management Convention, Atlanta. 1979.

Eric Trist. A Concept of Organizational Ecology. Australian Journal of Management. 1978. Pp. 161-175.

Joan Weiner. Mandated Third Sector Organizations as a Transition From Organization to Population-Based Forms of Regulation. Ph.D Dissertation. The Wharton School, University of Pennsylvania. 1981.

- Setting an agreed direction expressed in shared images of a desirable future and a pattern of development into that future.

- Shaping the boundaries, size, and activities of the domain in terms of the agreed patterns of development.

- Evolving a structure for mutual accommodation among the parts of the domain.

As outsiders, we could only contribute a little bit to forming a domain around the common interest of improving home and family support. Within the limits of our resources we provided small experiences of each aspect.

- Each project activity brought together people from varied parts of the field of formal and informal organizations engaged in home and family support issues. Tasks were developed to focus attention on a common theme which can shape many efforts of each represented organization.

- Both major activities, but especially the search conference, underlined the existence and identity of diversity and interdependency. We purposely avoided pressure to make organizational decisions or commitments to super-structures for coordination. We did expect people to listen and share their perceptions and evaluations of the situation and to look for patterns that linked divergent ideas and values.

- We continually raised the question of how people wanted home and family support to be experienced and what they saw as patterns of activity that would lead in desirable directions.

- As often as we noticed people talking about accommodating their organization's activity to the activities of others, we underlined the importance of the offer to collaborate and linked initiatives to statements about desired direction and underline their importance.

A MODEL FOR PLANNING

Our ideas about improving home and family support in the Doyon region led us to concentrate on bringing people together to share their ideas about what-is now and what-to-do to create a more desirable future. Our aim was not a plan that resolved all the problems on paper. We wanted to structure shared experiences and ideas that would provide a foundation for action.

The Doyon region process differs from common human service planning practice in two ways. It is based on an alternative idea of how planning influences what organizations do, and, it follows a different strategy for thinking about problems.

Alternative Forms of Influence

Many human service plans are ambitious. As a reflection of the complex circumstances that create deep problems for people with disabilities and their families, they often call for major reorganization and substantial increases in funding. They are filled with many recommendations which demand great influence from the top down to implement.

Many plans are made because some external authority thinks they should be. But the plans that change things most aren't usually thought of as plans at all. Most of the time, human services are controlled by small changes in annual budgets. What is called planning is disconnected or at best loosely related to budget decisions. And synchronizing changes in one program with changes in other programs strains top down management past the breaking point. No wonder so many human service planners worry about how to sell decision makers the answers they discover.

This project tried to develop a different kind of influence. We thought that we could contribute to a pattern of improvement in home and family support by...

...bringing people from many different parts of the field face to face...

...to learn together...

... by searching for new understandings of their common interests...

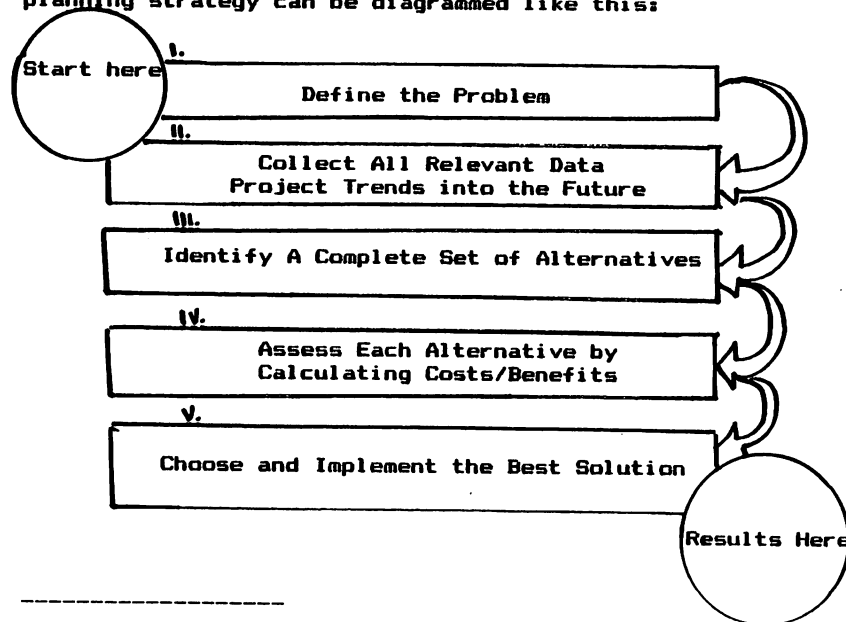
... and identifying small constructive steps that each could take within the bounds of her or his personal and organizational resources.

This calls for big changes a little bit at a time. Its

not the same as representatives of different groups agreeing on a single common project, to which all will contribute. That might happen, but a single project with many parents is less likely to work than many projects in many places which express common values and patterns for growing. Its also different from nearsighted muddling through: taking small steps with no clear sense of direction. Direction comes from agreement about the environment containing people's efforts, the values people want to express in a desirable future, and the strategies they think will get them there. Direction is exercised by learning together, across organizational boundaries, through a pattern of trying a change, sharing what worked and what needs improvement, and trying another change. This planning process has the same kind of influence as a dandelion.

Alternative Planning Strategy

This process also differs from some other human service plans in its basic strategy. The most common planning strategy can be diagrammed like this:



* Christopher Alexander, et al. The Oregon Experiment. New York: Oxford University Press. 1977.

Calvin Pava. Toward a Concept of Normative Incrementalism. Ph.D. Dissertation. The Wharton School, University of Pennsylvania. 1980.

This strategy has three important characteristics:*

- It is linear. Each step follows the one before. Successful completion of every step depends on how well each previous step has been done.
- It is comprehensive. Good solutions depend on collecting all important data and exploring all possible alternatives.
- The objective is to find one best answer. When that answer is found planning is over and implementation begins

These characteristics suggest when this strategy will work best. When a situation can be separated into distinct problems which can be clearly defined and solved one at a time, a linear strategy will solve more problems than it creates. When information needs can be met satisfactorily with available data and research methods, a situation will allow a comprehensive solution. When the problem can be solved with a specific set of actions that can be identified in advance, and when decisionmakers with sufficient power to implement solutions can accurately calculate costs/benefits of alternatives, the objective of a single answer can be met. In short, this strategy assumes a high degree of certainty and control.

Improving home and family support in the Doyon region presents a complex set of tightly connected problems. The most important information about what-to-do and how-to-do it is widely distributed in the experience of many people who live with handicaps, direct service workers, and managers. Both family life and the operations of supporting agencies are changing rapidly with the effects of environmental turbulence. Not only is there high uncertainty, there are no decision makers with enough power to implement a comprehensive solution even if one could be found.

Circumstances in the Doyon region won't presently support improving home and family support by straight line planning. So we designed a planning process to support action learning among participants. The Doyon process has these characteristics:

- It supports invention of new forms of home and family support by encouraging many trials in different places. A final, exclusive definition of the

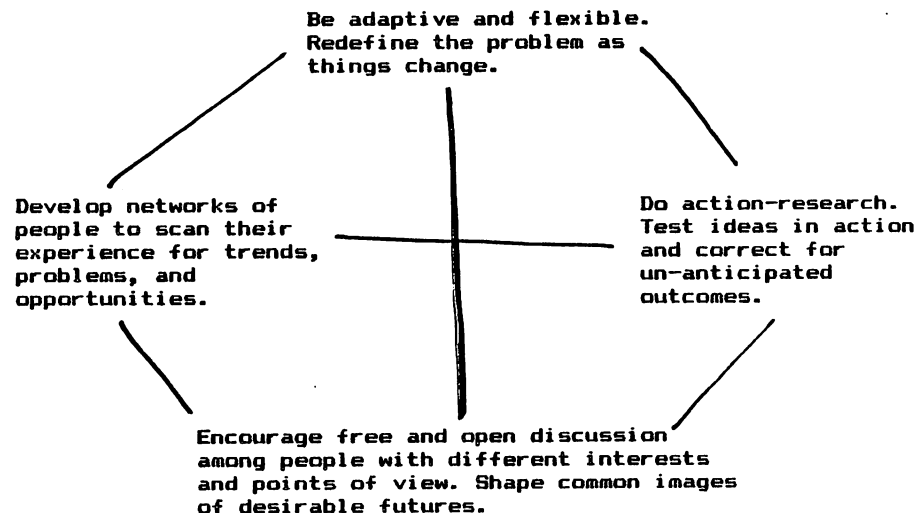
* This discussion is based on Timothy Cartwright. The Science and Art of Long Range Planning. Contact, 13:1, 23-36 (1981).

problem isn't necessary to begin. Progress and problems will lead to redefinition. Sometimes there will be enough information to confidently generate a set of alternatives; sometimes implementation of part of a solution will generate new information. Many costs and benefits won't be discovered until after a possible solution is tried. This way of planning doesn't describe a straight line of progress. It cycles back on itself. It is not linear but iterative.

- It aims at many small steps guided by shared values and a common vision of desirable futures. Instead of looking for a total answer, this way of planning is a search for patterns of improvements. It is not comprehensive but incremental.

- It is an ongoing process of trying, reflecting, and trying again which involves people from many places. The benefits come as much from how the planning is done as from what is decided. This process is not a once a year activity for planners but an ongoing chance for many people to be active learners. It is not terminal, but continuous.

The Doyon region process combines four basic tactics to create a planning network. It can be pictured like this:



This way of planning recognizes high uncertainty and imperfect control. It offers people a chance to actively identify and work toward future they desire. It calls for collaboration and learning together, through action.

EXPLORING WHAT IS

Phase I of the Doyon region's planning process involved twenty-two people in exploring home and family support in Fairbanks, Fort Yukon, Holy Cross, and Galena. Participants represented a variety of roles and organizational affiliations and came from different parts of the region and state. They worked in five teams from 20-25 September 1982 to visit and interview people who rely on home and family support and representatives of service providing agencies. Some team participants were also among the people interviewed.

GOALS

Phase I had five goals:

- To bring people who have a stake in home and family support services together and, through their work in an ad-hoc, task focused group, encourage them to share their perceptions, evaluations and ideas about home and family support.
- To include people with different roles (including consumers of services, direct service providers, agency managers, and state officials), places of residence, and cultural identifications both as team members and sources of information.
- To encourage personal and group reflection on the nature of home and family support, its present status in the Doyon region, and opportunities to improve its quality.
- To create a shared account of the essential ingredients of effective home and family support, and the issues and opportunities facing people who want to improve the quality of support available in the region.
- To develop a focus for Phase II of the planning process by including team members in the December search conference and producing a document that reflects the Phase I group's learning.

ACTIVITIES

Preparation

Based on their 1981 study and their extensive network of personal contacts, GCHG staff identified people in the region who have a stake in home and family support and invited them to participate as team members and as information sources. The stakeholder group included representatives of service providing agencies, consumers of home and family support services, people who have had to leave their homes and move into a nursing home because home and family supports were unavailable or insufficient, and people from other regions of Alaska who saw this project as an opportunity for learning that would benefit their home or job interests.

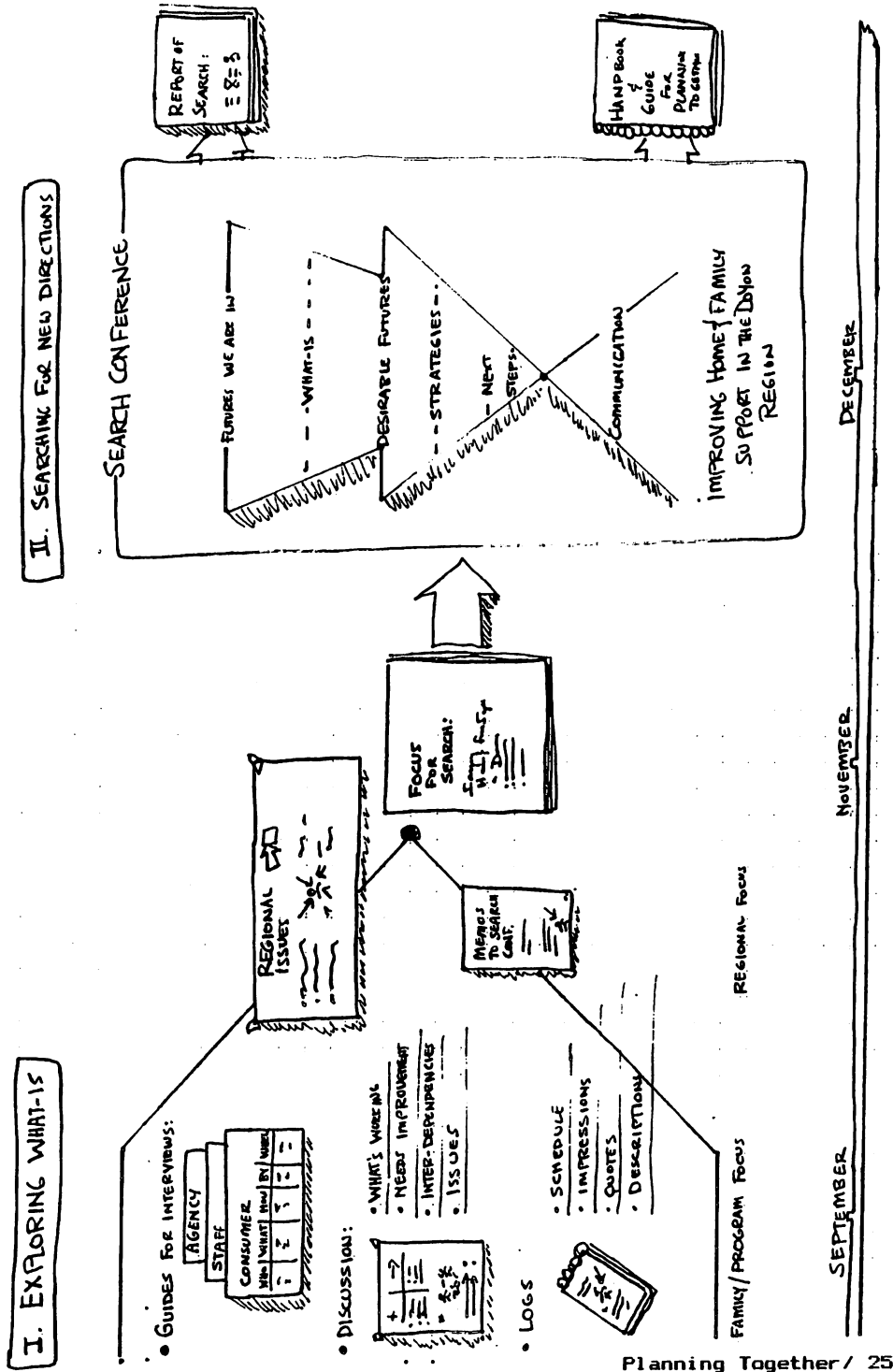
Each of the five teams included at least one person who had been previously involved in GCHG sponsored PASS training and thus was familiar with the general style of inquiry and analysis of Phase I.

During preparations, the project made a commitment to send three of the five teams to visit Fort Yukon, Galena, and Holy Cross for three days each. With the cooperation of the Tanana Chiefs Conference, people from each of these villages were involved in every step of Phase I. This was a major investment which turned out to be critical to the success of the entire project.

GCHG staff developed a schedule (see Appendix D) and arranged transportation and work spaces.

Orientation

Team members and a number of people scheduled to be interviewed met for three hours of orientation on the evening of September 20. We presented the process as a collaborative effort aimed at sharing perceptions and jointly identifying issues. We discussed the contrast between this approach and the sort of expert consultation, program monitoring, or external evaluation which is more familiar to the group. We used the diagram reproduced on the next page to describe the project as a whole.



Information Gathering

Information happens in response to a question about what-is and how it came to be that way. These activities gave participants the opportunity to define questions related to the theme and pursue their answers. Team members had a set of general questions to start from, a way to share ideas, perceptions, and evaluations, and a process for identifying patterns of information. Because many team members are themselves the decision makers who will determine the way in which change in home and family support will be implemented, we put more emphasis on participant's experience of the questions and their answers than we did on standardizing data collection methods.

We developed an open ended interview guide (see Appendix D) which we offered team members as a starting place. The interview guide has three parallel versions: one for consumers and family members, one for direct providers of home and family support services, and the third to describe home and family support programs. Each of the forms raises similar questions for discussion:

- Description of supports with a set of "newspaper reporter" questions: Who receives what supports and why? How is the support offered and by whom? How much support is available and when?
- Identification of what is working well in available supports and people's ideas about what accounts for the things that work well.
- Identification of what needs improvement and ideas about how improvements could be made.
- Description of needed supports that are not available and suggestions for developing them.
- Discussion of coordination issues by identifying who else the worker or agency needs to work with to support a person or family and describing their different responsibilities and contributions.

To encourage personal reflection, we asked each team member to keep a daily log. We encouraged recording the team members daily schedule, personal impressions, direct quotes and detailed descriptions of settings that made a strong impression on the team member, people who should be involved in later stages of the process and further questions, problems, and issues for action. Some team members found keeping a log useful and wrote a great deal. Others said they were unsure of "what we wanted" and so wrote very little. Several team members did not keep logs at all, preferring the team discussion process as a way to

clarify their thinking.

Each team met daily to discuss their impressions and build a summary of questions and issues for improvement. This gave people daily opportunities to look for patterns in the many ideas and impressions they were hearing. For many team members it was also a time for thinking about the connections between what their experience as temporary outsiders, observers of this region's situation, and their everyday role as insiders, responsible for influencing the quality of support people experience at home. These meetings, shared meals, and shared journeys also allowed people to get to know one another better. Some team members agreed to assist one another with projects of mutual interest as a result of their team contact.

As the teams went about their work they discovered differences that had to be negotiated with one another. Some team members had other business that took them away from the team's work despite their real interest in the theme and in the process. Others found themselves involved with people or agencies with whom they had a history of conflict. Cultural differences in styles of group participation, different preferences for gathering and remembering information, and different ways of relating to formal schedules were part of each team's work. The process made real some of the issues that any attempt to make home and family support more responsive must face. One participant wrote in her log,

"I've discovered that part of what I'm exploring is myself and how I relate to the real differences among the people I have to work with if I want to change things."

The important contribution home and family support makes to the quality of community life became more real for many participants as the week went on. So did some fundamental ambiguities. Because visits were scheduled with people and agencies who were stakeholders in improving home and family support rather than the few programs with that specific, circumscribed mission, team members had to wrestle with the question of definition. A team member wrote,

"Home and family support is a lot more than a specific service, at least as far as the families are concerned. But it's very hard to define. Today I was sitting in an interview wondering 'What does this have to do with support services?' Then it hit me: You can't define support neatly without missing important elements. Lots of what my agency does could support families better, and some of it is personal --how I relate to people in

my work and in my home life. It isn't just homemakers and respite."

Developing Intelligence

Intelligence develops as people examine patterns of information (what-was and what-is) and decide what-to-do and how-to-do-it. Team members gathered to share the information they had discovered and to identify opportunities for improvement.

All five teams joined together in a four hour meeting on 24 September to share information about what-is in the region around the themes of home and family support. Group members reviewed the past four days to identify common themes that organize their experience of many different people and settings, events or ideas that stand out sharply for them, and personal learnings.

These comments were recorded on a large chart which was organized as a cluster diagram. A cluster diagram is a graphic format for identifying patterns by grouping contributions that relate to each other close together and using graphic boundaries and connectors to express relationships. The recorder asked participants to indicate where on the display to put their contributions and made frequent summaries to test the emerging relationships between ideas.

This meeting and the resulting cluster diagram were organized largely around the question of what home and family support means and the tensions that are created at the intersection of the personal, professional, and agency worlds. The discussion between the grey bars is adapted from the Phase I report. It reflects the group's learning on these topics. If you are more interested in the process than the content of our discussion, turn to page xx.

WHAT DO WE MEAN BY HOME & FAMILY SUPPORT SERVICES?

Most services for people with disabilities have clear boundaries. They happen in specific places (like group homes or school buildings). They have definite schedules ("open 8 to 5"). They do predictable things for clients whose eligibility can be reliably certified. They are staffed by people who share a common identity (such as teachers or house parents). They generally have a single, straightforward administrative structure. Clear boundaries make definition easy.

In contrast, home and family support services are difficult to define.

Part of the difficulty arises from the way home and family support services have developed. Most home and family support services have been added on to existing agency missions as need and resources have become available. Each agency that adds home and family support brings its own purposes and perspective to its definition. Funding sources add further qualifications. So the region has a variety of home support activities which are funded from different sources, staffed in different ways, with different eligibility criteria.

It's tempting to try to resolve this confusion in the obvious way: define home and family support services by making a complete list of well defined services and then divide up administrative responsibility on a rational basis. But this would miss the most important sources of ambiguity: people's widely varied needs for home and family support and the kind of inventiveness necessary to meet these needs effectively.

To think clearly about home and family support services means trying to understand by surrounding the concept. It's like putting together a jig-saw puzzle: you look for pieces that will help you make up a picture.

Describing Some Qualities

In home support means...

"Filling up the spaces."

One mother who uses home support services provided an important part of the puzzle. Asked to describe what home support services did for her family, she said,

"It fills up the spaces between what my daughter's day program can do for her and what our family can do for her. By itself, its not any one big thing. Its several little things. But our family life, and our daughter's life, is much better because of it."

The spaces between what a family can do for a person with a disability and what a program can do for a person will be different for different families. And, in any particular family the space will change over time as the person with a disability changes, as family circumstances change, and as services change.

The spaces for one family won't necessarily be the same shape as the spaces another family experiences. So it doesn't make sense to think different families needing different amounts of home support in the same way that they need different amounts of whole milk. The most important question about milk is about quantity, "How many quarts do you need?" But home support is different. Questions about quality are primary, "Exactly what kind of assistance does your family need now?" So family support can't be well defined in standard units. One hour of home support may be paid for at the same rate as the next hour, but its likely that very different activities will happen.

Sometimes "More for my family than for me."

A man from a small community who used homemaker services during his convalescence from a disabling injury provides another part of the picture.

"It was more for my family than for me. I could look after myself, and my brother made sure we had wood and water. I did some of the cleaning but I couldn't do all the cleaning and cooking for myself and my four kids. I needed help with that."

"It was good that [the homemaker] came and did just what I needed and not more. And it was good that when I didn't need them any more they stopped coming."

It isn't easy to identify a single client in this man's situation, or in most home and family support services. Sometimes a home support activity is focused directly on the person with a disability, as when a home health aide give a person a bath. But sometimes another part of the family is in focus, as it is for this man.

It's also important to notice that this man, like most other users of home support, has a clear idea of what he wants from the home support worker. Much of his satisfaction with the service comes from his perception that he got what he wanted and not more than he wanted.

"So getting help won't be so hard."

Another part of the puzzle comes from a service worker in a small community.

"The way services and benefits get set up can be very hard on people. The paperwork and the deadlines are confusing. And its hard to know what you can get. Lots of people don't get what they need, or what's coming to them because they don't know who to ask, or they don't know who to trust to ask. Part of my job is to explain all that to people I know so getting help won't be so hard."

Home and family supports involve more than doing a set of predetermined tasks for people and their families. The successful home support worker may perform many vital services which are incidental to the activities for which s/he is hired. This can include such things as connecting people with other necessary services or helping them figure out their entitlements. For some people, being able to count on home support is, in itself, a helpful thing. As one person in a small community said, "It keeps me going to know that [the home support worker] will be there everyday."

"Sometimes doing what you aren't quite supposed to do."

Another service worker offered a final bit of the puzzle.

"Lots of programs seem to be built on the idea that people's needs come in neat packages so you can make and keep rules about what to do and what not to do. I think everybody knows that really isn't so, but the rules are made as though it was.

"When you get involved with a family and start to figure out what they really need, sometimes you end up doing what you're not quite supposed to do. Of course, being able to say 'That's not my job.' is a good way to deal with requests you may not feel ready to deal with. But those are often the things that matter the most to people.

Home and family support needs to be inventive to be effective. Situations vary so much from home to home and from person to person that committed workers will often find themselves with a choice between ignoring what seems an important and reasonable request and doing something that seems to them to be outside of rules that clearly don't quite apply. For example, the boundary between homemaker services and home health aide services -- which is very clear in terms of funding and job definition-- seems difficult for many homemakers to maintain in practice.

On the other hand, without clear role definitions it becomes difficult to decide when a request is unreasonable, or beyond one's competence. Workers can rightly wonder, "How much of what I'm not quite supposed to do should I do." As one worker put it, "I don't want to act like a bureaucrat. People don't need any more of that."

After this first meeting, we asked team members to spend an hour or so alone reviewing their logs and thinking through the week before going to bed. As they reflected, we asked them to make some preliminary notes on things they wanted to inform the December search conference about.

The team's final meeting began with an hour long writing period. We reminded team members about the December search conference and asked them to write a personal letter or memo to its participants. We encouraged them not to be concerned with the formalities of writing but to focus instead on giving search conference participants clear and specific information to think about. We told the group that their memos, along with the records of group discussions, would form the basis of a written report which would be distributed to search conference participants. In response to questions and some discussion, the group agreed that all twenty memos would not be delivered to search conference participants as written. Their primary function would be to sum up each team member's experience and contribute to the report.

The writing period led to a very active three hour group meeting which focused on three questions:

- How do we describe home and family support briefly and clearly? This question came from several group members after the discussion summarized above. They felt that exploring the theme broadly stimulated new ideas and new connections but left them without a way to introduce others to the topic.
- How can we summarize what we have learned about what makes home and family support work?
- What opportunities for significant improvement in the quality of home and family support can we identify?

The next section, between the grey bars, summarizes the group's discussion on these issues. The written report drew its structure and emphasis from the groups discussion. Team member's memos and logs provided details, quotations, and a variety of perspectives and suggestions. If you are more interested in the process than the content of our discussions, turn to page xx.

THE PURPOSES & ACTIVITIES OF HOME & FAMILY SUPPORT

The people we interviewed identified three related purposes for home and family support.

I. To help people remain in or return to their own homes rather than having to live in congregate living arrangements.

II. To support people's participation in family, neighborhood, and community life.

III. To assist people to develop or restore their abilities.

Home and family support services can focus directly on the person with a disability or on another household member, or on the household as a whole.

These purposes may be served by many different activities.

- Making physical changes in a person's home like building a ramp, or adapting a kitchen or a bathroom so that they are convenient for a person with a disability to use.

- Providing equipment and appliances which will maintain or improve people's abilities and assisting people to use them at home and in natural community settings.

- Keeping house and insuring that people are warm and adequately fed.

- Providing direct personal care such as bathing, administering medications, or assisting with bowel care routines.

- Supervising a person with a disability in the absence of the person who usually looks after them.

- Involving a person with a disability in settings, activities, and relationships that will develop abilities.

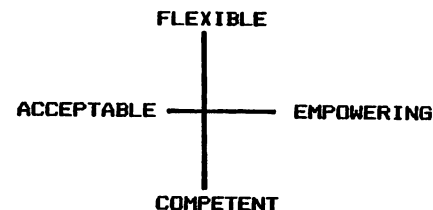
- Teaching a person with a disability or a family member to carry out a personal care routine or activities which will develop a person's abilities.

- Giving advice and guidance to assist a person with a disability or a family member set goals or solve a problem.

The wider the range of activities available as needed by a household, the better able the region's services will be to fulfill all three purposes for people with a wide range of disabilities and household circumstances.

WHAT MAKES HOME & FAMILY SUPPORT WORK?

According to our interviews and discussions, home and family support services will be effective if the people and families who use them experience them as...



Home and family support services are **FLEXIBLE** if service workers respond to different personal and family needs as active problem solvers. As a result, support activities change as personal, family, or other service circumstances change.

Home and family support services are **EMPOWERING** if service workers find out what a person with a disability can do for him/herself, and what others in the household, neighborhood, or extended family can do with and for the person with a disability. Home and family support activities **BUILD ON WHAT'S ALREADY AVAILABLE** to a person. They extend and expand what natural support systems can do.

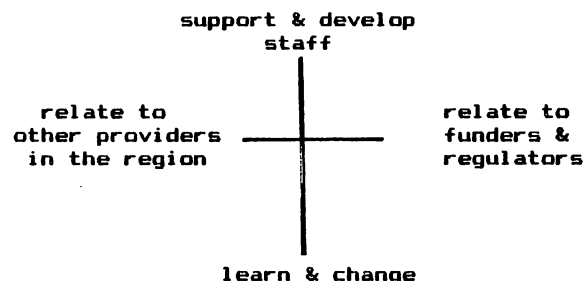
Home and family support services are **COMPETENT** if service workers have the knowledge and skills to help people and their families develop realistically high expectations of themselves and services and then work systematically to meet them.

Home and family support services are **ACCEPTABLE** if service workers are sensitive to service users cultural values and preferences. Many home and family support activities are personal; some are

intimate. Making and keeping a positive relationship often means taking extra effort to accommodate people.

These four elements are closely related. Together they create a personalized service.

Delivering personalized home and family support services poses significant management challenges. The quality of support services depends on service manager's ability to...



SUPPORT & DEVELOP STAFF: Staff won't be able to deliver effective service unless there is a real investment in improving their ability and supporting their initiative. This is difficult because most support workers are paid less and have a lower status than most other human service workers. High turn-over also discourages investment in developing staff.

COLLABORATE WITH OTHER PROVIDERS: Many situations call for active collaboration among different providers. No agency's resources are sufficient to meet complex needs alone.

LEARN & CHANGE: Effective managers reflect on experience and modify the way they offer service on that basis of their understanding of what's working and what needs improvement. Strong consumer participation and balanced representation of different cultural groups in the management of services builds a climate for learning.

POSITIVE RELATIONSHIP WITH FUNDERS & REGULATORS: Achieving necessary flexibility means taking an active role with funders, planners, and regulators so that people's real and changing needs for family support are reflected in policy and budgets.

WHAT OPPORTUNITIES ARE THERE TO IMPROVE HOME & FAMILY SUPPORT SERVICES?

The Doyon region has a number of significant opportunities to develop more effective home and family support services.

Possible Responses to The Present Environment for Service Development

Develop Locally

- The physical environment poses awesome challenges to region wide service systems. Widely dispersed population, long distances, and difficult travel make it important to develop home and family support competencies at the local level.

- There are strong trends which support development in local communities throughout the region.

- Doyon Limited and the Tanana Chiefs Conference (TCC) are actively investing in developing local economic and service resources. The TCC subregional offices could be a key resource in developing in home supports.

- A number of communities are developing or exploring development of local educational, health and social service powers. As plans are laid for new services, there are two opportunities. 1) Some resources may become available for designated home support services; 2) Other services can be designed with a focus on family and household support.

Build on local values

- People express strong values of self-reliance, respect for elders, concern for child development, desire to look after ones own. Many communities have at least some positive examples of mutual aid to families with disabled members. These values may present a real challenge to the acceptability of home support services, but they provide a strong foundation for support services dedicated to empowerment.

Take Responsibility for Planning

- There is no centralized master plan for regional service development and there is a regional history of development of a relatively large number of small agencies. Though there are many examples of turf problems and lack of information about one another's work, this creates a favorable climate for innovation in home and family support. If service providers can accept responsibility for planning together, a strong, varied system might be built from the bottom up.

Consumer Organization and Participation is Essential

- Alaska's legislature has proven responsive to direct expressions of citizen concern for people with handicaps. In particular, parents of people with disabilities and disabled people themselves have found willingness to assist. If service users organize their concern for home and family support and if service providers can develop meaningful strategies for working together with service users on developing more powerful support services it might prove possible to influence state policy and appropriations.

Opportunities for Improving Services

Develop an Individual Planning Process that Attends to the Person in Context

- Providers need to develop a functional way for people from different agencies to plan together with individual disabled people and their families. There is no established way to create a shared sense of a person's home situation and a shared vision of a person's possibilities. Consequently, responses are more fragmentary than they need to be and there is less empowerment of existing support networks than is possible. Services developed without a strong sense of a person's context will miss many opportunities for collaboration.

Create an Expanded Role for A Family Support Worker

- Bush communities should explore the possibility of developing a new role for home and family support specialists. Community health aides have established themselves as a vital service, but their priority is, necessarily, on acute care and care for children. It would likely take sometime for this role to become established, but long term care will become more important as communities develop. Developing new competencies for people in small villages would make a further step toward building local skills and career options.

Provide Hands on Training To Build Worker's Skills

- All support service workers would benefit from consultation and training to expand the image of what abilities people can develop. The most effective training would come from active participation in individual planning meetings and hands on assistance from professional who visit homes along with them to implement new plans.

Reacquaint People With Institutionalized Community Members

- Many communities seem to have forgotten their institutionalized members. Providers should plan ways for local people to become reacquainted with people in institutions in the context of determining what specific support would be necessary to restore a person to community membership.

Support the Resolution of Advocacy Issues

- There are a number of advocacy issues which, if resolved in favor of people with disabilities, would greatly strengthen home and family support services.

- Increasing the accessibility of Fairbanks' transit system, streets, and buildings would literally open the community for many people.

- Increasing the availability of adaptive aides and devices would increase many people's competencies.

Provide Individualized Attendant Care

- Service users and providers should work together to initiate at least a small project which would provide extensive, individualized attendant care and other supports to people with very substantial physical handicaps.

Explore Cooperative Action by Service Users

- Providers and service users should explore the possibilities for further cooperative exchange of skills and supports.

SEARCHING FOR NEW DIRECTIONS

Phase II of the Doyon region's planning process was a search conference, held at the University of Alaska on 1 - 3 December 1982. Thirty five people worked together intensively to develop plans to improve home and family support services.

GOALS

The search conference had five goals:

- To provide an opportunity for people to build a network around the issue of improving home and family support.
- To develop a shared appreciation of the present and emerging environmental trends that shape the context for improving home and family supports.
- To create shared images of a desirable future for home and family support in the Doyon region.
- To identify strategies for improving home and family support.
- To plan constructive actions to implement the strategies.

APPROACH

Phase II was structured as a search conference.* This method has developed over the past fifteen years to create conditions for people to work together to understand and plan action on complex issues. The search conference format has proven especially useful in helping people work across role and organizational boundaries.

* Eric Trist. The Search Conference Concept. In the readings section.

Merrelyn Emery. Searching: for New Directions; in New Ways; for New Times. Canberra: Australian National University, 1982.

Trevor Williams. The Search Conference in Active Adaptive Planning. Journal of Applied Behavioral Science. 15: 146-59. 1979.

To facilitate the work of the search conference, we drew on Group Graphics*, an approach developed by David Sibbet. This style of group leadership literally helps people see what they are saying by producing large, color displays which record the words and images of a meeting. These displays focus interaction and provide a vocabulary for identifying patterns of ideas. When photographically reduced, the displays provide participants with a powerful record of their experience and a useful aid in telling non participants the story of a meeting.

ACTIVITIES

Invitations

Phase I team members identified people whom they felt had an important stake in improving home and family support. GCHG staff and a small group of local Phase I participants listed potential participants. On the advice of the Phase I team, they placed special emphasis on recruiting direct consumers of services, people who live in communities outside Fairbanks, and community leaders who are not identified specifically with human services. People were personally invited, through face-to-face or telephone contact. Those interested in attending received this written explanation of the process.

WHAT IS A SEARCH CONFERENCE ON THE FUTURE OF HOME & FAMILY SUPPORT?

You are invited to meet with other people who share your concern with the future of home and family support for people with disabilities in the Doyon Region. The meeting may be different from other conferences you have attended. It is specifically designed to involve people with a wide variety of roles, interests, and viewpoints in an active search for new understandings and new directions for home and family support services.

- You will not be listening to "outside experts" presenting all purpose answers. Each participant is a resource person for the whole group. By actively sharing your values, experiences, views and dreams for the future of home and family life for people with disabilities, you will help

* David Sibbet. I See What You Mean: A Workbook Guide to Group Graphics. San Francisco: Sibbet & Associates, 1982. A description of the graphic formats which form the basic patterns in this method is included in the readings section.

discover new understandings of the present and future circumstances which influence the quality of home life for people with disabilities.

- You will not be reacting to a plan prepared by others. The emphasis is on working together to define new opportunities and future directions for home and family support services in the Doyon Region.

- You will not be asked to make specific decisions or commit your family or your organization to any particular group solution. Getting involved with a number of other people who share some of your concerns and thinking about the future you face together will provide you with new and renewed connections, relevant information, and new options for action back home.

The search conference is a well designed sequence of activities. Participants will move from a shared sense of the present and emerging future situation which influences the quality of home and family support, to the creation of images of more desirable futures, then to the development of strategies and actions for the redesign of the region's home and family supports. Finally, the group will decide whether and what further action is desirable.

Searching is an active process that moves through well defined stages. Please arrange your schedule so that you can be fully involved in the whole conference.

About three weeks before the meeting, potential participants got a focus document (Appendix A). This document repeated the description of the search conference format, reported what people had learned in Phase I, and offered examples of the questions the search conference would address.

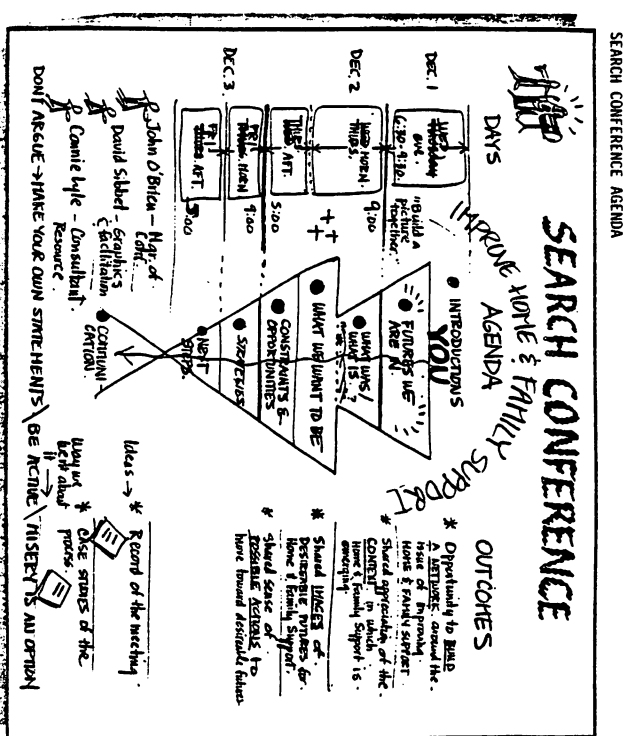
The process of inviting people was another opportunity to focus attention on the projects theme and served to keep alive some of the personal connections made around the theme in Phase I.

Interest in the search conference was high. People from communities outside Fairbanks were well represented and a number of service consumer leaders participated. Several community leaders who do not have a special identification with human services agreed to attend, but none finally did.

Finding appropriate meeting space that was accessible to people with physical disabilities proved a problem. The meeting space, in the University of Alaska Student Union, was adequate for about 35 people. This meant that some people who wanted to attend the search conference had to be refused invitations. Several participants pointed out that this was inconsistent with the overall goals of the project. Others noted the trade-off between more people and access for people with disabilities.

Orientation

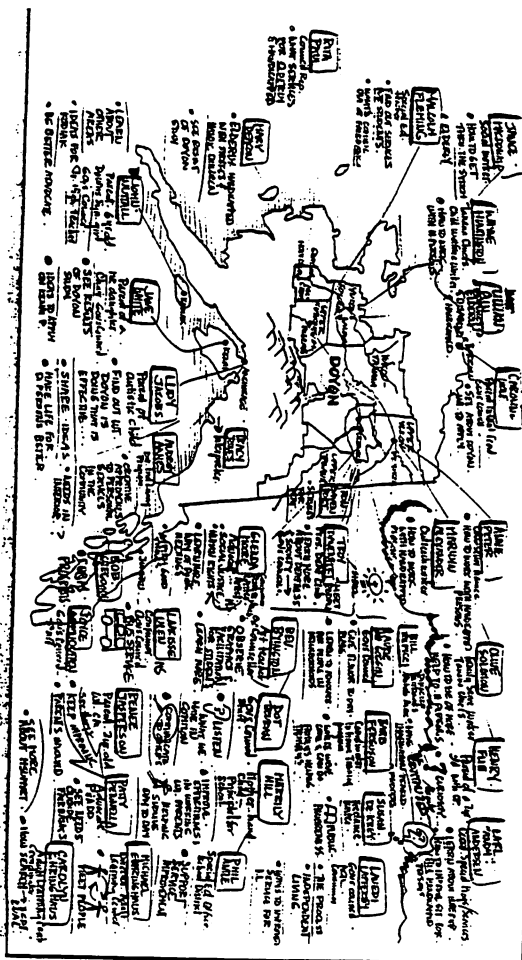
When participants gathered, we provided an overview of the meeting format, schedule, goals, and ground rules. This display summarizes. Like the other displays in this section it is a photographic reproduction of the large (approximately 4' X 10') display that was made during the meeting. Appendix B, the report of the search conference, contains somewhat larger versions of the displays.



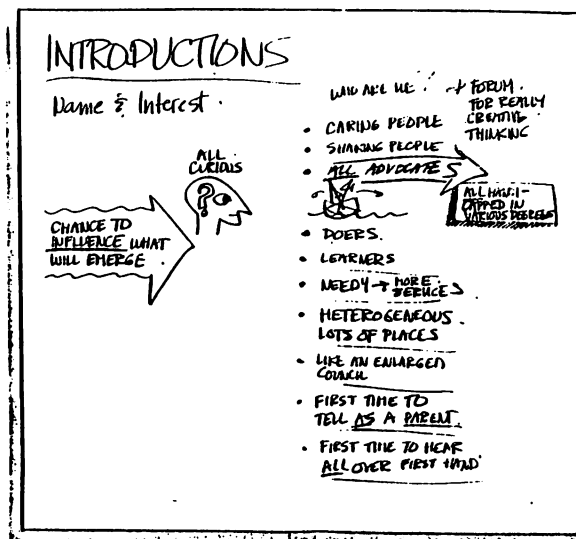
Introductions

People introduced themselves by locating themselves on a large outline map of the region and Alaska and stating their interest in attending. This served the network building process by allowing everyone time to speak about his or her interests. The display, which was created as people spoke, usually underlined people's relationship to common territory and concerns.

INTRODUCTIONS.



After each person had spoken, participants answered the question "Who are we, as a group? What generalizations can we make about ourselves?"



Scanning the Future Context

People who are planning have a choice about the way to think about the future. Some people plan as if the future will be no different from the present in any way that is significant to their purposes. If this is true, discussion about the future is a waste of time. Other people plan as if the future belongs to experts who can predict important differences through specialized techniques. If this is true, people who aren't experts ought to listen respectfully to predictions and prepare to live with what is foretold.

The search conference is based on a different image of the future. As Eric Trist puts it:

"One cannot predict the future, one can only invent it (or fail to invent it). In fact, there is no such thing as the future, only futures. Which of the possibilities will be realized depends not a little on the choices we make --which in turn depends on our

values-- and also on our taking an active rather than a passive role. The paradox is that under conditions of uncertainty one has to make choices, and then endeavour actively to make these choices happen rather than leave things alone in the hope they will arrange themselves for the best."

Each of us has a personal sense of the futures we are in. Everyone has ideas, feelings, and evaluations of current and emerging trends which influence the quality of life and the probabilities for successful action.

We asked search conference participants to share their sense of the current and emerging trends that shape the context for all family life in the Doyon region, and especially the life of families including handicapped members over the next ten to fifteen years. The group began the discussion in small groups of 4-6 and then, after about a half an hour, moved into a total group discussion.

People's contributions were recorded on this cluster diagram. The diagram reads from left to right, with current trends toward the left and emerging trends to the right. Trends that people evaluated positively are symbolized by upward moving arrows; trends people felt negatively about in downward arrows. Each trend and its evaluation was accepted and recorded as offered, in the contributor's own words. We asked people who disagreed to make a statement reflecting their views rather than arguing with others.

This discussion sets the theme of improving home and family support in context in two dimensions. People can think about the theme from a longer view by taking account of the future horizon. And, they can consider the theme against the background of the complex, interacting trends symbolized by the diagram. Any attempts to improve home and family support becomes another force toward the future. Plans are evaluated in both dimensions:

■ Will action along this line move us toward a future we feel positive about?

■ What forces in the environment that surrounds us can we correlate our action with?

About 25 people were active in the large group discussion of futures. The rest of the group made a few contributions to the smaller group discussions and listened to the large group. A brief summary and overview of the schedule concluded the evening session.

Participants worked in small groups to answer two questions "What is going on now in the region that supports people with handicaps and their families at home?" and "What are the main events that have shaped these response until now."

Small groups reported back and a number of people made contributions in the larger group. Much of the discussion centered on the differences between Fairbanks and the rest of the region. There was little discussion of the events that shaped service agencies. Only a few participants had been involved with any of the formal service agencies long enough to know their history. There was lively discussion of traditions of informal helping and several consumer participants shared their personal history with both formal and informal supports. While a number of people only participated minimally in the small groups, almost everyone joined the large group discussion.

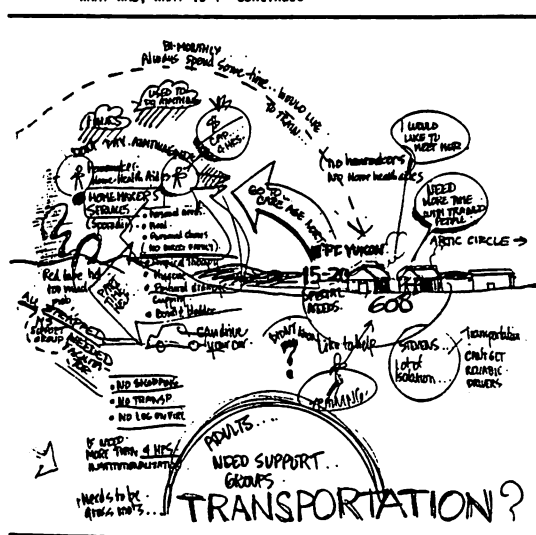
The display that summarizes this discussion is organized by a cross section of the region's geography. Fairbanks is central, the Lower Yukon area is to the left, Fort Yukon is to the right. Formal agency related support services are "above the ground". Informal supports come up out of the ground.

At the end of this discussion, participants recorded their reactions in these phrases:

- Sense of our ease of interacting one on one.

- Hope and concern
- Fear
- We want to live
- Disabled people bring a re-awakening
- Importance of family--consumer involvement
- Training
- Rural needs
- Solutions are tough

[illegible]



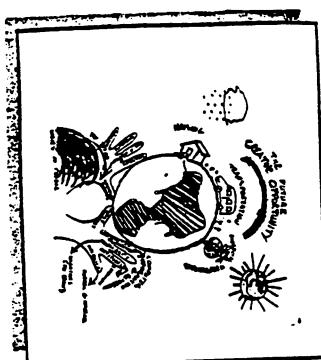
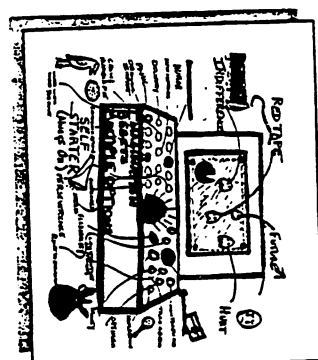
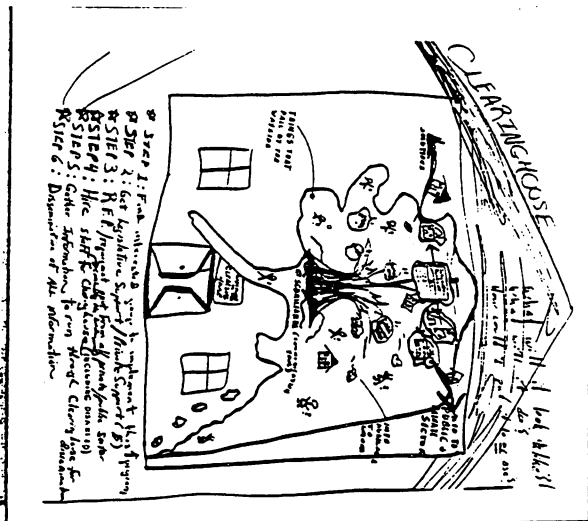
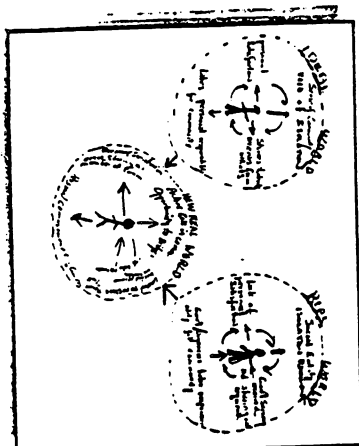
A complex environment made turbulent by rapid change in tightly joined systems challenges reason and will. As one participant said,

The discussion of what is concluded that without action natural supports are unlikely to grow strong enough to reverse the trend of people with substantial disabilities having to leave their homes, families, and natural communities and move into expensive, segregating, artificial environments. Participants from outside Fairbanks spoke of the undesirability of having to come into the city in order to get needed supports. People from Fairbanks made it clear that their options were only a little better. City dwellers with major disabilities are also at high risk of being uprooted from their own families and neighborhoods. They are isolated by an inaccessible transit system and services built on the assumption that congregate living and working arrangements are best.

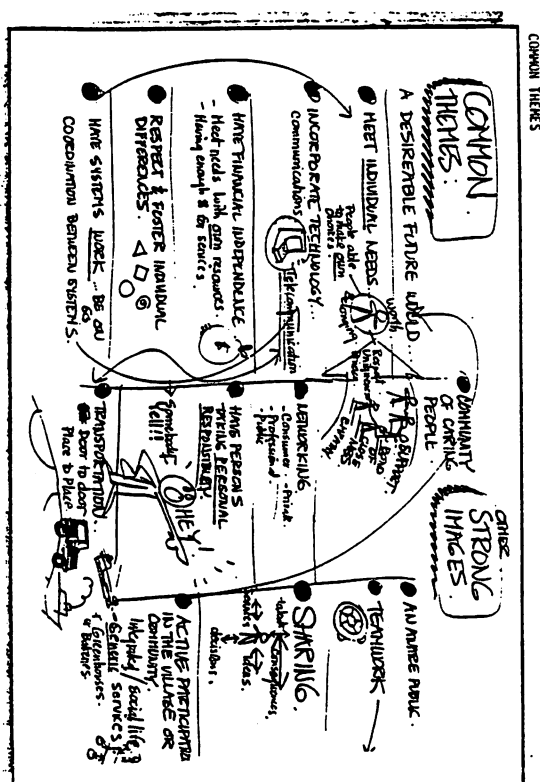
Clear, vivid images of a desirable future are a powerful medium for the values that direct action. In its qualities as a vision or a dream is the variety necessary to guide adaptations to complex, rapidly changing circumstances.

Participants worked in small groups to express their sense of what-should-be. In order to decrease the group's reliance on the conference staff for pictures, we actively encouraged each group to take markers and paper and make their image visual. After some stuckness ("We can't draw."), each group produced and presented a vision of what should be. The quality of these images is diminished by black and white reduction. They were indeed vivid and groups presented and received them with enthusiasm. Conference staff moved into the background for these presentations.

See Appendix B for larger reproductions of all of the images.



The large group summarized this step by sharing common themes and images that were strong in the several presentations.



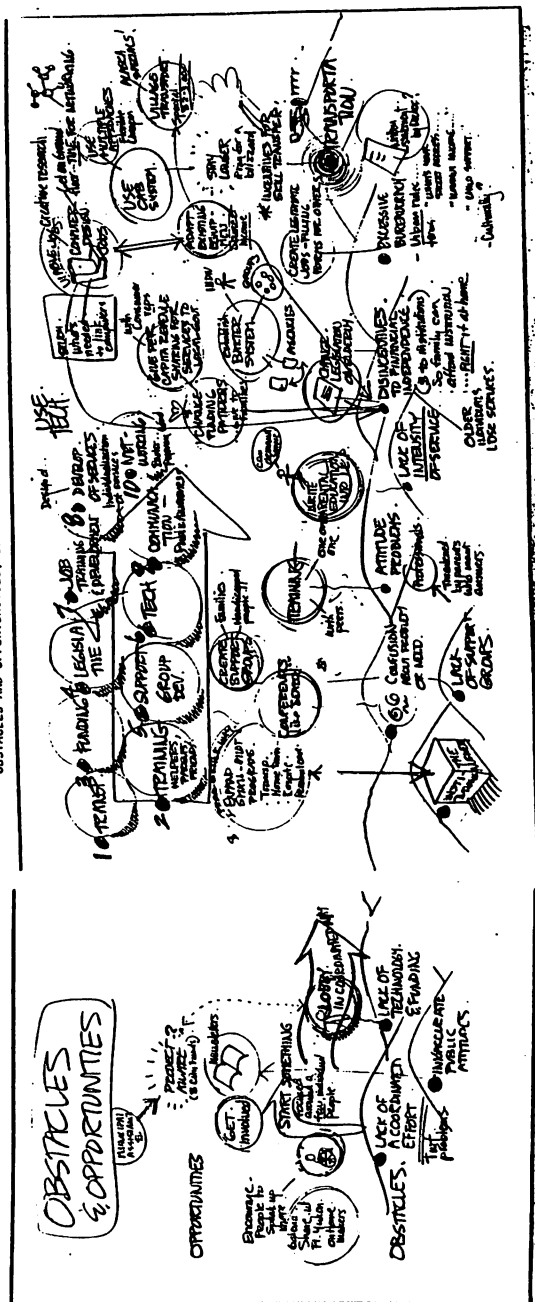
Obstacles/Opportunities

Guaranteed futures depend on simple problems, stable environments, and high control. Improving home and family support in the Doyon region means thinking and acting to increase the probability of experiencing a desirable future.

Small groups considered their images of desirable futures by reviewing the present situation and current/emerging trends to identify obstacles to the realization of their choice of a desirable future and opportunities for positive movement. Group's tested obstacles to decide whether or not they also constituted an opportunity: "If we could solve the problems associated with this obstacle, do we increase the chances of experiencing the future we want?"

After an hour and a half of discussion, which a number of people found frustrating and difficult in contrast to the excitement of creating images, groups reported back. This display organizes their ideas. It pictures obstacles as hills to negotiate and opportunities as balloons that rise above the hills. Obstacles that present

OBSTACLES AND OPPORTUNITIES, Continued



The final day of the conference focused on interest groups working independently to develop strategies to move toward more desirable futures. The large group negotiated for about forty-five minutes to develop four interest groups around these topic areas:

- Conference staff provided four suggestions about the process of the workgroups.

- Each group should have a recorder. The role can rotate if members want.
- Interest groups are free to use any process that they choose, but should take a few minutes to think about alternatives and agree about how they are going to work.
- One way to think about strategy is as a story with five elements: a specific group of people, with a clear sense of what should be, start from a particular place, and act together to deal with obstacles and opportunities. Strategy is a story, or a set of stories that combine these elements in ways that motivate action.
- A useful technique for planning a strategy is to work backwards. Project your group forward to a time when you are much closer to a desirable future than you are now. Role play a situation with one member of the group playing an interested stranger interviewing group members about what they did to accomplish their goals.

Planning Together / 55

Villages needs:

- More hours for homemakers.
- Trainings:
 - Getting the training.
 - On going without professional.
- Inter-agency potential at site.
- Sorting out the sources of assistance:
 - What providers?
 - Where providers come from?
 - What providers can/cannot do?
- Home Health Aide:
 - Training.
 - Program/process/procedures.
- Inside/outside communications:
 - Understanding communication system.
 - Learning to use the system.
 - Changing the system.
 - Adapting the system.

GOAL chosen from above needs:

A home health aide in EVERY VILLAGE.

ASSUMPTIONS:

1. Someone in Village who wants to be HHA.
2. Someone in Village who needs assistance.
3. There is a funding source.
4. There is a training source.

OBSTACLES/OPPORTUNITIES

1. Funding source non-existent.

There is funding through HI services, Area Office on Aging, etc. Go to legislature through existing channels. "Piggy back" for start-up. Profit Native Corporate Structure, Municipal Aid Grants. Opportunity creatively examine village based sources (raffles, bingo, door to door, Lion's club, dog mushers, city itself.)

2. On-site need for HHA not known.

To systematically assess the "true" need--conduct needs assessment. Go through schools SW, PHN, Local Health Aides, churches, Village Police, State Troopers, TCC, Village Mayor, Leader, Elders.

3. Training available is poor.

Use available expertise to create a training process. Use a procedure unique to village site!! Training on-site, but needs to be shared too--regional + area-based.

4. The villages get the left-overs!!

Seek other/additional funding sources to eliminate being "locked in" to existing systems. Develop "better" on-site communication with alternative "language" formats. (Recognize the existing culture as a possible barrier).

5. Trainers are unavailable.

P.A.'s and PHN's to "share" skills, knowledge in a different than usual way!

6. Can't hire relatives.

Change the "rules." Options for funding--using other sources--FREEDOM!!

7. Paperwork, i.e. RED TAPE.

Job opportunity for "somebody."

1) Who ended up paying the bill?

- Lion's club came through.
- Auctioned
- Bingo twice per week, with Med. proceeds going to a special fund.
- Area Office on Aging
- TCC helped with funding

2) What was done to find a person for HHA position?

- TCC helped organize interviews.
- Publicized via radio, TV.
- Advertized at local village level--posters in public places.
- Called to V.H. Aide, visiting PHN--with their help a job description for HHA was developed.
- Spouse came up with who would-could work well with a disabled person.
- HA + alternate HA aides--as candidates for HHA position.

3) How did training effort get underway?

- Tapped "available" training aides, i.e. VTR's.
- Volunteered help from village based "outreach" person.
- Sent candidate to training in FAI.
- An "alternate" candidate is always included.
- Wrote to ANC for "sources" of HHA training.
- Joined AK film club--for film resources. 1 film per week schedule in village.
- Using PHN as itinerant "trainer"/consultant.
- Bought out, utilized ANC based resource person to provide specific skill training on site.
- Using itinerant M.D. to provide on-site training.
- Area Office Aging saw advantage of fiscal support for training.
- World Health Organization (WHO) as a literature, training material's source.

4) How do you "cope" with paperwork overload?

- Donated time from an already trained secretary.
- In Village "mobile" secretary as HHA team member.
- Use school district sponsored computer training to transfer records to data-base/i.e. for ease of management of records, etc.
- Utilize existing "paper management" sources in Village-- City Clerk, City Manager's office, etc.
- Establish a roster of data/info. gatherers who will make home visits.

5) Biggest changes occurring as a result of the HHA Program?

- Happiness index goes up!
- Elders remain in Village--are not sent to Fairbanks.
- Foster Grandparent notion is started.
- Services more equitably/equally distributed.
- Opportunity for someone to GO to you to COME to you.

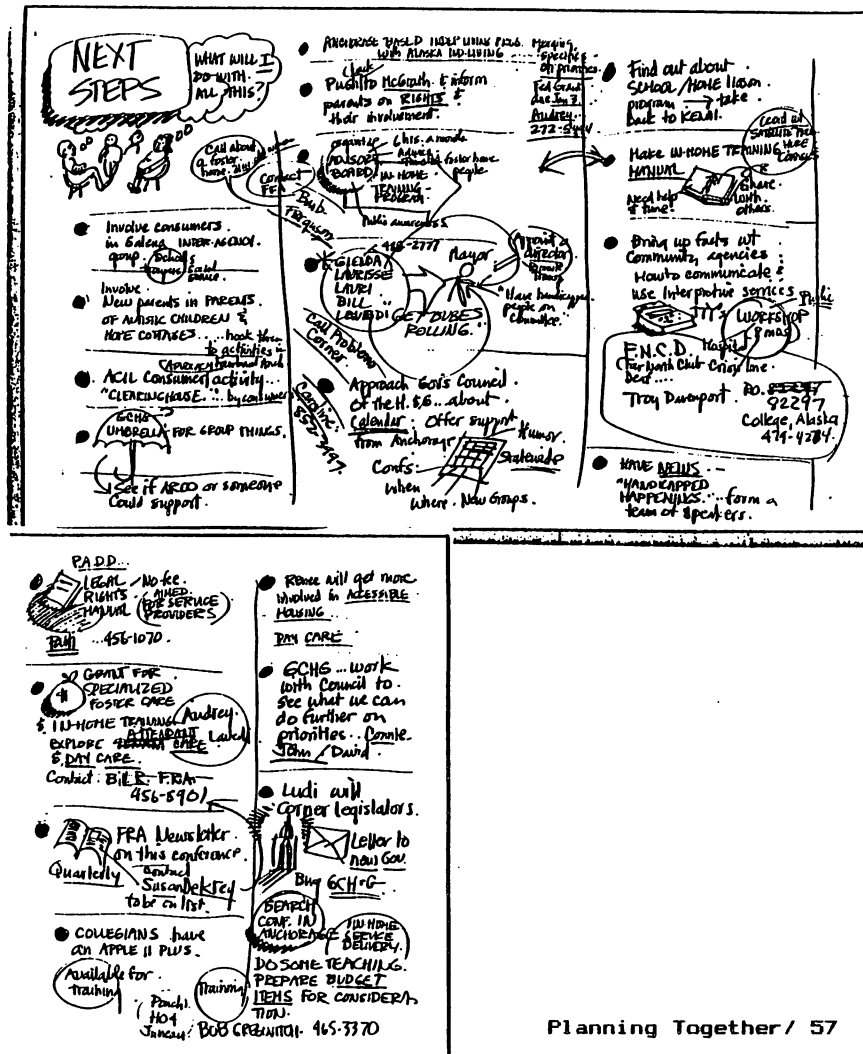
HOORAY! YEAH TEAM(WORK)!

STRATEGY DEFINED:

ADVERTISED POSITION (HHA) VILLAGE WIDE SOUGHT. FOUND INDEPENDENT FUNDING SOURCES. TAPPED AVAILABLE EXPERTISE. PROFESSIONAL/ITINERANTS DESIGNED-CARRIED OUT TRAINING PROCESS. PLANNED FOR ON-GOING CONTINUOUS TRAINING.

Next Steps

Search conference participants attended out of personal interest. This step, near the end, gave people an opportunity to identify specific next steps they wanted to take within their present personal and organizational resources. The list includes a number of joint activities among people who had not met before the search conference. It reflects participant interest in reaching out to involve a variety of others (from the newly elected governor to other parents of children with severe handicaps) in action on the theme of improving home and family support.



Search Conference Evaluation

We concluded the search conference by asking: "What worked well for you?" and "What could be improved?"

WHAT WORKED FOR US

- + graphic recordings--keeps attention
- + small groups
- + talking/sharing as big group
- + positive reinforcement
- + finding out about villages
- + facilitators wouldn't tell us what to do (A NOVELTY!!)
- + repetition...where we've been...where we're going...giving reasons
- + getting objective overview--focusing on issues
- + learning a PROCESS we can use...work & personal
- + opportunity to DO IT
- + mixture of consumers and service providers
- + healthy
- + positive energy John, Connie, David threw out--"You're special"
- + VICE VERSA!
- + nobody dominated
- + having an interpreter
- + sharpened awareness of Alaska...with specifics for job & responsibility.
- + opportunity to do more
- + excitement of different ideas...snowballing
- + holding to a schedule
- + came down to CONCRETE THINGS
- + accessible place
- + good food
- + blank walls (plenty of room to write and stick papers)
- + NEW/old friends
- + adequate lighting & temperature
- + THANKS GCHB!! LAURIE AND DOT!!
- + no smoking
- + with graphics, didn't have to take notes
- + Ludi contributing

WHAT COULD HAVE BEEN BETTER?

- didn't end on time
- work & breaks mixed was hard
- 3:30-5:30 burn-out Day 2
- size of room limited access...people turned away...both consumers and providers
- more time to just VISIT
- use VTR...segments to take back (would have inhibited some people, could possibly have staged some sessions with David and John and taped some small group work if participants did not mind)
- TYPE of space not ideal...where do we go in breaks?
- use tables
- didn't get to smoke

TAKING CONSTRUCTIVE ACTION

The planning project concludes with the distribution of the search conference report and this manual. Improving home and family support in the Doyon region will require continuous action learning among the many people who have an interest.*

The situation will improve for people with handicaps if those who have been involved in Phase I and Phase II work together to increase their understanding of home and family support and the opportunities arising in the changing contexts that shape it. The most powerful such learning will come from trial of the strategies developed in Phase II. Action and shared appreciations of situations across organization and role boundaries will build an increasingly strong base for collaboration.

Nothing can happen if people decide not to use their personal and organizational resources to support one another's efforts at improvement.

FORCES TO OVERCOME

Several forces work against people in the Doyon region establishing a pattern of constructive action to improve home and family support.

- Though participants in Phase I and Phase II learned that home and family support makes a critical contribution to the quality of community life, it is one need among many. It competes with better funded, more visible, more clearly defined services (like special education, residential and vocational services) for attention from people directly related to the service system. It competes with economic development and basic health services for the attention of community leaders and families. The project provided small experiences of working around this theme, but there is still no organized constituency for improved home and family support in the region.

* See David Morley and Rafael Ramiriz, Food for the Future of Mexico: An Action Learning Perspective, in the readings section.

- Fiscal policy still concentrates Alaska's long term care resources in out-of-home residential settings. Expanded home and family support service initiatives seem to some policy makers to open a new, and unpredictably large, demand on public funds.**

- Most of the funds available for organized in home and family support are categorically related to agencies that are separate at the state, and often the federal level. Reallocation of resources within the region will be difficult at best.

- The divisions of culture, geography, organization, and role that Phase I and Phase II participants experienced, struggled with, and largely overcame in their temporary roles of exploring what-is and searching for new directions, are powerful influences on everyday behavior. The incentives that separate people from each other are more immediate than the rewards of working across boundaries.

SUPPORT FOR CONSTRUCTIVE ACTION

Constructive action is desirable and possible but unlikely unless participants in the early phases of this process work together. Some people need to develop the skills of "walking through walls" to keep relationships alive and focused. We can identify at least eight kinds of activities that will support constructive action by keeping the theme of improving home and family support alive:

- Maintain and expand the network of people involved with the theme. Make the theme the topic of telephone and personal conversations. Identify new people with an interest in the theme and involve them personally with others in the network.

- Develop collaborative trials of strategies for improving the theme. Work together to test possible improvements.

- Use the theme for self-assessment. Focus on the effects of overall organizational policies and priorities on home and family support and on support from natural helpers. Discuss the experience of supports with families and people with handicaps.

** Stephen Crystal. America's Old Age Crisis: Public Policy and the 2 Worlds of Aging. New York: Basic Books, 1982.

- Display activities related to the theme. Make formal and informal initiatives to improve home and family support the subject of newspaper stories, slide shows, television and radio shows, and professional papers.

- Invite people from outside the region to assess efforts to improve home and family support. The more network members tell and retell stories related to the theme, the more alive it will become.

- Organize learning journeys by network members. Travel within the region and outside the region to see other's efforts to improve home and family support not only diffuses information it builds relationships among the travelers.

- Hold celebrations around the theme. Conferences, retreats, and meetings give network members opportunities to share their understandings and identify new opportunities for collaborative action.

- Support people who accept the role of "network weavers." People who make the theme and its surrounding network an important concern and act as organizers of theme focused activities need cooperation and practical help from network members.

Participants in the preliminary phases of the Doyon region process have laid a good foundation for improving home and family support. We look forward to hearing stories of what they build together.

APPENDIX A

IMPROVING HOME AND FAMILY SUPPORT IN THE DOYON REGION

A SEARCH CONFERENCE
DECEMBER 1-2-3, 1982

UNIVERSITY OF ALASKA
FAIRBANKS, ALASKA

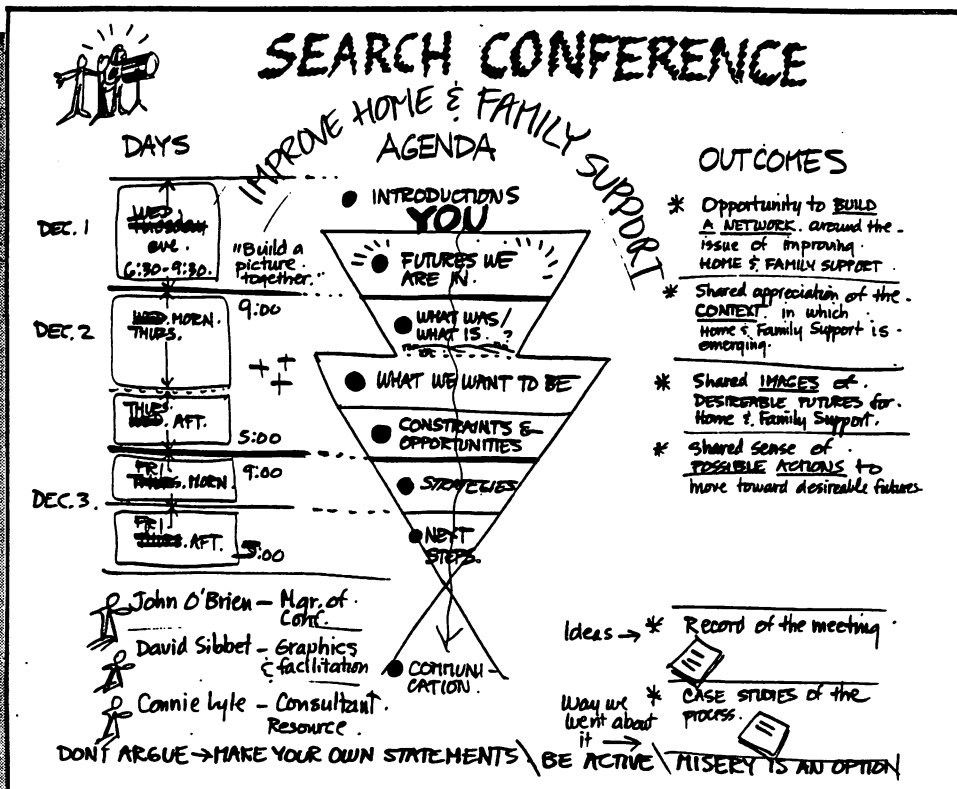
In the winter of 1982 the Governor's Council on the Handicapped and Gifted sponsored a gathering of persons from all over the Doyon region who were concerned about supporting homes containing persons who have developmental disabilities. The conference was designed and facilitated by John O'Brien and Connie Lyle of Responsive Systems Associates and by David Sibbet of Sibbet & Associates - a team with experience in the DD field and specialists at helping people form visions of the future upon which plans can be based.

The charts and computer copy included in this report were created during the Search Conference. The graphics are photographic reproductions of large, full-color wall displays recorded actively during the meetings by David Sibbet. John O'Brien provided the word processed material from records kept by working groups. The entire report is created to serve as a living memory of the conference and not an interpretation.

PREPARED BY: SIBBET & ASSOCIATES
762-16th Avenue
San Francisco, CA 94118
(415) 221-0660

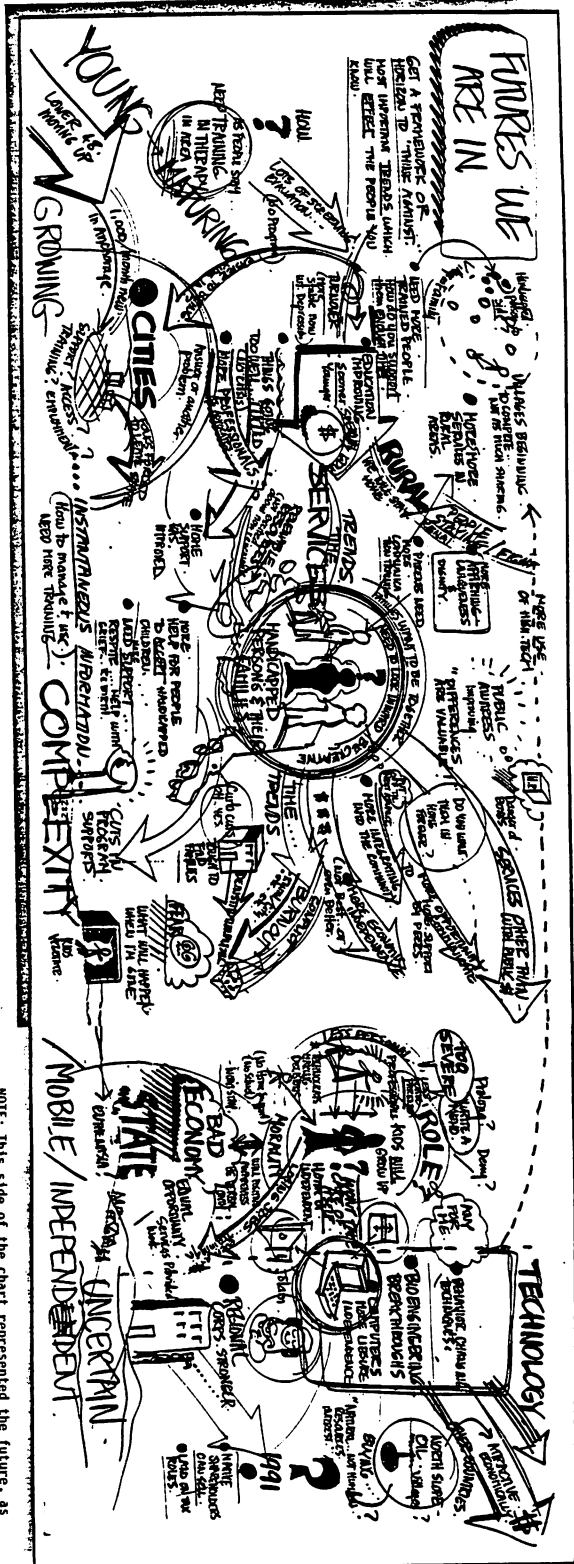
RESPONSIVE SYSTEMS ASSOCIATES
1447 Peachtree Street, NE #811
Atlanta, GA 30309
(404) 987-9785

SEARCH CONFERENCE AGENDA



NOTE: The strategy for the conference was explained at the beginning by John O'Brien. The focus begins big (see middle figure) and narrows, re-expands and narrows again, ending with an identification of specific next steps. The outcomes are described on the right. Some general rules for discussion are noted at the bottom.

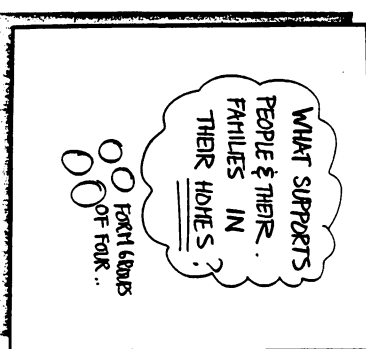
FUTURES WE ARE IN* DISCUSSION



NOTE: O'Brien facilitated a discussion of the trends and forces influencing handicapped persons and their families, represented by Sibbet in the figure in the circle on this page. The discussion moved dynamically, with Sibbet clustering information that went together. Forces on the upswing literally show as arrows moving up. Negative forces identified point down. Notes on the rural situation are in the upper left and cities lower left. Under all is the complexity of the situation.

NOTE: This side of the chart represented the future, as best people could see it.

FUTURES WE ARE IN, Continued



NOTE: As people left for the evening, O'Brien said we would chart the current situation as it applies to the conference theme, stated above. In the morning, the work began in small groups.

NEXT DAY EXERCISE

- How could your relationship with this agency be improved?

- ### 📍 How? Who?

AGENCY: _____

WHO receives	WHAT which home support	WHY to accomplish what	HOW by what means	BY WHOM	TO WHAT EXTENT

WHO receives	WHAT which home support	WHY to accomplish what	HOW by what means	BY WHOM	TO WHAT EXTENT

AGENCY: _____

WHO receives	WHAT which home support	WHY to accomplish what	HOW by what means	BY WHOM	TO WHAT EXTENT
<ul style="list-style-type: none"> • Area served (see map) • Eligibility • Numbers, ages, other demographic characteristics of substantially handicapped people served • Who is excluded... What happens to them? 	<ul style="list-style-type: none"> • Program, service designations • Brief agency definitions 	<ul style="list-style-type: none"> • Anticipated accomplishment for person with substantial handicap <ul style="list-style-type: none"> • measures used • possible measures • Anticipated accomplishment for family <ul style="list-style-type: none"> • measures used • possible measures 	<ul style="list-style-type: none"> • Individual planning process • Means to each objective 	<ul style="list-style-type: none"> • Organizational unit • Competencies <ul style="list-style-type: none"> • Available • Needed • Staff supports 	<ul style="list-style-type: none"> • Size of budget • Proportion of total agency budget • Staff • Amount budgeted for subsidies, devises, equipment, etc.

WHO receives	WHAT which home support	WHY to accomplish what	HOW by what means	BY WHOM	TO WHAT EXTENT
<ul style="list-style-type: none">• Area served (map)• Caseload (Group)• Total number & proportion of people with substantial handicaps• Any specialization?	<ul style="list-style-type: none">• What service do you provide (brief description)				<ul style="list-style-type: none">• Proportion of time spent with people with substantial handicaps?• Schedule
Examples: <ul style="list-style-type: none">• Select a person with a substantial handicap from the group/caseload you feel you work effectively with• Describe the person's/family's needs for home support (Do what, why, how, by whom)• Then, select a person/family you have had difficulty with serving effectively, and repeat	<ul style="list-style-type: none">• What service do you provide this person?	<ul style="list-style-type: none">• What are you working to accomplish for this person?<ul style="list-style-type: none">•• how do you know how you are doing?• What are you working to accomplish for the family?<ul style="list-style-type: none">•• how do you know how you are doing?	<ul style="list-style-type: none">• For each accomplishment, what methods do you use?	<ul style="list-style-type: none">• What skills do you need to work effectively with this person?• What support from your organization do you need to work with this person effectively?	<ul style="list-style-type: none">• What was your schedule with this person--last week? for the past month?

• Which workers from other agencies do you need to work with to provide home support to people with substantial handicaps?

• What do you need from them?

• What do they need from you?

• What is working well for you in providing home support to people with substantial handicaps?

• What makes this work well?

• What do you feel could be improved in the home support you presently provide?

• Do you have any ideas of how these improvements could be made?

• What home supports do the people with substantial handicaps whom you know need that are not available?

• Do you have any idea of how these supports could be developed?

- What makes this work well?

- Do you have any ideas of how these improvements could be made?

- Do you have any ideas about how these supports could be developed?

- Could the ways they work together for your family be improved? If so, how?

CONSUMER/FAMILY MEMBER: _____

WHO receives	WHAT which home support	WHY to accomplish what	HOW by what means	BY WHOM	TO WHAT EXTENT

LOGS

- Please spend some time each evening writing up your overall impressions and the questions & issues that arise for you from the day.
- Save direct quotes for your log. These can be very powerful as a source of information for the Search Conference. Identify each quote by the role of the speaker ("Service Administrator", "Mother", etc.). If you paraphrase, please note it.

MAPS

- Please have each person you talk to locate him/herself on the regional or borough map either by outlining the area in which he/she works or by locating the place he/she lives.

Schedules

- It can be helpful to go through a typical day & week with a person to get some sense of the intensity of home support offered. Don't focus on exact times & durations as this may lead people to think you want to check up on them. What is valuable here is the way a person sees the flow of work.

CONSUMER/FAMILY MEMBER: _____

WHO receives	WHAT which home support	WHY to accomplish what	HOW by what means	BY WHOM	TO WHAT EXTENT
<ul style="list-style-type: none">● Family context<ul style="list-style-type: none">● Who lives with the person?● Extended family available?● Family mobility? (how long at this address, in this area?)● How is this person handicapped?● What is it about this person's handicap that you need help with at home?● What other help does your family need to support the person who is substantially handicapped?	<ul style="list-style-type: none">● What does this person with a substantial handicap do during the day?● Which home support services does the person receive? (For each service, do "Why?"	<ul style="list-style-type: none">● What does this home support service accomplish for you? (For each accomplishment, do "How?"	<ul style="list-style-type: none">● How is this service provided?	<ul style="list-style-type: none">● Who provides the home support service?	<ul style="list-style-type: none">● Schedule

APPENDIX E

POINTS FOR INTRODUCTIONS

- We are part of a study on how to improve home support services for people with substantial handicaps in the Doyon Region sponsored by the Governor's Council on the Handicapped and Gifted.
- We want to get as many ideas and points of view as we can about what will improve home support services for substantially handicapped people, so we are asking people from different parts of the region and from different perspectives to share their ideas with us.
- No one will be identified by name in the report of the study. If we quote people we will describe only their role (eg., "A direct service worker..." or "a family member...")
- People in the region, including the person you are talking with, will be able to decide what action needs to be taken at a Search Conference that will be held in December.
- There will be a written report which people can get from the Governor's Council Office in Fairbanks.

NOTES

- If a setting--eg., a day care-- is not presently serving anyone with a substantial handicap, explore what they feel would be necessary to do this.
- If a person's home support system has failed, try to get a description of how it has failed and any ideas the person may have as to how to improve things.

DEFINITIONS

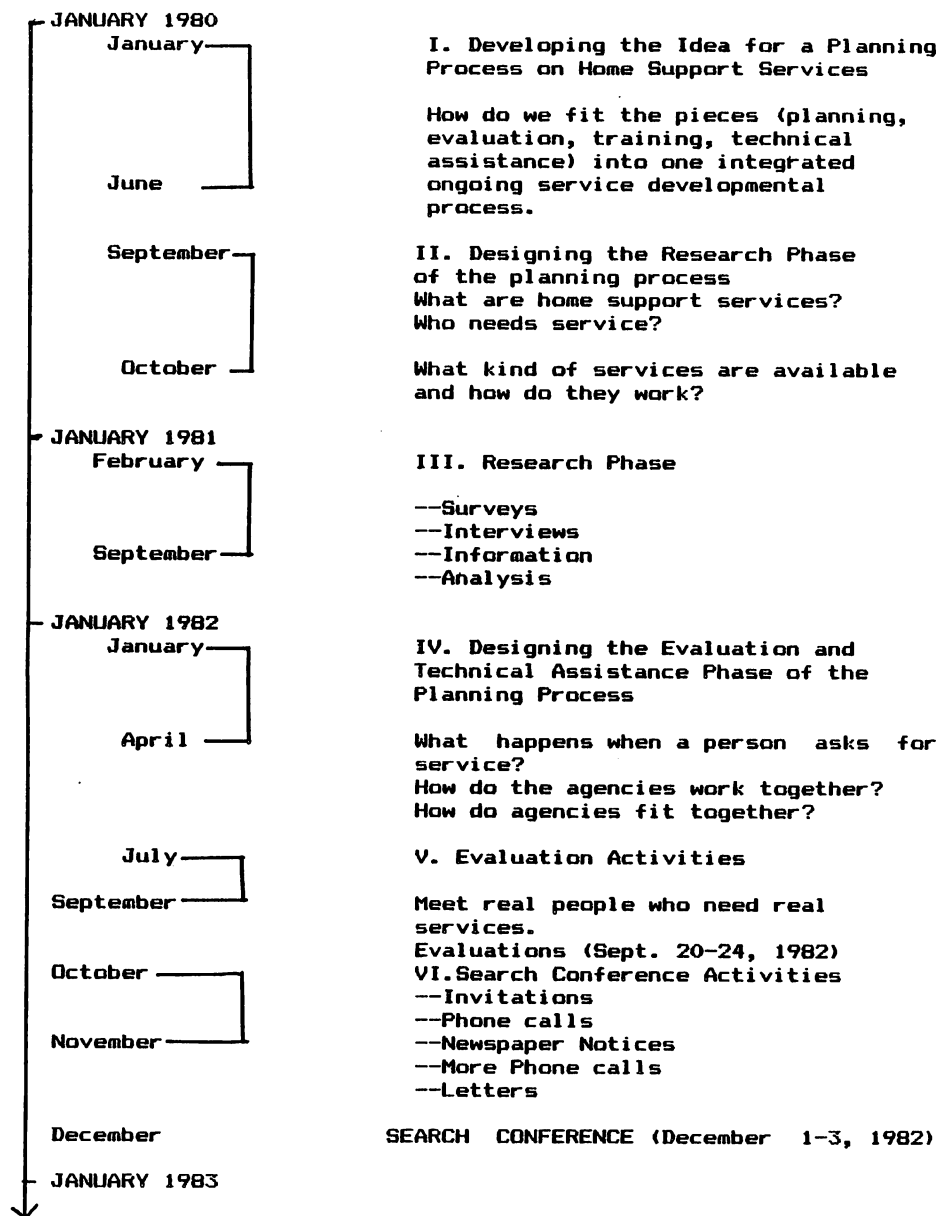
- "Person with a substantial handicap" -- A person likely to need well organized, consistent, long term support to maintain him/herself in a community setting. For this study, does not include: elderly people; people with chronic mental illness; people with alcoholism; or, people whose need for home support is not long term.
- "Home Support Services" -- Services other than residential or day services (education, work, etc.) which assist a person to stay in or return to his or her own home. Services which assist a person's family to provide adequately for his/her special needs.

latter hope did not materialize.

Special efforts were made to assure consumer participation. Although our unwritten policy was to show no special treatment of any particular group, person, or agency in publicizing the conference, in the case of consumers, we did make special efforts. A list of people who were called and invited to attend. If there were special circumstances surrounding their attendance (like transportation or the need for an interpreter), these arrangements were made. We also asked agency people in Fairbanks to assist us in contacting consumers and letting them know that they were especially invited to the meeting. To assure participation by consumer from the villages, we asked the Tanana Chiefs contact person to try to ask at least one consumer among the three people from each village that could attend and be reimbursed by Council funds. These special efforts really were worth the effort--the balance of consumers:others attending the Search Conference was approximately 40%/60%.

One of the ways we kept track of all of the arrangements was to set up a master filing system in which we kept records of the types of contacts that were made with each individual invited to the conference. This master filing system proved invaluable for at any time we could tell how many people had responded to the invitation, needed special assistance, or had been sent confirming letters.

TIMELINE OF ACTIVITIES LEADING TO THE DECEMBER 1982 INTERIOR ALASKA HOME SUPPORT SERVICES SEARCH CONFERENCE



suggested by ageancies and/or people already interviewed in the research phase of the planning process).

VI. SEARCH CONFERENCE ARRANGEMENTS

The arrangements necessary to plan the "Search Conference" took approximately one fulltime work month. This work was spread out over the months of October and November 1982. In sequence, the activities conducted prior to the "Search Conference" are listed below. It should be noted that the Council staff and the Responsive Systems Associates had a meeting immediately after the evaluations were completed at which time the contractor outlined certain criteria they felt necessary to assure the success of the "Search Conference". Those criteria were:

Advertise the Search Conference sidely.

Try to organize a core group of people (preferably consumers) to help plan the Search conference.

Find a stable room, the larger the better, with good lighting and access to eating and change of scene to encourage people to stay during the whole period of the Conference and be comfortable in their surroundings.

Try to have a balance of people with different "stakes" in attending the meeting. It is especially important to make special arrangements to encourage consumer participation so details like an accessible facility, arranging for necessary transportation, interpreter services, etc. are really important.

In advertising the "Search Conference", do not promise that "big deals" are going to be struck during the meeting. The idea of a "Search Conference" is that the people who are participating come up with the ideas on how to solve problems based on their individual and collective personal experiences.

The following is a sequential listing of activities that preceeded the "Search Conference."

Based on the amount of funding available to pay per diem and travel costs for people, we decided to ask people from the villages of Fort Yukon, Galena, and Holy Cross to come to the Search Conference to give us their ideas on how services ought to be developed in thier communities. We needed to make arrangements through a contact designated by Tanana Chiefs Conference in each of those communities to arrange t get people to attend. There were several phone calls and letters exchanged over the two-month period to make the necessary arrangements to get people to the meeting.

We started searching for a suitable room in early October and found the availability of a suitable room to be an unforeseen

obstacle to planning the meeting. Because we were not sure about how many people would be attending, we were hoping to find a very large room that was barrier-free, had meal service close by, and has appropriate lighting. This proved to be a real problem. We finally decided to preliminarily book three separate locations and cancelled two at the last moment. In retrospect, making arrangements for appropriate space for the meeting was the biggest frustration in making meeting arrangements. We finally settled on using a relatively small room at the Wood Center, University of Alaska, as that facility had all the amenities we were looking for but the size was questionable until the last moment when we were finally fairly certain of the attendance.

We developed a mailing, describing the Search Conference, and distributed it widely, using lists of people who had been on evaluation teams in September, all of the agencies whom we had contacted in the research and evaluation phases, consumers who had been interviewed previously, elected officials (both local and state-level representatives) and others whom we knew from past experience would be interested in this type of conference. This mailing went out in mid-October and people were asked to respond by November 15. The announcement made clear that participation was by prior registration. This process worked fairly well, but we found that lots of people waited until after the deadline for responses to let us know that they were interested in attending. We allowed these late registrants to participate, up to room capacity. We had to turn about five people away because of lack of room. In the future, if a larger room could have been arranged, this number of people wanting to attend would not be a particular problem.

Each participant was sent a confirmation letter, detailing the particular travel and lodging arrangements made for him/her, about two weeks before the conference. The letter included a copy of THE FUTURE OF HOME AND FAMILY SUPPORT SERVICES IN ALASKA'S REGION: A FOCUS DOCUMENT FOR A SEARCH CONFERENCE. Participants were asked to read this document before attending the meeting to help them focus on the purpose of the meeting. In the confirming letter, we stated that people were expected to attend fulltime, trying to minimize the typical issue of people attending conferences only part-time and spending the rest of the time taking care of other business.

Press for the Search Conference included a legal block and placed in the local newspaper twice--about a week before the meeting. Additionally, a local column, "The Safeway News" carried a short description of the conference. In both cases, it was made clear that attendance was by preregistration (because of the problem with the size of the meeting room). A local newspaper reporter was also contacted and given background information on the conference in hopes that a feature story would be written after the conference. This

improving locally available home support services for people with handicaps and their families. Training in group process techniques and technical assistance on how to work constructively within a group to arrive at mutually-agreed decisions were parts of the design of the "Search Conference."

V. EVALUATION ACTIVITIES

During the week of September 20-24, 1982, evaluation activities were conducted. The evaluation process was very different from what is the typical evaluation of an agency or service. Approximately 25 Alaskans, about one-half of whom had been trained in a PASS workshop, were involved in conducting the evaluations. The people were divided into five (5) teams and assigned to visit with every known service provider in Fairbanks, Fort Yukon, Grayling, and Holy Cross, Alaska to discover how home support services were being delivered. Additionally, each evaluator visited with at least two consumers to ascertain their opinion about how services should be designed and delivered. The purpose of the evaluation was not to "rate" individual agencies, but to find common themes of issues and needs to be addressed in order to improve local development of services.

This evaluation process asked in-depth questions about how people get services from an agency. How does your agency make sure that people are really getting the services to which you referred people? What services do you think are lacking for people with handicaps and their families in this community? If you would like to provide more/different services to people with handicaps and their families, what services would you provide? Why? How are consumers involved in designing services provided by your agency? Outside formal services, how do people with handicaps and their families get support in this community? To consumers, questions such as the following were asked: What kinds of help do you get that enables you to live in your own home (or keep a handicapped family member at home)? Who provides this help? What kind of help do you need that you are not currently getting? Who would you like to see provide this help?

Following the individual team efforts, the evaluators met as a group to identify the major issues that needed to be addressed. The results of the evaluation activities are compiled in THE FUTURE OF HOME AND FAMILY SUPPORT SERVICES IN ALASKA'S DOYON REGION. (available at the Council office).

It should be noted that the logistics involved to enable these evaluations to occur were quite time-consuming and complicated. The Council staff was responsible for logistical support for the evaluation efforts. Approximately one fulltime month of work was required for making arrangements for the evaluation. The following is a step-by-step outline of the activities leading to the evaluations:

July 1982

Outline the agencies to be contacted and possible communities to be visited. Analyze the issue of balancing the desire to get a comprehensive view of how services work in various parts of the region with a limited budget for travel.

Begin contacting agencies in Fairbanks individually to ask them to participate in the evaluation process. Phone contacts were made initially, followed up by individual visits if agencies seemed reluctant to participate. Requested agencies to supply brief written information on their services.

Contact all people who were trained in PASS to ask them if they wished to participate in the Doyon Region evaluation.

Contact people at Tanana Chiefs Conference to find the best way to get contacts in villages for purposes of conducting the evaluations. (NOTE: The administrative staff at Tanana Chiefs Conference needed to clear the participation of the Tanana Chiefs Sub-regional staff located in the villages of Holy Cross, Galena, and Fort Yukon. The Sub-regional staff was then contacted for assistance in getting the approval of the traditional village councils for the evaluation teams to visit in the village).

August 1982

Make follow-up phone calls/visits to agencies in Fairbanks to schedule their participation.

Send confirming letters to people chosen as evaluators (both people from outside the region who had been trained in PASS and people in the region who were known to be respected in their communities and interested in the provision of home support services).

Make follow-up phone calls to the Tanana Chiefs Conference sub-regional staff regarding getting a "host" in each of the villages to accompany the evaluation teams on their visits with agencies and consumers.

Begin to book motel and air reservations for evaluators.

Review the budget to make sure that the travel funds designated for the participants in the evaluation phase and the Search Conference would not be over-extended.

September 1982

Work out final schedules for the evaluations. Make up a master file of each team's schedule. Call the participating agencies to confirm their participation. Get a list of consumers to whom the team members could speak about home support services concerns. (The names of consumers were

II. DESIGNING THE RESEARCH PHASE OF THE PLANNING PROCESS

In September and October 1980, the Planning and Evaluation Committee designed the strategy for the research phase of the planning process. The Council set aside \$20,000.00 for this research. It was decided that the available resources dictated that the scope of the research phase be limited--both in terms of subject matter and geographic scope. The Doyon Region (Interior Alaska) was chosen as the geographic area in which to conduct the research. The Doyon Region was chosen because it was felt that this area of Alaska was fairly prototypical of the population patterns and geographic conditions of much of Alaska--a vast area with a relatively large population center and many smaller communities and villages scattered throughout the area accessible only by water or air.

The scope of the research activities was outlined as follows:

- Define the term "home support services" by identifying the discrete services which together comprise "home support".
- Provide working definitions of each discrete "home support service".
- Identify the location, ages, and disabling conditions of all people with substantial handicaps living in the Doyon Region.
- Ascertain consumer opinion of home support service needs.
- Identify the number, type, and scope of home support services currently available in the region.
- Analyze the strengths and weaknesses of currently-available programs.

III. RESEARCH PHASE

From March-September 1981, the Council hired a temporary employee to conduct the research activities as outlined by the Planning and Evaluation Committee. A local advisory committee, constituted by providers and consumers living in the region, was formed to provide ongoing advice to the staff hired to conduct the research. The research activities resulted in the publication of the INTERIOR ALASKA HOME SUPPORT SERVICES STUDY available at the Council Offices.

The Council staff made a deliberate attempt and concerted effort to visit several bush communities in the process of conducting the research phase of the planning process. Over 150 personal interviews with disabled people or family members were conducted to ascertain consumer opinion of service needs and service design. The trips to villages and the interviews with consumers re-affirmed the importance of including consumers in this and any service planning process.

IV. DESIGNING THE EVALUATION AND TECHNICAL ASSISTANCE PHASE

After receiving the report of the research phase, the Council decided that the evaluation and technical assistance phases of the planning process must foster local development of services. This decision was based on the fact that consumers interviewed during the research phase indicated their desire to see local development and control of services, especially in rural parts of the region. It was decided that further work needed to be done to identify the administrative and coordinating activities of existing agencies to ascertain what barriers and resources there might be for local design and delivery of services. It was also decided that the best way to get input on how to develop and improve local services would be to call together people from throughout the Doyon Region to sit together and talk about the issue.

A "Request for Proposals" (RFP) was designed to seek a contractor to assist in evaluating the system of currently-available home support services and to facilitate a gathering of local people to give direction to the design of locally-available home support services.

The RFP called for utilizing an evaluation activity that would look at how services fit together and whether or not they were responsive to local consumers' desires for service delivery. The RFP suggested that the PASS (Program Analysis of Service Systems) evaluation system be used as the base for development of the proposed evaluation of the system of available home support services in the Doyon Region. PASS is an evaluation system which looks at the quality of services from the perspective of the principle of normalization. The specific inclusion of the PASS evaluation system in the RFP was a result of the fact that the Council had committed considerable resources in 1981 to train Alaskans in the PASS evaluation system and had previously conducted PASS evaluations of services located in Valdez and Anchorage. It was envisioned that the Alaskans already trained as PASS evaluators could be a tremendous resource to use in conducting the system-wide evaluation of services in the Doyon Region.

A contract was awarded to Responsive Systems Associates of Atlanta, Georgia to facilitate the evaluation, training, and technical assistance activities. Responsive Systems Associates proposed to facilitate the evaluation portion of the contract by leading a group of Alaskans (some of whom were PASS evaluators) in looking system-wide at the home support services available throughout the Doyon Region.

The training and technical assistance phases of the contract would be encompassed in a "Search Conference" to follow the evaluation activities. This "Search Conference" was envisioned as a calling together of interested people from throughout the Doyon Region to sit together to try to find answers to the issue of

APPENDIX C

TIMELINE OF ACTIVITIES LEADING TO THE DECEMBER 1982 INTERIOR ALASKA HOME SUPPORT SERVICES SEARCH CONFERENCE

LAURIE GOGGIN

APPENDIX C

The "Interior Alaska Home Support Services Search Conference" held in Fairbanks on December 1-3, 1982 resulted from over two years of preliminary planning and development activities. The "Search Conference" is viewed as a step in an overall planning process designed by the Governor's Council for the Handicapped and Gifted (GCHG) to foster the development of locally planned and designed home support services for Alaskans with handicaps and their families.

I. THE IDEA FOR A PLANNING PROCESS ON HOME SUPPORT SERVICES

In early 1980, in the process of developing the F81-83 State Plan for Services to Persons with Developmental Disabilities, the Council laid the groundwork for planning and development activities related to improving the local availability of home support services for Alaskans with handicaps and their families. For several years, the Council had been conducting planning, evaluation, technical assistance, and training activities aimed at improving the availability of community-based services for Alaskans with handicaps and their families. It was decided that the time had come to find a way to link these separate activities of planning, evaluation, technical assistance, and training on single issue so that limited resources of the Council could be used in a focussed effort to improve services.

In the state plan development process, "Community Living Services" was chosen as a priority service area because a disproportionate amount of funding was being spent on institutional care for people with handicaps while people with handicaps and family members were saying that they wanted services available at the local level which would assist people to stay in their own homes and communities.

The Council directed that a three-year planning process be designed that would produce a model for local development of community residential options and home support services. The Council further directed that the planning process attempt to incorporate a number of different planning tools--research, evaluation activities, technical assistance, and training. We weren't sure how to do this, but originally envisioned working on home support services the first year, community living services the second year, and producing a master plan which would target allocation of resources for new services the third year.

CONFERENCE EVALUATION

WHAT WORKED FOR US

- + graphic recordings—keeps attention
- + small groups
- + talking/sharing as big group
- + positive reinforcement
- + finding out about villages
- + facilitators wouldn't tell us what to do (A NOVELTY!!)
- + repetition...where we've been...where we're going...giving reasons
- + getting objective overview—focusing on issues
- + learning a PROCESS we can use...work & personal
- + opportunity to DO IT
- + mixture of consumers and service providers healthy
- + positive energy John, Connie, David threw out—"You're special"
- + VICE VERSA!
- + nobody dominated
- + having an interpreter
- + sharpened awareness of Alaska...with specifics for job & responsibility.
- + opportunity to do more
- + excitement of different ideas...snowballing
- + holding to a schedule
- + came down to CONCRETE THINGS
- + accessible place
- + good food
- + blank walls (plenty of room to write and stick papers)
- + NEW/old friends
- + adequate lighting & temperature
- + THANKS SCHG!! LAURIE AND DOT!!
- + no smoking
- + with graphics, didn't have to take notes
- + Ludi contributing

NOTE: At the very conclusion on Friday, Sibbet and O'Brien sat down and listened to the group provide some feedback on what worked and what could have been improved. The notes are included to help any future groups have an even better conference.

WHAT COULD HAVE BEEN BETTER?

- didn't end on time
- work & breaks mixed was hard
- 3:30-5:30 burn-out Day 2
- size of room limited access...people turned away...both consumers and providers
- more time to just VISIT
- use VTR...segments to take back (would have inhibited some people, could possibly have staged some sessions with David and John and taped some small group work if participants did not mind)
- TYPE of space not ideal...where do we go in breaks?
- use tables
- didn't get to smoke

NEXT STEPS, Continued

P.A.D.D...

LEGAL RIGHTS MANUAL (NO FEE. AIMED. BY SERVICE PROVIDERS)

PAULI ... 456-1070

NO GRANT FOR SPECIALIZED FOSTER CARE

IN-HOME TRAINING (Audrey) **ATTENDANT CARE** (Lauri) **EXPLORE FOSTER CARE** **E.D.A.Y. CARE**

Contact: **BILL FRA** 456-8901

FRA Newsletter on this conference. Quarterly (Contact Susan DeKrey to be on list)

COLLEGIANS HAVE AN APPLE II PLUS

Available for Training: **Patch** HO4 Juneau **BOB GREENWICH** 465-3370

RENEE WILL GET MORE INVOLVED IN ACCESSIBLE HOUSING

DAY CARE

GCHS ... WORK WITH Council to see what we can do further on priorities. **Connie** **John** **David**

Ludi will corner legislators.

Letter to new Gov.

Buy GCHG

SEARCH CONF. IN ANCHORAGE (IN-HOME SERVICE DELIVERY)

DO SOME TEACHING. PREPARE BUDGET ITEMS FOR CONSIDERATION.

NEXT STEPS

NEXT STEPS

WHAT WILL I DO WITH ALL THIS?

ANCHORAGE BASED INDEPENDENT LIVING PROGRAM (WITH ALASKA IND-LIVING) ... **specifics on priorities**

PUSH TO McGrath & inform parents on RIGHTS & their involvement.

CHS. A model ADVISORY BOARD (IN-HOME TRAINING PROGRAM)

Call about a foster home (Contact FEA)

Involve consumers in Galena INTER-AGENCY group (Schools, Parents, Service)

Involve New parents in PARENTS OF AUTISTIC CHILDREN & HOME COPIES ... hook them to activities in Anchorage

ACIL consumer activity ... "CLEARINGHOUSE" ... by consumers

GCHS UMBRELLA FOR GROUP THINGS

See if ARCO or someone could support

Find out about SCHOOL/HOME liaison program → take back to KENAI

Make IN-HOME TRAINING MANUAL (Need help & time)

Bring up facts w/ Community agencies ... How to communicate & use Interpretive services

F.N.C.D. Workshop (Fair North Club Crisis line)

Troy Davenport ... 92297 College, Alaska 474-4284

HAVE NEWS ... "HANDICAPPED HAPPENINGS" ... form a team of speakers

Approach Gov's Council of the H.S.E. about calendar ... Offer support from Anchorage

Conf's ... When Where New Groups

Public awareness ... 465-2777

Appoint a director ... Have handicapped people on Committee

GET BUBBLES ROLLING

Call Problem Corner

Call Line ... 852-3497

NOTE: As discussion wound to a close on the specific small group plans, the group as a whole looked at next steps that seemed possible. The ideas are listed one by one. Written on a slant are names and numbers of persons who said they would take responsibility for followthrough.

Persons involved:

Arctic Alliance for People Programs
Consumers/advocate task force to be set
up by AAPP.

Time frame: March 1983

OBJECTIVE 2: Obtain funding to assist 10 low/moderate income persons with handicaps to renovate their private residences and/or provide adaptable equipment

ACTION PLAN:

Contact Candace Magnusson to request that \$150,000.00 be set aside in the FY 84 Block Grant funding.

Persons involved: Arctic Alliance for People Programs (AAPP)

Time Frame: March 1983

3. DAY CARE

3.1 GOAL: To have Day Care opportunities available to families with handicapped family members

ASSUMPTIONS:

1. There is a need for both persons under and over 11.
2. That there is no formal service presently available in the Fairbanks area that even begins to meet the need.

3. That there are resources available who are interested in doing this.
4. That there may be a funding problem for low income families with family members over the age of 11.
5. That is a need in general for quality day care in the area

OBJECTIVE 1:

To make available day care for individuals with handicaps who are over 11 years of age—which includes both formal & informal mechanisms

FORMAL

ACTION PLAN:

Contact FIAC to see if they have any interest in providing such service.

Write a grant to Division of DD to provide seed money for training of staff of generic day care centers and homes on environmental and care needs of special people

People involved: FRA

Time frame: February, 1983

INFORMAL ACTION PLAN: Develop a plan to determine how to get more neighborhood and community involvement in such care provision

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4. FOSTER CARE

4.1 GOAL: To increase the ability of the community to provide Specialized Foster Care for severely handicapped persons in the Fairbanks community by 4 persons

ASSUMPTIONS:

- 1) Institutionalization must be avoided at all cost.
- 2) There are four area persons presently institutionalized who could better thrive in a home environment.

OBJECTIVE:

Placement of 4 previously institutionalized persons or persons at risk of institutionalization in area home during FY '84

ACTION PLAN:

Develop a grant proposal

Persons involved: FRA

Time Frame: February, 1983

Consumer group:
Lavedi Lafferty
Lurisse Ulen
Glenda Moore

Advocates:
Laurie Goggin
Bill Repicci

c) Time Frame: Before Christmas contact
Bill Allen for meeting.

d) Measurement: Commitment from mayor to
put effort into determining a system
of transportation.

2. HOUSING

2.1 GOAL: That accessible housing does not
become a barrier to handicapped people
living as independently as possible in the
community.

ASSUMPTIONS:

1. That people who are handicapped want &
need to have a range of housing options
available to them:

- a) to purchase a home.
- b) renting apt's/houses.

2. That builders/contractors are not aware of
the need.

3. That housing in general is tight and
expensive in Fairbanks.

4. That many persons with handicaps have
low incomes and cannot afford market rate
housing.

5. That builders do not know how to make
housing accessible.

6. That state/federal agencies (ASHA/HUD/HFC)
do not have local decision making offices
in Fairbanks.

7. There is funding available (public) for
housing projects.

OBJECTIVES:

To obtain 10 affordable/adaptable rental
units in the Fairbanks area by Sept 1984.

ACTION PLAN:

a) Find out where funding is available,
including:

—call
HUD office
Borough
City
Community Development Block Grant

b) investigate contractors (private);
use Chamber of Commerce, Alaska General
Contractors

c) collect list of persons needing
housing & the specific housing needs.

SERVICES AND SERVICE DELIVERY

- (1) transportation (bus system)
- (2) day care—over 11 and under 11
- (3) attendant care
- (4) housing (accessible)
- *(5) in-home training
- (6) specialized foster care

Goal	improvement of systems (red tape)
Assumptions	increase flexibility in state agencies
Objective	how to make services local & individualized
Action Plan	referral/follow through with information system
Persons in- volved	
Time Frame	
Measurement	

1. TRANSPORTATION

GOAL: To make the community of Fairbanks
accessible to persons with handicaps in regards
to transportation.

ASSUMPTIONS:

- 1. That there are people with handicaps who
need transportation services.
- 2. That the people in need and the types of
needs have been identified.
- 3. That there is capital money available to
buy vehicles.
- 4. That local gov't has the responsibility to
provide such transportation.
- 5. That the service needs to be designed
locally due to uniqueness of the area.

OBJECTIVES:

- 1. To determine a system or combination of
systems to meet the identified
transportation needs.

1.2 Action plans:

a) to lobby the Borough for action
on the issue by talking to the mayor
and convincing him of the need for a
consumer action committee.

b) persons involved:

Borough Mayor—Bill Allen
DOT—Transit Director
Transit Advisory Committee

VILLAGE NEEDS, Concluded

- 4) How do you "cope" with paperwork overload?
 - 0 Donated time from an already trained secretary.
 - 0 In Village "mobile" secretary as HHA team member.
 - 0 Use school district sponsored computer training to transfer records to data-base/i.e. for ease of management of records, etc.
 - 0 Utilize existing "paper management" sources in Village— City Clerk, City Manager's office, etc.
 - 0 Establish a roster of data/info. gatherers who will make home visits.
- 5) Biggest changes occurring as a result of the HHA Program?
 - 0 Happiness index goes up!
 - 0 Elders remain in Village—are not sent to Fairbanks.
 - 0 Foster Grandparent notion is started.
 - 0 Services more equitably/equally distributed.
 - 0 Opportunity for someone to GO to you to COME to you.

HOORAY! YEAH TEAM(WORK)!

STRATEGY DEFINED:

ADVERTISED POSITION (HHA) VILLAGE WIDE SOUGHT:
FOUND INDEPENDENT FUNDING SOURCES. TAPPED
AVAILABLE EXPERTISE. PROFESSIONAL/ITINERANTS
DESIGNED-CARRIED OUT TRAINING PROCESS
PLANNED FOR ON-GOING CONTINUOUS TRAINING.

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COMMUNICATIONS

GOAL: One system capable of acquiring and disseminating information on exceptional people.

ASSUMPTIONS/ GIVENS:

1. System doesn't exist.
2. People need it.
3. Technology is available.
4. People don't have information.
5. Some technology is in place.
6. People will use it.

OBSTACLES AND OPPORTUNITIES

1. Getting the funding for system.
2. Agency Ego—competition for funds, clients and jobs.
3. Indifference— it's someone else's problem.
4. Eliminate redundancy.
5. Linking vast geographical areas.
6. Turnover of people.
7. Training people to get information.
8. Resistance to change—fear of taking risks.

TYPES OF COMMUNICATIONS

Active advocacy.
SEARCH for legislators.
"Handicap Happening's" —public awareness.
Develop one service delivery system.
Link local agencies.
Barter systems—(consumers/service providers).
Professional with time to communicate with clients.
Schools communicating with parents.
Public awareness.

HOW TO

- a. Identify a person(s) in each community we can who would be willing to coordinate a local effort of developing a list of

- (1) speakers (disabled, others)
- (2) films, tapes, etc.
- (3) Media opportunities

and who could conduct lobbying activities.

- b. Statewide calendar of events/possibilities about awareness/activities

- staff
- money (xerox, etc.)

VILLAGE NEEDS, Continued

4. The villages get the left-overs!!

Seek other/additional funding sources to eliminate being "locked in" to existing systems. Develop "better" on-site communication with alternative "language" formats. (Recognize the existing culture as a possible barrier).

5. Trainers are unavailable.

P.A.'s and PHN's to "share" skills, knowledge in a different than usual way!

6. Can't hire relatives.

Change the "rules." Options for funding—using other sources—FREEDOM!!

7. Paperwork, i.e. RED TAPE.

Job opportunity for "somebody."

December, 1983 INTERVIEW FORMAT USED:

1) Who ended up paying the bill?

- ☐ Lion's club came through.
- ☐ Auctioned
- ☐ Bingo twice per week, with Wed. proceeds going to a special fund.
- ☐ Area Office on Aging
- ☐ TCC helped with funding

2) What was done to find a person for HHA position?

- ☐ TCC helped organize interviews.
- ☐ Publicized via radio, TV.
- ☐ Advertized at local village level—posters in public places.
- ☐ Called to V.H. Aide, visiting PHN—with their help a job description for HHA was developed.
- ☐ Spouse came up with who would—could work well with a disabled person.
- ☐ HA + alternate HA aides—as candidates for HHA position.

3) How did training effort get underway?

- ☐ Tapped "available" training aides, i.e. VTR's.
- ☐ Volunteered help from village based "outreach" person.
- ☐ Sent candidate to training in FAI.
- ☐ An "alternate" candidate is always included.
- ☐ Wrote to ANC for "sources" of HHA training.
- ☐ Joined AK film club—for film resources. 1 film per week schedule in village.
- ☐ Using PHN as itinerant "trainer"/consultant.
- ☐ Sought out, utilized ANC based resource person to provide specific skill training on site.
- ☐ Using itinerant M.D. to provide on-site training.
- ☐ Area Office Aging saw advantage of fiscal support for training.
- ☐ World Health Organization (WHO) as a literature, training material's source.

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VILLAGE NEEDS

Villages need:

- ☐ More hours for homemakers.
- ☐ Training:
 - Getting the training.
 - On going without professional.
- ☐ Inter-agency potential at site.
- ☐ Sorting out the sources of assistance:
 - What providers?
 - Where providers come from?
 - What providers can/cannot do?
- ☐ Home Health Aide:
 - Training.
 - Program/process/procedures.
- ☐ Inside/outside communication:
 - Understanding communication system.
 - Learning to use the system.
 - Changing the system.
 - Adapting the system.

GOAL chosen from above needs:

A home health aide in EVERY VILLAGE.

ASSUMPTIONS:

1. Someone in Village who wants to be HHA.
2. Someone in Village who needs assistance.
3. There is a funding source.
4. There is a training source.

OBSTACLES/OPPORTUNITIES

1. Funding source non-existent.

There is funding through HM services, Area Office on Aging, etc. Go to legislature through existing channels. "Piggy back" for start-up. Profit Native Corporate Structure, Municipal Aid Grants. Opportunity creatively examine village based sources (raffles, bingo, door to door, Lion's club, dog mushers, city itself.)

2. On-site need for HHA not known.

To systematically assess the "true" need—conduct needs assessment. Go through schools SW, PHN, Local Health Aides, churches, Village Police, State Troopers, TCC, Village Mayor, Leader, Elders.

3. Training available is poor.

Use available expertise to create a training process. Use a procedure unique to village site!! Training on-site, but needs to be shared too—regional + area-based.

COMMONALITIES AMONG "SOMEBODY OUGHT TO"

- 0 In-home training (1) (3) (18) (19)
- 0 Out of home training (6) (9)
- 0 Village needs
- 0 Communication (Helping People Helpers) (1) (4) (8) (9) (10) (12) (13) (23)
- 0 Services Design & Development (2) (7) (13) (17) (22)
- 0 Jobs (5) (15)
- 0 Technology & Equipment
- 0 Transportation

NOTE: This list shows what the group clustered on the previous page.

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IN HOME TRAINING IN GALENA

NOTE: The following pages are reproduced from the word processor transcript of small group plans produced in four topic areas.

IN HOME TRAINING IN GALENA

VILLAGE NEEDS

COMMUNICATIONS

SERVICES AND SERVICE DELIVERY

Each group was free to to develop its own plan, following whatever process seemed best to generate a good discussion.

POPULATION to be served—Elderly, handicapped, DD (?)—We had already gotten into this assuming to be developing program for people with DD, when we asked a group member how many people with developmental disabilities live in Galena. We discovered that to our knowledge there are none. Our plan would be appropriate for elderly and physically handicapped people who live there and would also serve people with developmental disabilities if any are born or move here.

FUNDING: Native corporation
Legislature
Parents
Church

PROGRAM: Homemaker/health aide (would probably be same person) Person would be chosen by the Village Council.

Train the person and families who are interested. This person then would be able to:

- 0 Train others in respite/training
- 0 Follow-up training of interested families
- 0 Liason work with school, agencies
- 0 Advocacy
- 0 Contract to outside agency to monitor payment to individual

This model can be used in other communities

- 0 Originating with the community.
"Professionals" used for the training would participate in the grant writing
- 0 Focus on existing resources
- 0 Use of telecommunication with
"professionals" & periodic follow-up

- 7* **KEEPING RED TAPE TO A MINIMUM.**
 - ~~paperwork reduction~~
 - license for handicapped persons.
 - doctor permissions
- 8* **BARRIER SYSTEM.**
- 9* **ACTIVE ADVOCACY**
 - Assistance representation.
 - Leg. advocacy.
- 10* **FIND, STRENGTHEN COMMUNICATION LINKS BETWEEN LOCAL SUPPORT SYSTEMS**

NOTE: All the ideas clustered into several categories. The group then narrowed these by seeing who would be in which groups. The four which generated task groups were: In-home training; Village Needs; Communications; Services and Service Delivery.

-
- 20* INCREASE FLEXIBILITY IN STATE AGENCY SERVICES
- 21* RELATING TASKS (HOURS) TO NEEDS
- 22* IMPROVE SCHOOL DISTRICT & FAMILY COMMUNICATION
- 23* BRING PEOPLE TOGETHER
- WOMEN'S TRAINING
- VILLAGE NEEDS
- CUT OFF HOME TRAINING
- COMMUNICATION



SOMEBODY OUGHT TO -- IDENTIFYING TASK GROUP TOPICS

SOMEBODY
OUGHT TO
WHAT WOULD START A...
SNOWBALL?

TONIGHT

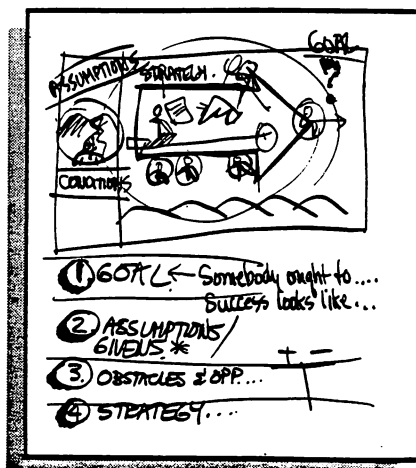
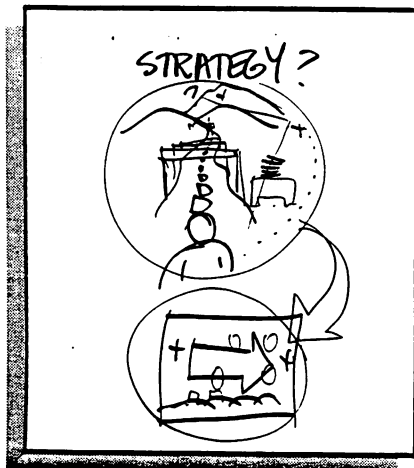
SOMEBODY OUGHT TO...

- 1 * HAVE A SEARCH CONF. FOR LEGISLATORS.
 - 2 * GET A BUS SYSEM.
 - 3 * HELP TRAIN PARENTS FRIENDS IN THE HOME. *... who actual help with training*
 - 4 * HANDICAP HAPPENINGS. *... I mean I mean I mean*
 - 5 * JOBS .. DEVELOPMENT
 6. *POSSIBLE CHALLENGES*
 - * SUPPORT GROUPS ... Beyond just state.
- (EXPLORE NEW AREAS, ANGLES)

15. * EVALUATE APPROPRIATE TECH — INDIVIDUAL NEEDS
16. * GET ACCESSIBLE HOMES & EQUIPMENT YOU NEED

17. * HOW TO GET VILLAGES THE SERVICES THEY NEED

18. * GETTING HELP TO HELP
Self help group startups
19. * TRAIN HOMEMAKER S' ON HOW TO TRAIN IN VILLAGES
Homos relate to needs not politics

NOTE: John had the group imagine those things that somebody really ought to be doing, and use the criteria of "what would start a snowball effect" as a way to decide what ideas to share. The chart on the far left was drawn the night before. The following charts record the ideas people generated. They are numbered, and then clustered on the following page.

THINKING STRATEGICALLY



NOTE: John O'Brien asked David Sibbet to begin the morning with a short talk on the nature of strategy.

Sibbet talked about the principle view of an action oriented person as being like down a road. The immediate obstacles seem closest (see far left illustration).

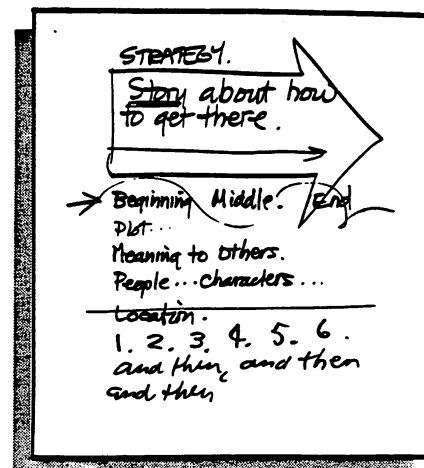
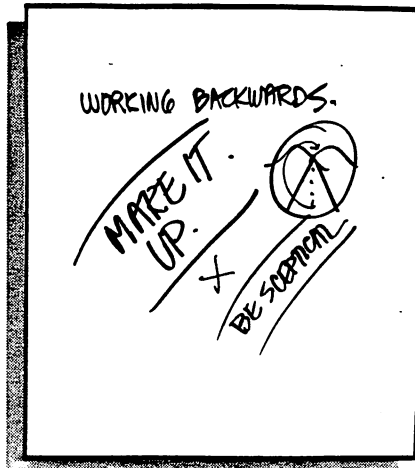
Strategy requires having an image of entire route of travel and various alternatives. This means getting off the road for a bit and developing a sidelines view. (see second illustration). From the side all the various hills and valleys are clear. Four things can be looked at:

1. The goal where you are heading.
2. The assumptions and givens or where you are coming from.
3. The obstacles and opportunities on the route of travel
4. Strategies or stories about how the trip is going to go.

With this view in mind, then one can return to the action and the "down road" view.

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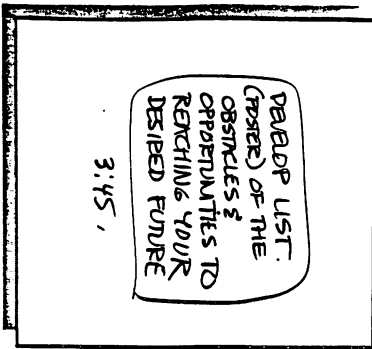
THINKING STRATEGICALLY, Continued



NOTE: Sibbet then bridged to the idea that the way to remember a strategy, including all four elements, is to tell a story about it. He led the group in a discussion of what a story entails, and showed that these are the elements which are often addressed in a strategic story.

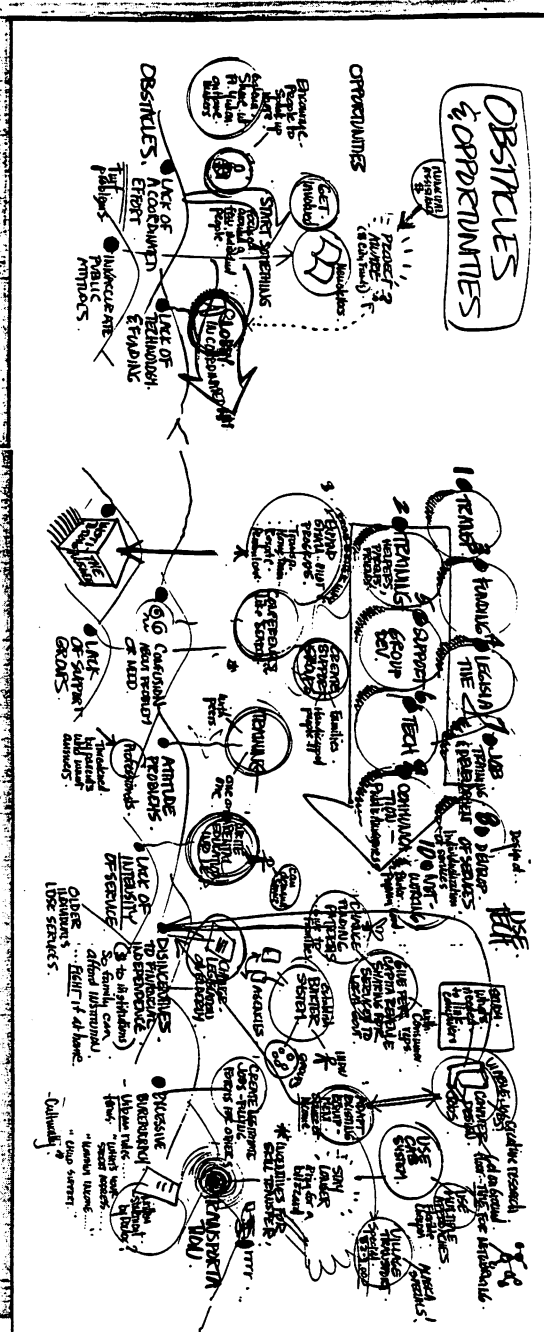
In instructing small groups to begin work on tasks, he suggested one way to develop this story, is to tell it backwards, as if it has already happened. This technique sneaks around the practical mind that is trained to look at the immediate situation first.

OBSTACLES AND OPPORTUNITIES



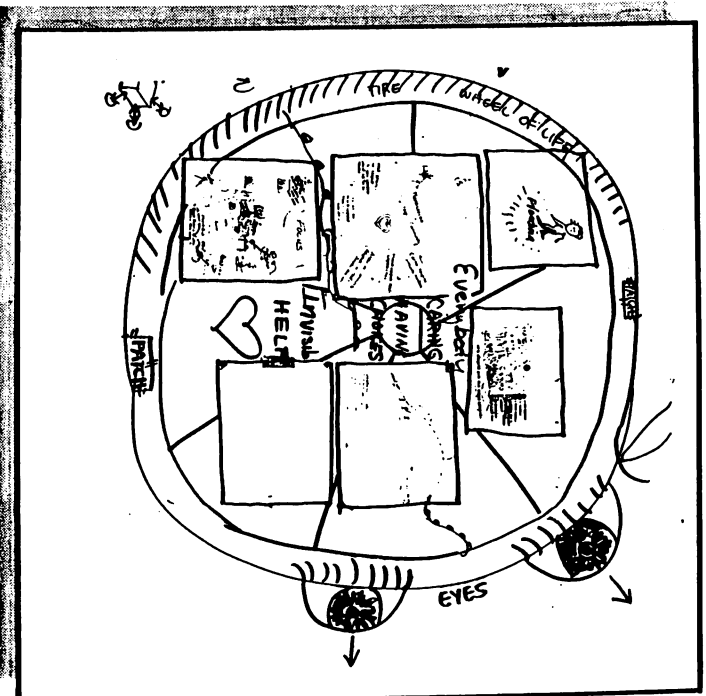
NOTE: The group began with small group discussion, then shared its ideas as a whole while Sibbet clustered the information. Opportunities are shown in circles, obstacles as mountains (though John pointed out not all obstacles are solid and not all opportunities are in the air).

OBSTACLES AND OPPORTUNITIES, continued

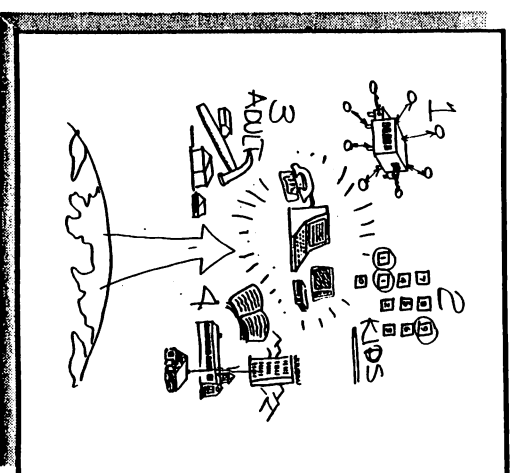
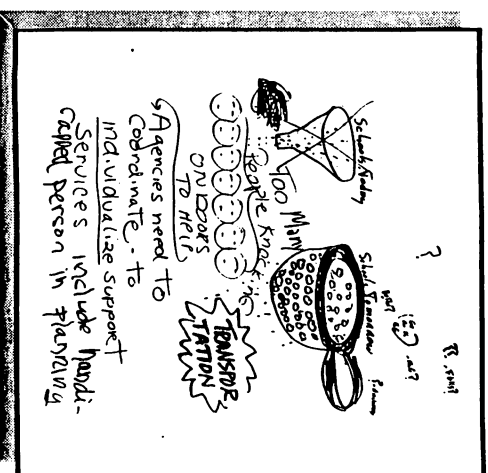


NOTE: As the discussion completed toward the end of the day, the group identified ten areas which might provide task group focus the following day. The decision was made to form the task groups in the morning after sleeping on the subject.

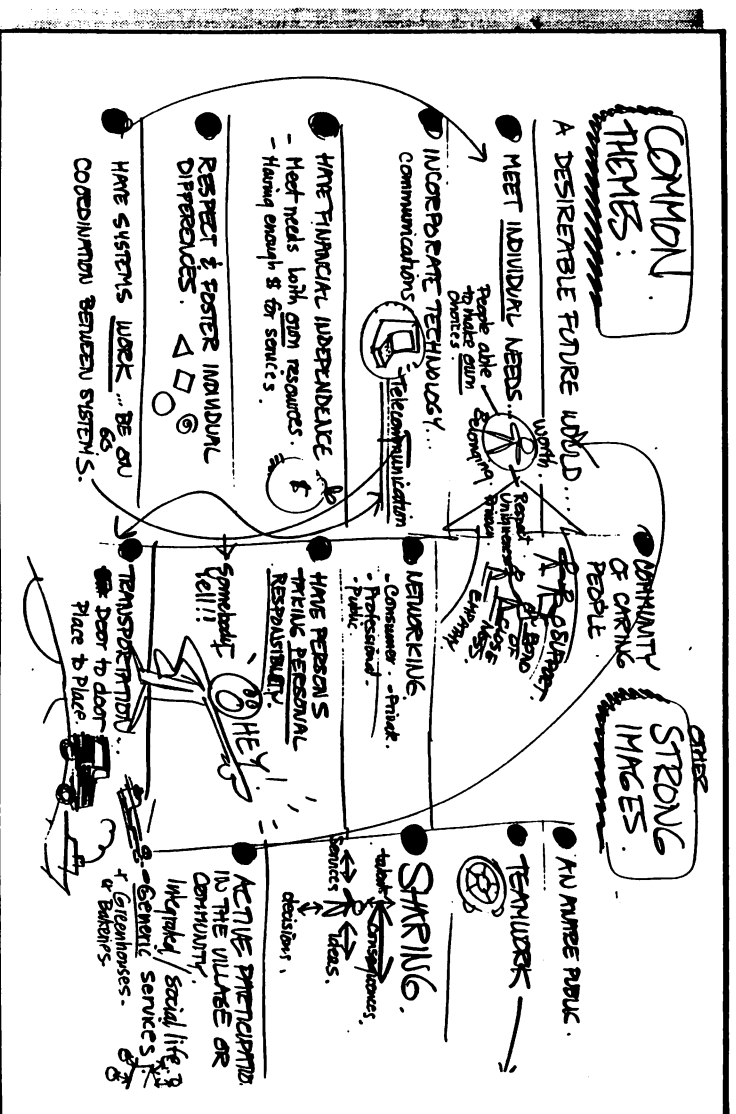
SMALL GROUP VISIONS



NOTE: The group above created a collage of everyone's individual ideas within the image of the wheel of life; the upper right group saw the future as a sieve rather than a funnel; the final group on the right envisioned the integration of support through telecommunications.

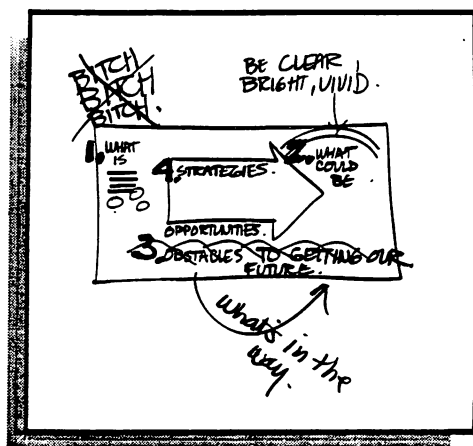


COMMON THEMES

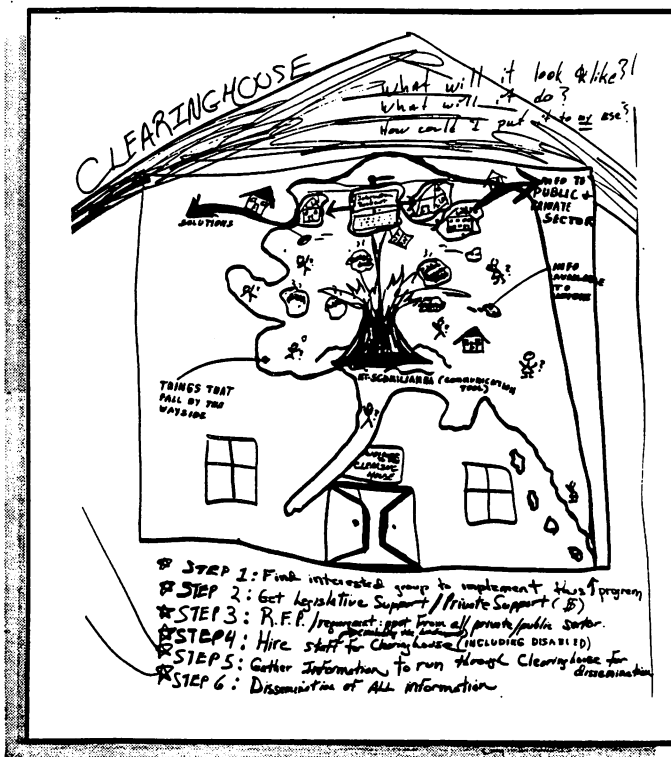


NOTE: Following the small groups sharing their visions, the group as a whole generalized about what they heard as the common themes.

A PLANNING MODEL



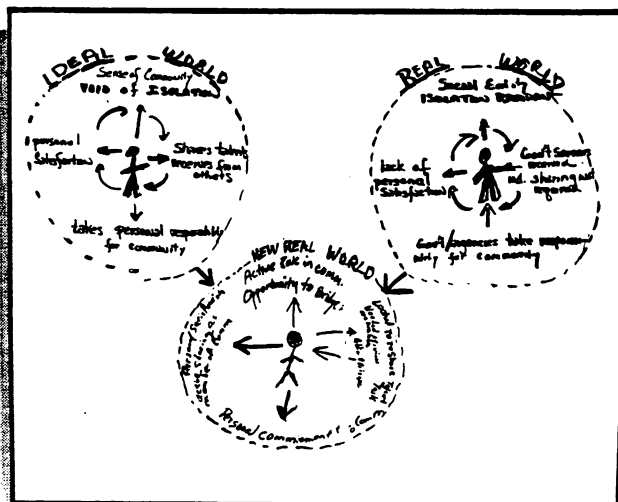
NOTE: Sibbet gave a small talk on the logic of the next couple of Search Conference steps -- showing that first the group was looking at "What is" then moving to "What could be" then identifying obstacles and opportunities, and finally looking at strategies for creating what could be. O'Brien encouraged the group to jump to a future look, and move to small groups, being as "clear, bright, and vivid" with ideas as possible.



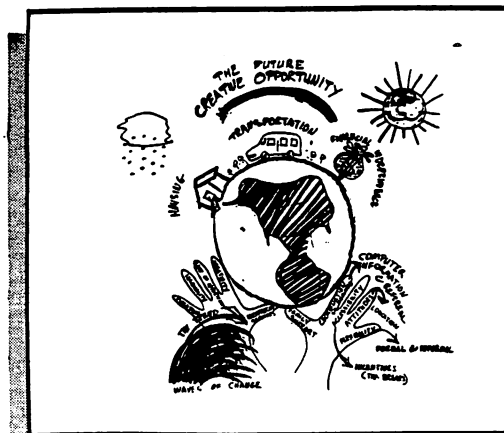
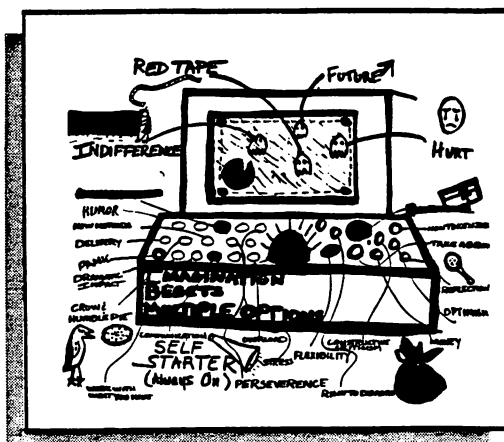
NOTE: This is one of several charts drawn by small groups. The overarching image is of a Clearinghouse, cast as a the communication volcano Mt. Schmiliamha. Implementation steps are included in their scheme.

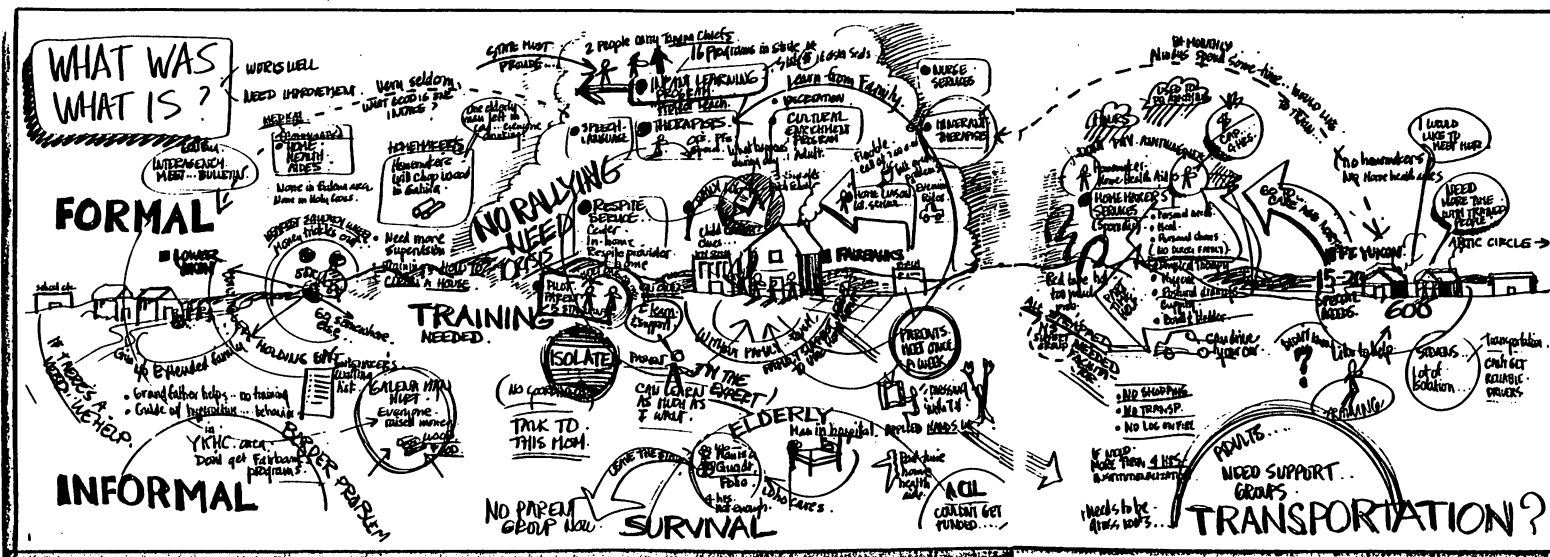
WHAT WE WANT TO BE, Continued

SMALL GROUP VISIONS



NOTE: These images include a synthesis of ideal and real world (above); the electronic home support game (above right) and the world as an opportunity to mould (right).





NOTE: Thursday began with people looking at everything that is current going on and has worked to support homes with special needs. The scheme Sibbet used to record included indicating formal programs on the top half of the chart, clustering information near the Lower Yukon area on the left, the Fairbanks area on the right, and the Ft. Yukon area (next page). Informal support systems and circumstances are recorded on the bottom half of the chart.

WHAT IS--RESPONSES

- 0 Sense of our ease of interacting ,
one on one.
- 0 Hope and concern
- 0 Fear
- 0 WE want to live
- 0 Disabled people bring a re-awakening
- 0 Importance of family--
consumer involvement
- 0 Training
- 0 Rural needs
- 0 Solutions are tough

NOTE: Connie Lyle began transcribing some of the list notes on the portable Osborn computer with a word processing program that she and John brought to the conference.

NOTE: The discussion moved around the difference between services and supports in the more rural areas and Fairbanks. Some things, like transportation, are situations common to both.