



FAMILY CENTERED CARE

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CHILDREN WITH SPECIAL HEALTH NEEDS

- Are above all children who want to live a happy healthy childhood
- They live in towns, cities and rural areas
- They go to school, church and enjoy community activities

CHALLENGING CONDITIONS

- Some have a physical disability, mental or emotional disabilities
- Others have a chronic health illness

OUR CHILDREN

- Some may have a brief but life threatening medical problem
- Others only need an accurate diagnosis
- Some may need treatment, medicine or technology

HEALTH CARE

- Children with special health needs receive their health care from a combination of private and public financing and delivery systems.

- In North Dakota 19,748 children are CSHCN

2009/10 National Survey of Children with Special Health Care Needs

- **CSHCN by Age Nationally**

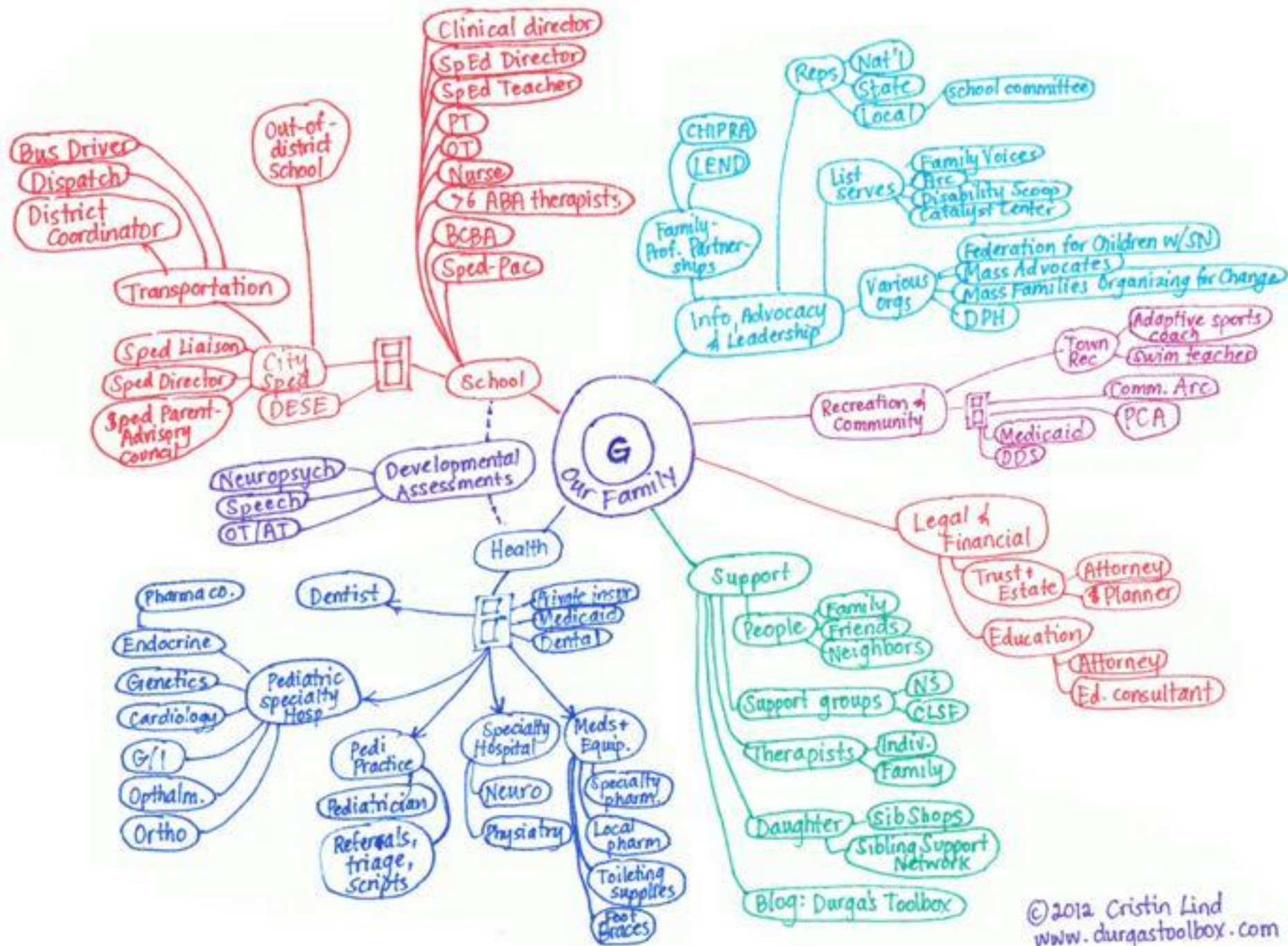
- 0-5 Years 20.2%
- 6-11 Years 38.0%
- 12-17 Years 41.8%
- There are 11.2 million CSHCN in the United States, representing 1 in 5 US households.

WHAT DOES FAMILY VOICES DO?

- Family Voices is a national grassroots clearinghouse for information and education concerning the health care of our children with special health needs.
- FVND is a state affiliate organization
- We are a Health Information and Education Center for families and professionals, providing information and resources on healthcare, disability and chronic health illnesses and issues affecting children with special health care needs
- There is a Health Information and Education Center in each of the 50 states.

FAMILY VOICES OF NORTH DAKOTA

- ND PARENT TO PARENT PROGRAM
- PNT
- In partnership with Designer Genes, Pathfinder Family Center: Project Carson



UNDERSTANDING COMMON ISSUES WITH FAMILIES

IN ADDITION TO ALL OF
THE PROVIDERS A FAMILY
MAY HAVE TO DEAL WITH

There are many additional
issues they may be dealing with

FINANCIAL

- ♥ QUALIFYING FOR PROGRAMS
- ♥ CO-PAYS AND PREMIUMS
- ♥ ONE WAGE EARNER
- ♥ SAVINGS????
- ♥ ASSETS
- ♥ FORMS AND MORE FORMS



MARITAL RELATIONSHIPS

♥ NO TIME

♥ COMMUNICATION

♥ BLAMING

♥ COPING STRATEGIES AND ACCEPTANCE DIFFER

♥ CAN MAKE OR BREAK

♥ "The best advise that one of my child's doctors ever gave me was to make a point to have at least one date night a week with my husband, well that never happened but it was good advice."

SIBLINGS

- ♥ UNINTENTIONAL NEGLECT
- ♥ HAVE TO GIVE UP "NORM"
- ♥ JEALOUSY
- ♥ ANGER
- ♥ HATE
- ♥ HURT
- ♥ HEALTH
- ♥ EMBARRASEMENT

EXTENDED FAMILY

♥ GRANDPARENTS

♥ DOUBLE GRIEF

♥ OTHER FAMILY MEMBERS

♥ MISUNDERSTAND

♥ “If I can’t even get my family to understand that he has a disability and that it is not bad parenting and my fault, how will anybody else every understand?”

FRIENDS

♥ INTERESTS BECOME DIFFERENT

♥ GUILT

♥ STOP CALLING

♥ CAN'T UNDERSTAND

♥ DON'T WANT TO HEAR IT ANYMORE

♥ "I feel guilty because my son is OK and hers isn't. It is hard to call her because I don't know what to say."

♥ "I call her all the time to go do things but she is always too busy, I finally just stopped asking, because she could get out if she really wanted to."

ISOLATION

- ♥ FEEL LIKE YOUR ALL ALONE
- ♥ NO ONE UNDERSTANDS
- ♥ NEED TO FIND NEW MEANING
- ♥ DON'T ENJOY OLD INTERESTS
- ♥ ANNOYED WITH THOSE SEEN AS NORMAL

ROUTINES

♥ CHANGE DRAMATICALLY

♥ MAY NEVER COME BACK

♥ FEEL STUCK

♥ “I feel like it was a successful day when I was able to get out of bed and maybe get a shower.”

VACATIONS

- ♥ ARE SOMETHING THAT DON'T COME BY EASY
 - ♥ BECAUSE OF MONEY
 - ♥ GUILT OF LEAVING
 - ♥ JUST TOO HARD
- ♥ NOT TAKEN FOR GRANTED

SOCIAL STIGMAS

♥ "WELFARE BUM"

♥ TAKE CARE OF OUR OWN

♥ PUBLIC HELP

♥ DISABLED AND SICK SEEN AS BURDENS

♥ UNCOMFORTABLE WITH DIFFERENCES

♥ "It is so hard to apply for something and have the intake worker act as if she is giving me the help out of her own pocket, does she not realize that I work and pay taxes too, we just need a little help to get the services my daughter desperately needs and we cannot afford!"

SPIRITUAL/RELIGION

- ♥ CAN BECOME MUCH MORE SO
- ♥ CAN WALK AWAY FROM BELIEFS AND COMFORTS
- ♥ CAN FIND NEW MEANING
- ♥ NOT WANTING TO ASK HELP FROM OTHERS

BUILDING NEW DREAMS

- ♥ PUTTING WHAT ONCE WAS TO REST
- ♥ FINDING HAPPINESS IN NEW WAYS OF LIFE
- ♥ FIND MUCH DEEPER APPRECIATION FOR THINGS OTHERS TAKE FOR GRANTED

NEW RELATIONSHIPS

- ♥ BUILDING FRIENDSHIPS AND SUPPORT AROUND NEW WORLD AND DREAMS
- ♥ PROFESSIONALS BECOME PARTNERS IN OUR CHILDRENS CARE AND FUTURE

JOB

- ♥ NO UNDERSTANDING
- ♥ MORE TIME OFF
- ♥ INSURANCE WORRIES
- ♥ CO-WORKERS FRUSTRATIONS

REOCCURRING GRIEF

♥ TRANSITIONS

♥ MILESTONES

♥ FOR NO REASON

BURNOUT

- ♥ BECOMES A 24/7 JOB
- ♥ ALL THE RED TAPE
- ♥ ALL THE IGNORANT PEOPLE
- ♥ LACK OF CARE FOR ONE'S SELF
- ♥ FEELINGS OF DEFEAT
- ♥ HAVE TO WORK AT EVERYTHING TO KEEP BALANCE

SACRIFICES

♥ TYPICAL ACTIVITIES

♥ WORLD VIEWS

♥ RELATIONSHIPS

♥ ACTIVITIES

♥ *"FAMILIES WHO RAISE CHILDREN WITH SPECIAL NEEDS OFTEN SACRIFICE THE EASE AND COMFORT MANY PEOPLE BELIEVE LIFE SHOULD BRING THEM, BUT THE DEFINITION OF **SACRIFICE** IS TO **GIVE UP ONE THING** IN EXCHANGE FOR **SOMETHING BETTER.**"*

FAMILYTIMES

FAMILIES ARE UNIQUE AND EACH ONE IS A CULTURE OF ITS OWN

♥ FAMILIES WANTS, NEEDS AND DESIRES ARE DEPENDENT UPON – *THE INFORMATION, TRUST, COMPASSION, RESPECT, EMPOWERMENT AND SERVICES THEY RECEIVE!*

FAMILY CENTERED CARE

- What is this stuff all about?

KEY ELEMENTS OF FCC

- Recognizing that the family is the constant in the child's life, while the service systems and personnel within those systems fluctuates
- Facilitating parent/professional collaboration at all levels of health care: care of an individual child; program development, implementation, evaluation; and policy formation

FCC ELEMENTS CONT.

- Honoring the racial, ethnic, cultural, and socioeconomic diversity of all families
- Recognizing family strengths and individuality and respecting different methods of coping
- Sharing with parents, on a continuing basis and in a supportive manner, complete and unbiased information

FCC ELEMENTS CONT.

- Encouraging and facilitating family-to-family support and networking
- Understanding and incorporating the developmental needs of infants, children and adolescents and their families into health care systems

FCC ELEMENTS CONT.

- Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families
- Designing accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs.

COPERNICAN REVOLUTION

- Copernicus put the sun rather than the earth at the center of the universe, causing a profound challenge to the conceptualization of the universe
- Similarly, family centered care places the family rather than the service system at the center of the universe

Rud Turnbull, Beach Center



FAMILIES OF CHILDREN WITH SPECIAL HEALTH NEEDS

- Families are the primary caregivers and advocates for their children.
- All of the family becomes involved with the coping and caretaking required when they have a child with special health needs.
- A family is at it's best when it meets the family member's needs sufficiently for the family member to grow and develop.

FAMILIES AND HEALTH CARE SYSTEM

- Children with special health needs bring caregivers and service providers together over longer periods of time
- For this reason it becomes increasingly imperative to work together in a collaborative manner

WHEN DID IT ALL BEGIN

- In the early 80's health care professionals called for change, recognizing the importance and impact of the family perspective
- Hence, the philosophy of Family Centered Care blossomed and evolved

PHILOSOPHY

Family centered care is based on the belief that all families care deeply and want to nurture and support their children

A fundamental element of family centered care is family involvement

**It is a process not a destination

WHO IS THE FAMILY?

Families are big, small, extended, nuclear, multigenerational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support...A family is a culture unto itself, with different values and unique ways of realizing dreams; together our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states and nations.... Polly Arango

PHYSICIANS' AND PARENTS' RANKING OF SERVICES

*Ranking

Service	Physicians	Parents
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-Respite care	1	9
-Day care	2	21
-Parent support groups	3	3
-Help with behavior problems	4	10
-Financial information or help	5	2
-After-school child care	6	20
-Assistance with physical household changes	7	15
-Vocational counseling	8	6
-Psychological services	9	5
-Homemaker services	10	22
-Recreational opportunities	13	4
-Information about community resources	14	1
-Dental treatment	16	8
-Summer camp	19	7

THOUGHT

- What families want depends on the difference between the support they already have and what they will need given their situation.

FAMILY-CENTERED CARE = BEST PRACTICE

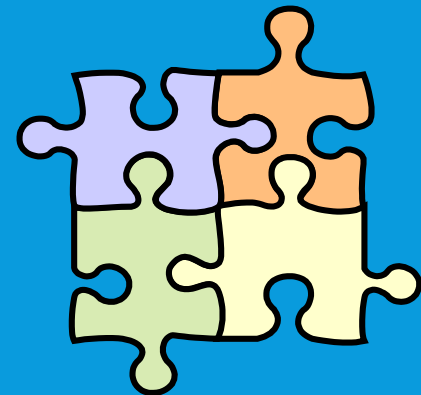
- Families involved in decision making are more satisfied with their primary care provider
- Families active in developing a CYSHCN care plan are more likely to follow and maintain the care plan



**HOW DO WE ESTABLISH A
COLLABORATIVE
PARTNERSHIP WITH FAMILIES
AND CYSHCN?**

FAMILY-PROFESSIONAL COLLABORATION

- Promotes relationship in which family & professionals work together to ensure the best services for the child & family
- Recognizes & respects the knowledge, skills and experience that families and professionals bring to the relationship
- Acknowledges that the development of trust is an integral part of a collaborative relationship



FAMILY-PROFESSIONAL COLLABORATION (CONT'D)

- Facilitates open communication so families & professionals feel free to express themselves
- Creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored
- Recognizes that negotiation is essential
- Includes acknowledgment of mutual respect for each others' culture, values, and traditions

HOW TO CREATE FAMILY- PROFESSIONAL COLLABORATION

- Have families fill out intake forms while in the waiting room to assess concerns and needs
- Put a suggestion box in the waiting room to help facilitate communication
- Make sure the office setting is reflective of various cultures and traditions that families honor



HOW TO CREATE FAMILY- PROFESSIONAL COLLABORATION (CONT'D)

- Speak to the family directly, using his or her name, and ask if they have questions at the beginning & end of visit
- Make sure adequate time is given when scheduling CYSHCN, so there is time for communication with family
- Written information from the office to families, should be written in family-friendly language
- If possible, construct a family advisory group to the practice

PRINCIPLE ONE

- Incorporating into policy and practice the recognition that the family is the constant in a child's life, while the service systems and support personnel within those systems fluctuate
- The family is responsible for the health, physical and emotional needs of the child

PRINCIPLE ONE:

- Service providers and health professionals may participate intensively and meaningfully in the lives of cshcn, but the families provide the long term.
- Families decide the options consistent with the values of their family culture and the best interest of the child.
- Informed decisions cannot be made if families are only provided with information regarding a slice of bread vs. the loaf of bread.

EXAMPLES

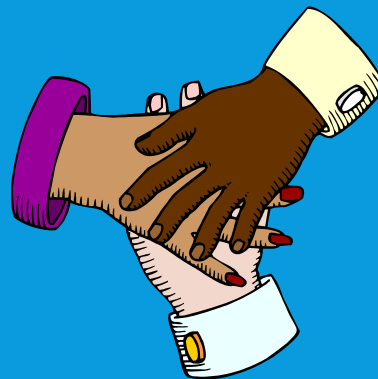
- Acknowledge who the key family members are
- Ask families what they value
- Identify family routines
- Recognize the expertise of families; listen to their ideas and opinions
- Is the therapy goal too much for the family at this time
- Is the office appointment within a time frame to allow as little absence of work as possible
- Has the family provided into goals and objectives

EXAMPLES CONT.

- Have you incorporated input from families regarding dietary likes and dislikes, level of pain, nap periods.
- Include the families input as much as possible in the care of the child.
- If families are not included in the process, their disapproval is frequently demonstrated or perceived as non-compliance
- What are the family dynamics and culture that need to be incorporated?

PRINCIPLE TWO

- Facilitating family/professional collaboration at all levels of hospital, home and community care:
 - care of an individual child
 - program development, implementation, evaluation and
 - policy information



EXAMPLES

- Listen to families and follow their lead
- Be accessible to families
- Build confidence in families, and tell them often what they do well
- Support families in their role as an advocate for their child
- Families and service providers share in the aspects of care for the child
- Families are involved in the full range of health care delivery as policy makers, as planners, and as evaluators of services delivered

EXAMPLES

- Families are fully participatory in the decision-making process and share responsibilities
- Professionals serve as coaches, information providers, and enablers of the meaningful participation of families
- Providing information in an understandable format well in advance if possible for any decision making deadline

EXAMPLES

- fully presenting all options, complications and projected outcomes
- Allowing families to add observations to documents
- Include families at the policy level such as advisory boards, strategic planning
- Continue dialogue on ongoing needs of families
- Assist other staff in implementation of family centered care

PRINCIPLE THREE

Sharing with parents, on a continuing basis and in a supporting manner, complete and unbiased information

- Encourage families to write down information, questions, and suggestions before an office visit
- Avoid making assumptions or speaking in jargon
- Offer opinions, but be sure the family understands all options
- Repeat critical information, expectations, and next steps

EXAMPLES

Knowledge eliminates feeling of powerlessness and dependence.
Access to information needs to be understandable, free of jargon, current and complete.

Parents relate “The more you know the less scary the future looks.”

- Invite questions and expressions of concern
- Provide written information, videotapes, audiotapes, or illustrations when possible as a backup
- Be available for follow-up discussions
- Schedule adequate time to talk with the family; provide privacy
- Suggest families contact a family resource center in the community or a local hospital

EXAMPLES CONT.

- Information exchange is vital...over days, months and years. Professional time invested early will save valuable time later
- Families need time, privacy, support and the opportunity to grieve the loss of a dream
- They need this time to formulate questions and process the information provided

PRINCIPLE FOUR

Honoring the racial, ethnic, cultural and socioeconomic diversity of families

- We need to understand cultures without stereotyping
- We need to define family composition and understand roles of family members

EXAMPLES

- Learn about other cultures; ask questions
- Be aware of your own values and beliefs and how they help shape your actions and decisions
- Respect family values and beliefs, including interest in alternative remedies
- Be nonjudgmental
- Traditional white Anglo families are composed of mother, father and siblings
- Asian, and Hispanic families will include grandparents, cousins, aunts, uncles

EXAMPLES

- Hierarchy within the families may vary
- Other dynamics may include birth, death, divorce marriage and changes in socioeconomic status
- It will need good communication, interpreters if necessary
- Consider ways to sensitize the entire office staff about the diversity of families
- Provide educational materials in multiple languages as needed, and offer translation and interpreter services
- Decorate the office to reflect cultural diversity
- Recognize what nonverbal behaviors are communicating to the family and vice versa

EXAMPLES

- Knowledge that in some cultures eye contact and shyness are a part of that culture
- Religious beliefs
- Family dynamics...each family carries with them their own traditions. No two families are the same

PRINCIPLE FIVE

Recognizing family strengths and individuality and respecting different methods of coping

- **I**dentify strengths: communication, knowledge, parenting style, support systems, culture
- **A**sk families
 - What are your strengths? Concerns?
 - What are your child's likes? Dislikes?
 - What is the best way to approach your child?
 - What do you want? Need?
 - What has worked in the past? Now?
 - What are your needs in the current situation?
- **D**evelop the plan of care to build on family strengths

EXAMPLES

- Families have responsibilities for meeting needs in areas such as economics, personal, physical, domestic, social, self definition, educational
- Families of CSHCN have needs that go far beyond the medical arena
- It is important to recognize the range of emotions in coping: fear, anger, confusion, agitation, sadness, isolation, powerlessness, tears

FCC offers an alternative to this powerlessness

EXAMPLES

Equally important to understand is no two families are the same, nor are members in the family the same

- Above all, if there is anger DO NOT feel that this is personally directed to you! As it is all part of the coping process
- Parents and families arrive with different levels of preparedness
- Professionals must be able to recognize and assist in addressing these situations
- A parent may be temporarily paralyzed by the child's crisis, and some may be well prepared...Above all don't make assumptions

EXAMPLES

- These needs are ever changing over time
- FCC policies would develop programs to bridge the gaps between the child's needs, family need and the available service
- What one family can accept another may have much difficulty with
- We need to be sensitive in our communication with families... "God doesn't give you more than you can handle"

PRINCIPLE SIX

Encouraging and facilitating family-to-family support and networking

- Be sensitive to family needs and the need for support
- Validate the value of family-to-family support
- Provide information about resources
- Be informed about area support groups and/or encourage families to create support groups, if possible
- Recognize the child's need for support
- Recognize the support needs of other family members (grandparents, siblings)

EXAMPLES

- Family-to-Family or parent to parent support is unique and different from the support provided by professionals
- Families want to hear from other families who have “been there, done that”
- Emotional issues of families are traditionally not dealt with in health systems. Family-to-Family support can assist professionals in this area.

EXAMPLES

- Families offer friendships, respect, empathy
- Family-to-Family peer relationships are vital from day one of a diagnosis
- Relationships are formal, informal, informational, disease specific, etc.
- Family-to-Family support networks provide skill building workshops which embrace the strengths of families and enhance their present abilities
- North Dakota has a Parent to Parent Program through FVND : 888-522-9654

PRINCIPLE SEVEN

Understanding and incorporating the developmental needs of infants, children and adolescents and their families into health care systems

- Ask questions about developmental issues
- Listen for family concerns
- Conduct developmental surveillance and appropriate screenings
- Assist families to understand and support the developmental needs of their children
- Make referrals to developmental specialists and support services
- Become informed about special education programs and services

EXAMPLES

- Make certain that treatment is adapted and adjusted for the developmental stage of the child
- Encourage family advocacy
- Encourage families to model self-advocacy skills for their child
- Design office space to accommodate developmental needs of children
- Plan for and support developmental transitions

EXAMPLES

Addressing areas on need as the child is transition into adolescents

FCC incorporates parent input from the beginning

On advisory boards, policy-making, quality assurance, surveys

Each of these examples family input embraces a partnership that is ongoing and interactive

Negative input can be a valuable opportunity

PRINCIPLE EIGHT

Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families

This comes from the increase in coordination and management with agencies, professionals and families

PRINCIPLE EIGHT

- Ask families what they need (a checklist can help)
- Inform families of available programs and resources; keep brochures and applications on hand
- Develop a resource library for families and CYSHCN
- Develop a parent advisory group to assist in designing and implementing care, services, and programs

Shifting from child centered to focusing on the needs of the family

- Supporting families beyond the identity of having a child with special needs
- The child is not her disability, but unique with individual needs as does the family

PRINCIPLE NINE

Designing accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs

- This is to say together families/professionals can design a health system that removes barriers physical and emotional that meets the needs of all
- Be available (flexible hours, evening hours, and weekend hours)
- Consider transportation needs and options for families seeking care
- Eliminate financial barriers to the greatest extent possible (flexible payment options, assist families to apply for services such as Medicaid, SSI, Title V)
- Use community-based care coordination services to help families gain access to needed community-based services

FINAL EXAMPLES OF FCC POLICIES, PRACTICES AND PROGRAMS

- Family members serve on committees which can be hiring committees, system and policy change committees etc.
- Provide in-service opportunities where families assist in the trainings
- A child life specialist or staff can be assigned to child and family before admission-increasing opportunities for a relationship to develop for families who have lengthy stays
- Families can assist with review of written materials and in the development of new materials
- Encourage family participation through family liaisons in areas of the NICU, agency programs in working with other families

FINAL EXAMPLES OF FCC POLICIES, PRACTICES AND PROGRAMS

- Provide access to medical library as well as a family resource library
- Assist families in making a call to agencies like FVND or F2F, get permission to call for them
- Meet as a team, including the family to develop and coordinate follow up care
- Design preadmission forms for CSHCN which will enable the staff to learn from the family about a child's care and family concerns
- Provide access to children's chart and Kardex and allow them to also write in them
- Provide brothers and sisters time in the PICU's and NICU

FINAL EXAMPLES OF FCC POLICIES, PRACTICES AND PROGRAMS

- Allow families to assist and co-instruct in curriculums for professionals
- Family members provide hands on community experiences for health professionals in training
- Provide a variety of ways to gather input from families: questionnaires, evaluation forms, phone interviews, parent advisory boards and suggestion boxes

Parent Leadership Growth



State and/or National
Systems Change

Local and
Community
Support

Self and
Family

THOUGHTS TO PONDER

From the moment the family walks into a facility, emergency care, or you have a home visit the communication expressed can either make or break the day's encounter

THOUGHTS TO PONDER

FCC moves us from a prescriptive
attitude to a collaborative one

THOUGHTS TO PONDER

An important step in developing this collaboration is seeking information regarding their preferences, opinions and suggestions about their child's care

THOUGHTS TO PONDER

Be cautious of labels such as
noncompliant, oppositional,
difficult, over reactive, or fragile

FCCTOOL

- FV National has developed a FCC tool through collaborative partnership with the Maternal and Child Health Bureau

http://www.familyvoices.org/work/family_care

HOW TO CONTACT FAMILY VOICES NORTH DAKOTA

- You may reach us by phone at 701-493-2634
or 888-522-9654
- E-mail: fvnd@drtel.net
- Web: <http://www.fvnd.org>