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The development of a community network to improve services for children with chronic health conditions and their families takes planning, commitment, enthusiasm and interest.

# Meeting Needs with Scarce Resources: Community Network Building for Low-Incidence Conditions

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## Introduction

It is estimated that at least 10 to 15 percent of all children and youth have a chronic illness or disability. Of this group, about 10 percent—or 1 to 2 percent of all children—have a condition severe enough to affect daily activities (Hobbs, et al., 1985). These children and their families have a special set of needs which require the involvement of many agencies and programs in their community. Families must cope with challenges in obtaining appropriate and available services, adequate financing of care, emotional adjustment and changing family dynamics as well as a definition of their place in the community. Such challenges often require the assistance of outside agencies as well as a community planning effort for these special services and needs.

In October 1983, Pathfinder was awarded a competitive grant from the Division (Bureau) of Maternal and Child Health, Department of Health and Human Services under the category of Special Projects of Regional and National Significance (SPRANS). The grant was awarded to Pathfinder for the development of a community network model for children with chronic health conditions and their families. The demonstration projects were located in the Minnesota communities of Albert Lea and Austin and in Eau Claire, Wisconsin. Specific activities included task force development, community needs assessment implementation, development of an action plan, and evaluation of the local network.

**Judith A. Kahn and Georgianna Larson work with Pathfinder which was established in 1983 as a cooperative effort of Gillette Children's Hospital, the Minneapolis Children's Medical Center, and several other health-related agencies in Michigan. Pathfinder's purpose is to improve systems of care for children with chronic health conditions.**

This article presents a model of community service planning and delivery that can be applied to the particular set of problems faced by children with special health care needs and their families in rural communities. While the model is presented in the context of health concerns, the principles of the model are generic and can be applied within any context and for any set of problems.

## Problem

Children with special health care needs and their families present a unique set of challenges to the standard health care delivery system. These challenges cannot be effectively addressed by a health care system geared to children with routine, acute or even fatal illnesses. The complexity of their needs requires them to obtain services from different agencies including the child's primary health care provider, medical specialist, school, county social services, advocacy organizations and other community groups.

Services for these children, especially in smaller communities and those communities with low-incidence conditions, can be fragmented and incomplete. Agencies tend to plan services for these children according to the disability and the current population (Perrin, J. M., 1985). Coordination and integration seem to be lacking; long range planning and systems change rarely occur. In this situation, children too often receive poorly coordinated or inadequate service—and families are caught in the middle.

## Solution: A Community Network

What is a network? Networks or networking have been called by different names: interagency collaboration, coordination or team building. A network is the integration of existing resources which may include people, organizations, information or institutions working toward a common goal. The process involves collaboration and coordination in order to overcome turf guarding and competition. Another way to put it is, networking is whatever works: it can be informal or formal, overt or covert, ongoing or ad hoc.

Anyone can initiate a community support network. Networking/interagency collaboration/team building are not new concepts; they have been utilized to plan and deliver services in the health, education, social service and voluntary sectors. Pathfinder took this familiar concept and developed a unique model for a specific population: children with chronic illness or disability.

## Pathfinder Community Network

This model is based on four key assumptions:

- *Children with chronic health conditions and their families face a common set of problems, regardless of the specific condition or disability.* Pathfinder believes that community service planning and delivery for children with chronic health conditions can occur if this population is perceived to have a common set of concerns, regardless of the specific condition or disability. Those concerns could include: public education, day care, school health services, transportation, parent support, information networks or respite care.
- *Services for these children and their families can be improved by enhancing cooperation among existing health, school and community programs, rather than creating new programs.* The population, which if identified by disability, seems very small. Seeing the children in larger groups makes the planning effort seem more workable. The community can then enhance the current service system to accommodate these special needs.
- *Community network building can be best facilitated if the network is begun at the community level.* Path-

finder was, and still is, committed to the belief that any community-based service works best if initiated and maintained informally at the community level. The "formal informality" of the local structure is a positive for long range efficacy of the model.

- *Community network building for these children and their families will be most effective if parents are involved in network planning and service development.* Parents are the key to the Pathfinder community network model. Although it was often difficult to solicit and maintain parent participation, their input was essential in both needs identification and systems planning.

The community network model is firmly based on the belief that flexibility is essential and that each community will develop a unique system to network services. The key is the development of a common commitment to the population and a willingness to try something new.

#### **Phase One: Formulation Of The Local Task Force**

Development of a community network is a structured, consecutive process. Working relationships must be developed among the parties involved and these relationships must be based on mutual respect and understanding. Ultimately, the formation of the local task force is catalyzed by the perception of common problems and a shared need to find solutions to those problems. Although network development may be supported by many agencies and individuals, a lead agency should be identified during phase one. The agency will provide accountability and structure for the work to continue.

An initial meeting should be called to bring key participants together. The purpose of this meeting is to help key participants become acquainted and familiarize themselves with other programs and services, to introduce the concept of community network development and to identify common problems. The key points to consider in planning this initial meeting are: Who should be invited? By whom should the invitation be extended? How and where should the meeting be conducted?

Next, begin the formation of the network by inviting service providers and parents to take part in meetings to identify unmet needs, resources and strategies for change. This begins the networking process and creates interest in both the identified problems and their solutions.

The role of leadership in this process is critical. The main function of leadership in a community network task force is to ensure that the tasks necessary to plan and carry out the group's goals are accomplished. This leadership responsibility may be undertaken by one individual or shared by several members.

Team members usually become more involved and committed to the work of the group when leadership functions are shared by the leader with group members. An Executive Committee, composed of the task force chairperson(s) and subcommittee chairpersons, can function as a governing board for the Task Force.

In setting up a new network, communities may want to consider bringing in a consultant. Pathfinder structured the development of the community networks around an outside

facilitator. An outside facilitator can be a valuable asset in providing important feedback to the group and objectively critiquing activities and ideas. This person can be instrumental in bringing the initial group together, coordinating the needs assessment and structuring the action plan. Communities and the outside facilitator, however, must work at building leadership within the community so that the network can be maintained at the community level.

#### **Phase Two: Community Needs Assessment**

In order to determine the needs and resources for children with chronic health conditions and their families, the task force must agree on the target population and the geographic area (community).

##### **Definition of Community**

A "community" can be defined in many ways. Each professional organization has different geographical boundaries in which it delivers services. Education might have a city-wide school district, public health and social services, a county-wide population, and a voluntary organization, a multi-county constituency. Each local task force must agree upon a common area for its functioning. In its demonstration projects, Pathfinder defines the community as the geographic area in which FAMILIES receive services, i.e., their health care provider, school, shopping and employment. This allows flexible boundaries which cross traditional catchment areas and reduces turf-guarding among the professionals involved.

##### **Target Population**

A definition of the target population also needs to be mutually agreed upon by task force participants. Pathfinder developed the following definition for use in the local demonstration projects in Minnesota and Wisconsin:

A chronic health condition is defined as an illness or disability which necessitates that a child, aged 0-21 years, receive individually planned services for an extended time.

##### **Assessment of Needs and Resources**

Once the target population and the community have been defined, the first activity of the task force should be to conduct a community assessment of current resources and needs. The format which was used by Pathfinder and developed with the assistance of evaluation consultants is a *key informant approach* which uses a questionnaire to assess current perceptions of resource availability, resource quality and prioritization of needed changes.

The questionnaire used by Pathfinder was adapted from *Community Workbook for Collaborative Services to Preschool Handicapped Children* (Magrab, P., Kuzak, E., and Green, L., 1981) by the American Association of University Affiliated Programs.

#### **Phase Three: Development and Implementation of the Action Plan**

The community needs assessment will provide the Task Force with a list of needs and resources. The Task Force can then set goals and priorities for action. Planning strategies to accomplish these goals is the next step. Tasks for carrying out the strategies should be clearly defined and assigned to subcommittees composed of persons who have a particular interest or expertise in an issue.

##### **Network Development Strategies**

The following are examples of various strategies used by the Pathfinder demonstration projects in Minnesota and Wisconsin. These strategies include:

- **Interagency Collaboration**

Working relationships based on understanding and mutual respect are the basis of a successful network. Issues of territoriality, responsibility, competition and costs are very real and need to be addressed. Pathfinder demonstration project interagency collaboration was based on informal linkages between persons/positions rather than agencies. Cooperative agreements were not developed; this allowed Pathfinder network activities to be viewed as an in-

formal structure which did not add a new agency to the local mix.

**Example:**

In one of the southern Minnesota communities, public health nurses (supplying school nurse activities for local school district), the district special education coordinator, and interested parents worked together to design a school nurse schedule, a clarification of the school nurse role, and a protocol for management of the student with diabetes.

• **Parent Group Development**

A parent support group or parent advocacy group may be part of a community network effort. It may be one solution to an area where parents are seeking mutual support or are advocating for services.

**Example:**

Parents of children with diabetes and the social services director at the local hospital formed a support group in one of the Pathfinder demonstration projects. The addition of the health professional to the group increased their ability to network with other support groups, provided free meeting space and access to hospital resources, and increased the group's ability to recruit new members.

• **Educational Programs**

A workshop geared toward health professionals, school personnel, community agency staff and parents is a useful networking tool. Workshops bring people together to share information and ideas. For these reasons, a workshop is also a good way to initiate a network. It can provide an atmosphere for collaboration toward a common goal and a forum to carry it out.

**Example:**

Each of the demonstration communities sponsored educational workshops for professionals and parents on issues for families of children with chronic health conditions and the professionals that serve them. The workshops brought together those who were participating in the network demonstration project with other parents and professionals in the region. It also proved to be an effective way to solidify and advertise Pathfinder Task Force activities.

• **Resource Development**

Collaborative efforts between agencies can produce valuable resources for children with chronic health conditions, their families and the professionals that serve them. The specific resource(s) will depend on the identified need and the resources of the cooperating agencies. With in-kind contributions from individuals/agencies working on the development of the resource, a quality product can be developed with limited funding.

**Example:**

Members of the Minnesota Pathfinder project developed a two-county parent resource brochure. The brochure featured health, education, social service, voluntary agency and parent resources in an easy-to-read format. Funding to print the manual was contributed by a local service organization.

**Phase Four: Evaluation of the Network**

An evaluation of the community network process is essential to obtain information on how well the local network functions and whether the group activities have made any impact on children with chronic health conditions. Pathfinder contracted with an outside consultant to independently evaluate community network model development in each of the demonstration projects. Whatever method you choose, focus on three features:

- The *process* of developing and implementing the model. Look at the cooperative energy of the participants, task force leadership and the role of the facilitator.
- The *results*, focusing on what has been accomplished by the task force; and
- The *impact* of the network model on the population of children with chronic health conditions, their families and the community.

The evaluation demonstrated that the local Pathfinder task force had become a "presence" in each community. Task force members felt that Pathfinder activities had been a valuable addition to the community. More importantly, each local group made the decision to continue beyond the funding period of the Pathfinder grant. Each had become a self-sustaining entity in their community structure.

**Conclusions**

The development of a community network to improve services for children with chronic health conditions and their families takes planning, commitment, enthusiasm and interest. The key ingredients for the development of a successful network are:

- cooperative working relationships between individuals and agencies;
- a formal needs identification process;
- leadership development in the task force and its sub-committees;
- realistic funding for projects to meet the identified needs; and
- clear and open communication.

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