

The purpose of this project is to show you what everyday life is like for a special needs child and their family. Its goal is to hopefully help you to become well rounded doctors who will be more aware of and sympathetic to your patients' situations. They are more than what you see in a routine visit.

Kathy Brom – family advisory council;

With her friend Sharon Pike started this group after a frustrating doctor visit with her daughter Allison – she wrote a letter to the physician and Sharon will read an excerpt from it at your first session.

We are very fortunate to have families willing to open up their homes and share their lives with you. They are eager to meet new students and welcome your questions. Be involved, ask questions. Look over the Operation Homefront information on the Dept. of Peds web site. Take a few minutes to read the poem, "This is Our Child".

Designate one person in your group to be the contact for the family. The family should be called within the next week to set up your first visit. You are permitted to miss any part of your assignment; you are not expected to go post call. When you talk with them, at the end of your conversation, please verify their address. After you set up your date, immediately contact the other person(s) in your group to get it on everyone's calendars.

The visits are usually 3 – 4 hours; they are not intended to be an intimidating experience, so be comfortable and relaxed. Dress is nice casual; no jeans; no white jackets. The families do two visits. The first is usually an in-home visit and one out in the community...perhaps a doctor's visit, an Easter Seals visit, dinner, the park, a show....this is up to the families. Be flexible and work with their schedules.

Out of courtesy, it is expected that you will please arrive on time. I have had complaints of students showing up late. Please google the directions well in advance and allow sufficient time. Don't arrive 15 minutes early...

Kathy is the family contact. She knows all of the families and their backgrounds. If you have any problem contacting a family, call her on her cell phone which is listed at the bottom of the page.

Sharon Pike will be here for your introduction session You may contact Sharon with any questions or concerns regarding your Operation Homefront visits.

A reflection paper of a minimum of page, double spaced is required. It must be submitted through SAKAI. It is not a graded assignment, but is required, as are the two family visits.

Contact Information:

Operation Homefront Coordinators:

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Sharon Pike

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Purpose: This project is intended to broaden perspective, learn to communicate better and have some fun.

Description: Families with children with special health care needs (chronic illnesses, disabilities, etc.) have invited students into their homes and communities for a hands-on, closeup view of life in these very real situations.

Mechanics: Supportive reading for this experience will be on our Peds Clerkship website. There will be an orientation to the program by Sharon Pike. Students are expected to complete an information form on the day of orientation and are then matched up in pairs with a family. It is then the student's responsibility to set up **two** visit dates with their assigned family. The student is excused from any other clerkship duties for this experience. The arrangement of the first visit should be completed within one week.

The Visit: The visits should be approximately 3-4 hours. It is expected that the students come prepared with questions. While discussion of the specific illness or illnesses that affect the family is appropriate, that should not be the focus of the visit. The focus rather should be on the life experience of these families and their perception of their encounters with health care and society as a whole.

QUESTIONS FOR USE BY MEDICAL STUDENTS DURING HOME VISITS

1. How did you learn of your child's disability?
2. How did your physician respond to your thoughts and feelings about your child's disability?
3. Did your physician provide you with information about your child's disability that was clear and thorough?
4. What other assistance or advice did you receive immediately following the diagnosis?
5. Was your physician able to explain fully the medical and/or developmental issues facing you and your child?
6. How does caring for your child who is disabled differ from that of your other children? Or if there are no siblings, how is it different from what you anticipated?
7. Who in the family is the primary care giver?
8. Are siblings expected to be care givers in any way?
9. Are social engagements for the family passed up as a result of the child's disability or for lack of appropriate home care?
10. Do you feel comfortable talking with your physician about concerns for your child? Do you trust his/her opinion and judgment?
11. Do you think your child's physician(s) have a good understanding of what life is like on a daily basis for you and your family?
12. Who do you turn to most often for assistance, help or advice regarding the needs of your child?
13. How many doctors or other professionals is your child/family currently involved with?
14. How many hours per week would you say is spent on coordinating care?
15. Do you feel that you and your family have the amount of support you need? If not, what are some of the things that you would ask for?
16. If married, does the presence of a child with special needs put a strain on your relationship?
17. What recommendations would you have for doctors, nurses or other health care providers when interacting with parents of a child with a disability?

18. Do you question the professionals caring for your child about their recommendations or findings? If no, why?

19. How would you describe your relationship with your child?

HELPING THE PARENTS OF CHILDREN WITH SPECIAL NEEDS

DO'S AND DON'TS

Do anticipate questions.

Do allow parents to see and participate in what you are doing to their child if possible.

Do allow your genuine concern and caring to show.

Do make yourself available.

Do give ACCURATE clinical data. Remember that it is not happening to you, the nurse, or doctor.

Do say "I'm sure you will do what's best".

Do refer to the baby by his/her name.

Do encourage hospital pictures, birth announcements and all other frills!

Do say: "Give yourself some time".

Do say: "I don't know" (when you don't).

Do encourage parents to write down any questions, maybe even keep a journal. Bring them paper and pen.

Do prepare parents and brothers and sisters for what they may see (i.e. IV's, tubing, needles, machines, etc.).

Do tell the truth (i.e. temp., B.P., Lab values, etc.). Parents need to participate in the care of their child.

Do offer to make phone calls if the parents cannot.

Do consider religion and parent's practices in what they believe (i.e. hospital visits by the clergy, hospital baptism, etc.).

Do ask how the other children in the family are doing.

Do keep in mind there was and never will be any sense to this child's problems, but spend your time with the new parents giving them ways that can be helpful to the child.

Do give options whenever possible (i.e. private room, remaining on the floor after visiting hours, etc.)

Do make good Discharge Plans.

Don't take away coping methods.

Don't tell a parent what she/he should feel or do.

Don't take parents' comments personally.

Don't even mention institutions, they are antiquated options.

Don't say: "These children give you so much joy!"

Don't say: "Looks fine to me!"

Don't suggest something related to intra-uterine position.

Don't see outside professional help that is not willing to work within this realm or they may say the one sentence that would undo any positive steps you may have reached.

Don't say: "It's God's will".

Don't tell parents they are "special" for having this child.

FEELINGS STATES OF GRIEVING AND COPING

Behavioral

***Denial**

-Allows time to discover inner strengths or develop external supports

***Anxiety**

- Mobilizes and focuses energy around the task of making changes

Existential Struggles

*Fear

- Exploration of vulnerability necessary to be able to love again

*Depression

- Redefinition of personal sense of competence, capability, value, power

*Guilt

- Of what meaning/impact/significance are my actions/beliefs/thoughts/feelings on the significant things in my life.

*Anger

- Redefinition of personal system of fairness and justice

THIS IS OUR CHILD/THIS IS YOUR PATIENT

By Peter Cummings

This is our child. This is your patient.

This is our life. This is your work.

This is the creation of our love. This is a problem for you to solve.

This is our only Paul. This is one of your many patients.

As long as our child is here, this is our home. This is your place of work.

If we had our way, our child would be home with us—with his family, where he belongs. If you had your way, he would be, too.

But he is not home where he belongs. He is here in a hospital. And here, we share responsibility for his wellbeing.

You take care of this child. But we love this child.

You administer his life here. But we conceived him, gave him life, nursed him in our hopes and dreams and bodies, long before he came to this place.

You use your expertise to try to solve his problems. We use everything we can to give him our love--thought, worry, prayer, and yes, knowledge.

If you could solve his medical problems, you would. If we could will life into his tiny body, exchange our lives for his, release him from his suffering, go back before the nightmare began, we would do it all—this very instant.

What we want is what any parent wants. We want our baby. We want him well. We want him with us. We want to be with him. With him all the time—not just when everything's okay. We want to be with him in his waking and in his joy, when he eats, for endless hours rocking as he sleeps, we want to be with him when he suffers, we want to be with him when he dies.

Adapted from Ken Moses, Ph.D.

Resource Networks, Inc.

The Parent Advocate

By Ginger Clubine

Executive Director, ARC Nebraska

Being a generalist in a specialized system! As a parent of a son or daughter with mental retardation that's what you must be... a generalist in a specialized system. *Webster's* says a generalist is not a particular or specialized... widespread... not precise... vague.

What about a specialist? A person who specializes in a particular branch.

Being a generalist among specialists is what parents are faced with as they advocate for their sons and daughters. Being a parent requires that you assist your son or daughter in making informed choices. Choices that vary widely with your child's age and cover an array of issues from lifestyle choices to medical procedures. Choices that reflect a rapidly changing field where

yesterday's wisdom is today's folly. It is an impossible task that we ask parents to assume. Parents are trying to assist their children's lives while trying to have a life of their own. The parent tries to understand the specialists' information and fit it into the mosaic that is their son's or daughter's life. They must piece together their general knowledge from a variety of specialists. Professionals, in all aspects of the disabilities field, are specialist, trained in their area of expertise. Families continually find themselves needing to understand the implications of the recommendations without having had the training to understand why the recommendation was made. Parent advocates have less time and information available to them than the specialist. Their lives are full of competing interests. There is so much to learn and understand when you are a family member. There is a new language to become proficient in, multiple agencies, each with their own agenda, and multiple professionals with their individual values. We expect so much of parents and offer them so little assistance. They must assimilate a vast sea of information so they can be an active, informed part of the decisions involving their sons and daughters.

Do we feel overwhelmed? You bet we do. As a parent advocate, I have the advantage of working in the field of disabilities. My career today allows me to network with the specialists who have the needed information. I have learned the language, and I am aware of the competing agencies and agendas in my state and in my community. I do not have young children at home needing my time. What about those who don't have the same "advantages" that I have? What would it be like to be in another profession and find that I have limited time to understand this field of developmental disabilities? I would feel overwhelmed...as a matter of fact that's how I did feel in the 70's. I continue to experience flashes of "I don't understand how this fits together. I don't have all the information. I don't have enough time." I am sure there are many families today that have similar feelings as they swim through their sea of agencies, professionals and information. Families and professionals alike must recognize that the disabilities field has grown into a complex specialized non-system. Families, consumers and individual professional cannot be expected to effectively use the knowledge they each have to put together a system of supports unless they work as a team of equals. Sadly, professional rarely convene the complete "team" and even more rarely include families as equal team participants.

Specialists need to look at the whole and not just their specialized part. They need to see the community in its complexity and help in integrating the individual and their wisdom.

Professionals must be willing to stop imparting words of specialized wisdom to consumers and families. As a parent-advocate there have been countless times over the years when a specialist has had "the answer" for my daughter and our family, instead of being part of a collaborative team where we look to my daughter's expressed preferences and then mutually determine the best answer we can find. Their words of wisdom reflect their specialty more than they reflect my daughter's desires or potentials (or the resources and limitations of the community). There is no divine wisdom that will answer all the questions, there are only individual choices. What my daughter wants in her life is unique to her and her family's values. The specialized system must have the flexibility to change and adapt to those individual values.

What can you as a professional do? You can be aware that your "specialized" information is just one piece of the larger family/consumer life plan. Share your information. Be a collaborator. Whether you agree or disagree with the viewpoint of a family member acknowledge its validity. Seek to make your contribution relevant to the lifestyle choices of the consumer. Parents and consumers must have complete and accessible information about the community resources. They must also be informed about the restrictions that may apply to some supports and services. You

can actively work at being a part of a team – a team that gives families and consumers equal membership. The formation of an equal partnership between parents and professionals at all levels of care often requires new skills. Take the time as a professional to gain those skills. Most importantly, remember to be honest and creative. If you don't know, say so. It's okay. No one can be expected to know everything. Don't say you can do something that you can't deliver. But be willing to take risks. Be willing to challenge your own system. Ask yourself regularly, are we here to support our programs or are we here to support people with disabilities? Are we user friendly?