

The FUTURE of  
HOME and FAMILY SUPPORT SERVICES  
in ALASKA'S DOYON REGION



A Focus Document for A Search Conference

by

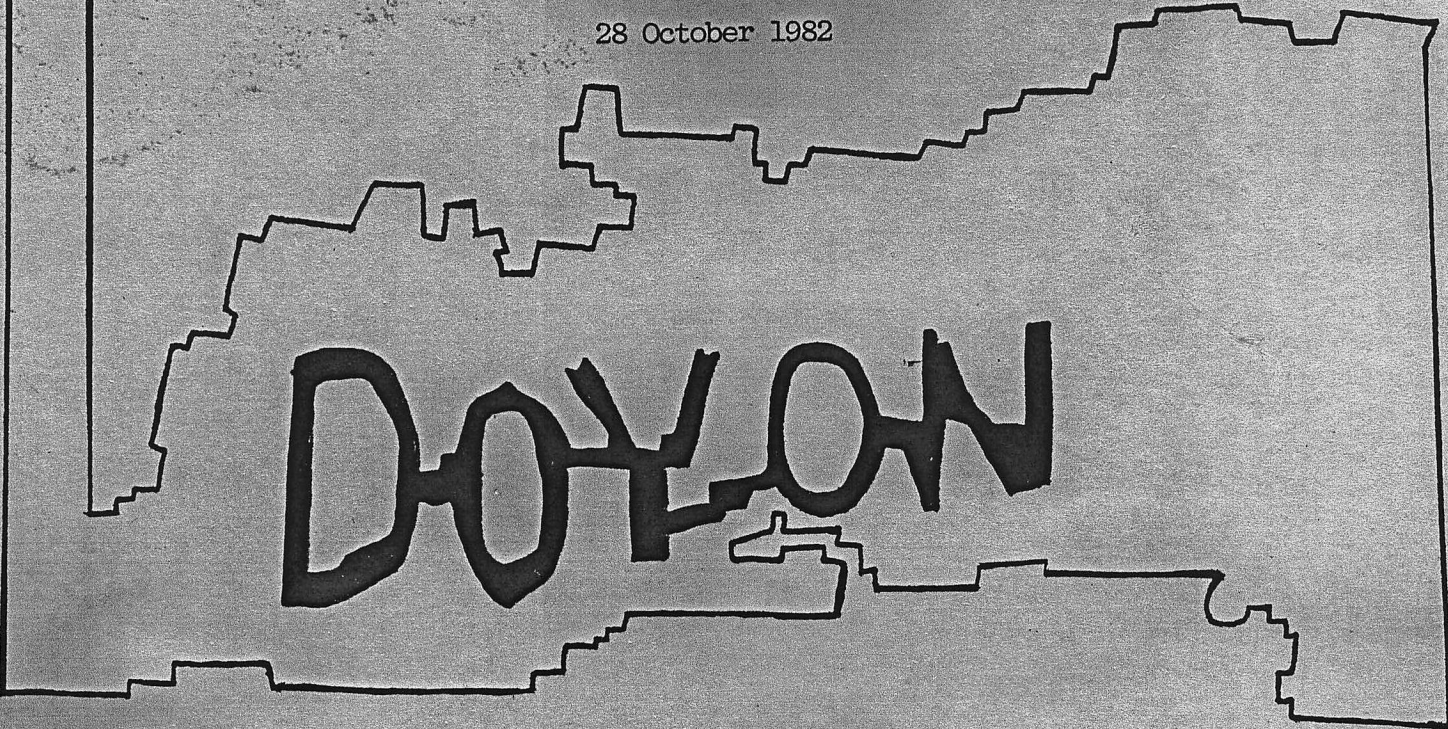
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DOYON

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

You are invited to meet with other people who share your concern with the future of home support services for people with disabilities in the Doyon Region. The meeting --which will be held in Fairbanks from 1 to 3 December-- 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 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.

## WHAT CAN I DO TO PREPARE FOR THE SEARCH CONFERENCE?

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.

You have been invited to participate in the search conference because of the knowledge you already have from your life experience. The rest of this document will help you reflect on your experience and focus your thinking. It has two parts: a set of focus questions and a summary of what was learned by a team that assessed the region's home and family support services in September.

### FOCUS QUESTIONS

These are questions to stimulate your thinking. They don't have single right answers; in fact, you may find that your own responses grow as you consider them and discuss them with other people.

Read the questions over now and let them rest in your mind for awhile. Then take a few minutes to write down ideas that seem important to you. You may want to discuss the questions with other people and see if you can expand your responses.

Don't worry if there seem to be lots of different parts to your responses, or even if the points you want to make seem to contradict one another. We are addressing a complex, changing situation. The goal at this point is to locate as many pieces of the puzzle as possible.

Many people find it helpful to make lists or diagrams to capture their thoughts. Don't feel bound to sentences and paragraphs.

## I. DESCRIBING THE CONTEXT:

These questions ask you to think about the circumstances that surround and influence the quality of home and family support services and identify the ways in which you feel these circumstances may be changing. The basic idea behind this set of questions is that the quality of home and family support services will be strongly influenced by changes in the forces that affect the over all quality of home life.

- What are the most important influences on the quality of home and family life for people with disabilities in the Doyon Region?

- As you consider the future --over the next ten years-- how do you feel these important influences are likely to change? What is your personal sense of the trends that will affect home and family life the most? (This question is based on the belief that if each of us share our sense of the future we will develop a background against which we can identify problems and opportunities for constructive action.)

## II. ASSESSING PRESENT STRATEGIES:

These questions focus in on home and family support services and shift from your sense of future trends to your views on the past and the present.

• From your point of view, what have been the most important milestones in the development of home and family support services for people with disabilities in the Doyon Region? (This could be an event in personal history --like the first time your family used respite services-- or an event in agency history --like increased funding for homemaker services.)

• How would you describe the present status of home and family support services? What strengths are there to build on? What are the most important problems to address?

### III. IMAGES OF MORE DESIRABLE FUTURES:

The final focus questions ask you to consider your hopes and dreams and define needed changes in terms of your image of ideal home and family supports for the Doyon Region.

- What is your personal image of the most desirable future for home and family support services. Make your image as specific and as vivid as you can.

- What are the most important changes that would have to happen in order to move toward the desirable future you have described?

## LESSONS FROM REGIONAL ASSESSMENT

From 21 to 25 September 1982 five teams visited and interviewed people who provide home and family support services and people who rely on them in Fairbanks, Holy Cross, Fort Yukon, and Galena. The teams included people from the Doyon Region and other Alaskans concerned with improving the quality of home and family support services.

Team members asked people to describe the home and family support services they are involved with, identify things that are presently working well and things that seem to need improvement, explain the way in which support services are coordinated, and identify issues that they feel need attention. Team members made a record of responses to interviews, kept a daily log of their impressions, and prepared a memo summarizing issues for the search conference. All of the teams met to outline common concerns that might form the basis for discussion among people from across the region.

These pages are based on team member's individual and group summaries. They provide one link between assessment and search. A more vital link is personal: a number of team members will participate in the search conference.

### WHAT DO WE MEAN BY HOME & FAMILY SUPPORT SERVICES?

The assessment team's first lesson came in trying to answer this apparently simple question. It turned out to be hard to establish a clear definition of home and 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, it's not any one big thing. It's 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 of 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 it's 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 gives 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 it's 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 is 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 boundry 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."

Supervisors have discovered a number of ways to make sensible exceptions and to invent effective ways to stretch resources to meet family needs. For example:

- In Fairbanks, a number of homemakers have been taking training as home health aides. This way the same worker can provide a greater range of services for a family, and funding sources that are administratively separate can be joined in practice on a family's behalf.

- Social service workers in bush communities have negotiated ways to pay people who are related to a service recipient to provide homemaker services. This increases the acceptability of service to some people and at the same time increases the number of potential homemakers for a family.

- In one community, the social worker and the homemaker service supervisor worked together to set up sufficient home support so that an elderly man could return home from a nursing home to be with his wife. They recently celebrated their 50th wedding anniversary, at home. (This situation also demonstrates how difficult it is to predict the exact amount of support a family will need. In this instance, workers significantly over-estimated the number of hours of support the family would need.)

- Respite workers at Fairbanks Rehabilitation Association say that their working climate encourages them to take initiative in responding to family requests. Open discussion of options helps them manage situations in which they feel uncertain.

## Defining Purposes What Can Home & Family Support Accomplish?

Effective home and family support services can make an important difference to people with disabilities, their families, and their communities.

"Without homemaker services to look out for me, I would have had to stay in the nursing home."

"It was hard at first to trust anyone else with our daughter, but we've all learned from her involvement in the respite program. She's making some real choices now about when she wants to be with us and when she wants to be more on her own."

"For our people, the greatest fear is being separated from our family and our village. We like to be free to move from place to place, but always to be able to participate. Being cut off and having to live away with no choice is bad."

"The river is the highway for our people. All his life my grandfather has lived on that highway and gone back and forth on it to hunt and to visit. Since he has had a stroke he can't be active any more, but he can see the river from his house. And people come and go and greet him on their way to and from the river. He can still know about the things that matter to him and be a part of life. So far, my grandmother and other relatives have been able to take care of him. But I'm afraid to think what would happen if something happens to her."

The "hows" of home and family support vary from home to home and with the ingenuity of each worker and agency. Getting agreement on an exhaustive list of family support activities would be difficult. But the purposes are more stable and easier to agree about. This means that it is important for managers, planners, and evaluators to focus on the fit between home support activities and their purposes rather than attending to the details of specific activities. [This sort of management in terms of purpose is growing in the private sector, see, for example, R. Pascale and A. Athos, *The Art of Japanese Management*. (New York:1981)]

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 a variety of kinds of 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 him/her.
- 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.

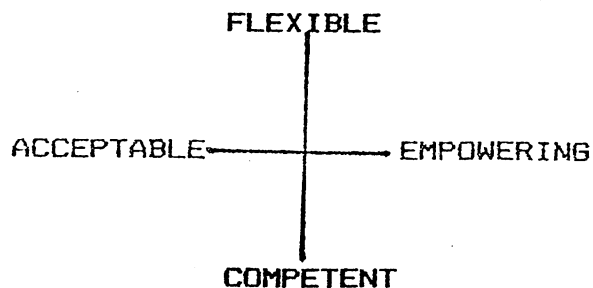
Though all of these activities are being carried out effectively somewhere in the region, the availability of many of these needed services depends on age, location, and level of competition from other households for similar resources. There is much to build better services on, but it will be a long time before each household has equal access to support services.

The intensity of need for home and family support can vary from 24 hour attendant care to very infrequent visits to provide information or advice. The greater the intensity of need a region's services can meet, the better they will be able to meet the needs of people with very severe disability or families that are very disorganized.

For most of the region's households, family support services are limited in the amount of service they can offer. People with severe disabilities and families with limited resources may have no alternative to institutionalization, isolation, and personal underdevelopment.

#### 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.

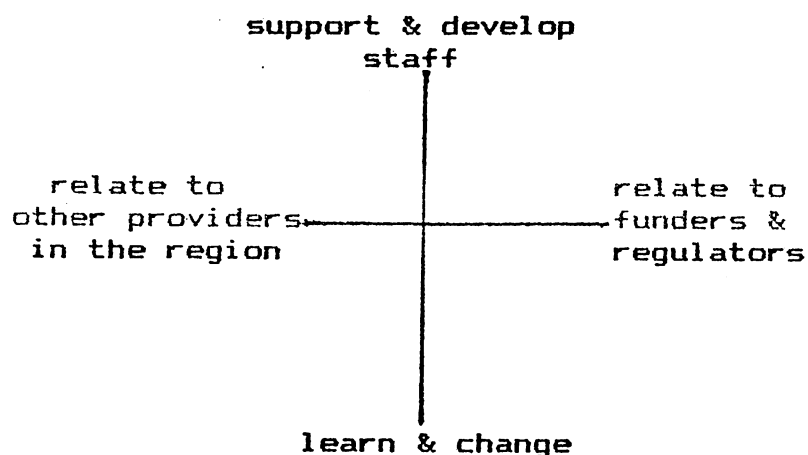
Home and family support services are EMPOWERING if service workers find out what a person with a disability can do for him/herself, and what others in the household, neighborhood, or extended family can do with and for the person with a disability. Home and family support activities BUILD ON WHAT'S ALREADY 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 a 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 payed 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 the 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 some time 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 professionals 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 Fairbank's 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.

### Conclusion

Soon you will attend a search conference. It will provide a forum to discuss these issues and any other concerns you believe are important. It can also be the occasion to develop action networks to begin to move toward a better future for home and family support services.

