



Assessing Your Community

Before launching into any outreach and education effort, it is important to take some time for your organization to assess and understand the issues that children with life-threatening conditions and their families in your community face so that your organization can better provide the necessary support.

This can best be done by getting information directly from key stakeholders such as **parents of seriously ill children, community organizations, and pediatric healthcare providers** as they can provide broad and diverse perspectives and information about what children and families need most. This section includes *specific strategies* and *sample questions* for your needs assessment with each key stakeholder mentioned above.

Overall, assessing in your community will help you to:

- Learn what those caring for children believe is important;
- Identify unmet needs for services or information;
- Establish your credibility as a collaborator interested in working with the pediatric community; and
- Identify potential partners in your outreach efforts

1. Getting Started

Below are some ideas to help you get started in the gathering of more information about the issues, concerns, and needs of children with life-threatening conditions so you can better formalize your assessment.

- ✓ **Attend meetings and support groups** where family members talk about caring for a seriously ill child, their personal needs and what is important to them ... *and just listen.*
- ✓ **Familiarize yourself with materials aimed at supporting children and families** such as local newsletters, Web sites, professional publications, and special interest magazines.
- ✓ **Reach out to other community organizations** that can help you gain access to more information.
- ✓ **Talk to the families of your pediatric patients** and let them tell you what issues are important to them. Tell them about what you've learned through your information gathering and ask if you are on target.
- ✓ **Strive for diversity when talking to families** e.g. varied attitudes, spiritual beliefs, background, diagnoses, and social and ethnic makeup.

2. Assessing Parents' Needs

The parents/families your program has served can help you understand how programmatically you can improve services and community outreach. If possible, gather information from parents or adult family members who are currently living with a child who is seriously ill and/or families who have been through the experience.

Because of the sensitivity of the subject, make sure you:

- **Approach the families with questions, not answers.** Let the information you've collected guide your questions.
- **Maintain confidentiality** — Always assure your respondents that you will never use their names (without permission) or attribute information. *Make sure you check with your organization about specific privacy rules.*
- **Pay attention to timing** — Prior to speaking with parents/families, make yourself aware of whether there is a special anniversary or a crisis in the family — the timing of your communication can either help or hinder your efforts.
- **Be responsive when talking with parents.** Respond to what is happening and to requests immediately, even if your answer is, "I'll find out and get back to you." This can help build relationships for their future help and assistance.
- **Most of all, be prepared to listen, listen, listen.**
- **Get familiar with national parent resources.** Go online and read about local, regional, and national disease-specific and topic-specific parent organizations. If you have questions or concerns about talking with family members, they will be able to speak with you and refer you to additional resources and information.

Sample questions for family members:

- How have you found your child's healthcare providers to be in terms of their interaction with you and your child?
- To what extent do you feel like you have gotten the information you need from your child's doctors and other healthcare providers about things like your child's diagnosis, prognosis, and treatment options?
- Was the information provided in timely manner?
- How could the needs of your family be or have been better met?
- What services do you wish you had access to that aren't or weren't available to you?
- What services did you receive when caring for your child at home?
- What other services would have been helpful to your family while your child is/was at home between hospitalizations?
- Other than your child's healthcare providers are there other sources that you have turned to for information, advice, guidance, or support?
- Is there anything that you know now or is there anything that you recently learned that you wish you'd known earlier?
- What do you know about pediatric palliative care?
- What do you think your pediatrician/specialist needs to know about pediatric palliative care?
- How can we best help you now?

3. Assessing Community Needs

To better understand the services that are available and needed in your community for children and families, find out the answers to the following questions:

- What healthcare facilities, home health and/or hospice agencies are currently caring for seriously ill children in your area?
- What palliative care programs, providers, and/or consult services are available?
- What community-based organizations currently provide the children and their families with emotional, psychosocial, spiritual, practical, and/or financial support?

Once you have a list of community resources and contact information, conduct a more formal needs assessment with each organization. See also, “Creating a Community of Care Network” located in the Outreach Guide.

Sample questions for community organizations:

- How many seriously ill children do you currently serve?
- What is your eligibility criteria?
- How is a child referred to your program?
- What services do you provide?
- How are you reimbursed and/or how do you fund these services?
- Where do you get the majority of your referrals?
- Do you collaborate with other community agencies, providers, and/or institutions when coordinating the children’s care? If so, who?
- What are the challenges you face in providing care for seriously ill children?
- What resources would be helpful to you in providing care for seriously ill children in our area?
- What are the unmet needs or challenges in caring for seriously ill children in our area?

4. Assessing Pediatric Care Providers

Conducting a needs assessment with pediatric healthcare providers can help you find out what services to which they refer and any knowledge gaps concerning pediatric palliative care and hospice. Also, talking with staff and volunteers can give you valuable perspectives that can help shape your outreach efforts and provide a venue to let them know about your forthcoming outreach initiatives.

Sample questions for pediatric healthcare providers (including physicians, staff, and volunteers):

- Are you currently caring for children with life-limiting illnesses or conditions? If so, approximately how many?
- Do you provide palliative and/or hospice care to children?
- How do you define palliative care and hospice services? Do you think palliative care is inclusive of hospice?
- Have any children you have cared for ever received palliative care or hospice?
- If so, what were your impressions of the care?
- Would you refer (other) patients/families to a hospice/palliative care program?
- Why or why not?
- What do you think children with life-limiting conditions most need that you are not able to offer them? What do you think their parents/families most need?
- As we begin to talk to people in the community about pediatric palliative care and hospice, whom do you think we need to get to know?
- What educational opportunities or training would be helpful for continuing education for your staff and volunteers? What topics need to be addressed?
- What are the challenges in caring for children with life-threatening conditions?
- Are there any constraints that limit you and/or your organization's ability to provide care for children with life-threatening conditions?
- If you do provide palliative care and hospice, are there any constraints or challenges that limit the number of children you are able to serve?
- In your opinion, how could we improve community-based care for children with life-threatening conditions in our area?
- What agencies/providers/institutions do you collaborate with when caring for children with life-threatening conditions?

5. Methods for Conducting Needs Assessments

Gathering information can be done formally or informally depending on the staff time and resources you have available. Methods for conducting needs assessment include:

- **Interviews:** One-on-one interviews can provide valuable insights from families and may be necessary instead of using the other strategies particularly since these topics may be sensitive. Make sure you ask the same questions in the same way which will makes it easier to find trends in the information you gather.
- **Focus Groups/Feedback Sessions:** Informal focus groups or feedback sessions provide an opportunity to hear families identify issues and needs in their own words. A good rule of thumb is no more than eight people in a focus group.
- **Written Surveys:** Your organization can create a simple, short, written survey and distribute it to carefully selected families to assess their needs related to their child's healthcare and your service delivery. Try to create a survey that will take no more than five or ten minutes to complete. Similar surveys can be targeted to providers and community-based agencies. Surveys can be distributed via electronically or by mail. You can often increase your rate of response if you follow-up by phone.

It is strongly recommended to work with research professionals in designing and administering focus groups and formal surveys. Remember that doing assessments whether informally or formally is not a one-time event. Ongoing listening and learning will help ensure that your outreach and educational efforts are in-tune with the needs of children and their families.