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1. Memo	To Stanley Herr from Marvin Krislov, 1p	4/16/94	P5
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P1 National security classified information [(a)(1) of the PRA].
P2 Relating to appointment to Federal office [(a)(2) of the PRA].

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Exceptional Parent

October 1993

PARENTING YOUR CHILD WITH A DISABILITY



See p 28, 42

Holiday Toys
Developing an
I(L)EP
Fathers' Voices

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Draft Article for Exceptional Parent 5-4-94 SSH

WORKING TITLE: EMPOWERING PEOPLE WITH DISABILITIES AND
THEIR FAMILIES

by Carol H. Rasco

I am very pleased and honored to share some thoughts with you about disability issues, particularly health care reform. I come to you to express my strong commitment, and that of the Administration, to the empowerment of people with disabilities, as well as to reflect with you on the challenges before us.*

You and your peers in this field -- whether as volunteers (the capacity in which I worked exclusively from my son Hamp's birth until he was over 7-years-old), administrators and family members -- boost our determination and our capacity to both take on responsibility and teach responsibility. ???? And above all you care.

I want to offer you an overview of domestic policy, emphasize the campaign for health care reform, and close with

some of the ideas and individuals that inspire me in my daily work.

The Domestic Policy Council coordinates the efforts of the White House, the Cabinet secretaries, and the other federal agencies concerned with the development of our domestic policy.

As the leader of the Council's day-to-day work, I bring this strong sense of purpose: All children shall be empowered to develop to their fullest potential. For our children to do so, they need each of us to believe in them and to have the opportunities to nurture their growth. It is in that context that I both address you today and carry out the daily tasks entrusted to me by President Clinton.

As the President has recently stated, "having a disability does not diminish one's right to participate in all aspects of mainstream society." On the Domestic Policy Council we take that right very seriously. Working together in public-private partnerships, we can respond to President Clinton's call to "craft policies of inclusion, independence, and empowerment that

will inspire positive changes in this country and in nations around the world."

Health care reform is one of those indispensable and imperative charges. I want to thank most sincerely Paul Marchand and all of Arc's Government Relations Office staff for their hard work in mobilizing you and your membership on health care reform.

I also commend the Arc and the over 100 sister organizations aligned with you in the Consortium for Citizens with Disabilities for your strong support for health care reform. We need to intensify those efforts and above all, we need each of you to work hard in helping to seize this moment of opportunity to guarantee private insurance for all our citizens, coverage that offers you choice, comprehensive benefits linked to your workplace, and freedom from unfair and exclusionary insurance practices.

[On May 2nd, I was delighted to be with the President as he hosted 125 leaders of the disability community in a tremendously enthusiastic rally for health care reform. As the President

emphasized: "This is the battle that you may be able to lead for the rest of America. You can break through to those members of Congress. You can do it." From the White House, these leaders were joined by about a thousand others who marched across the Memorial Bridge to rally at the Lincoln Memorial, then lobby on Capital Hill].

The President's Health Security Act (Senate bill 1757 and House of Representatives bill 3600) is a dramatic advance for people with disabilities and their families. Here's why:

- It guarantees universal coverage for Americans, and the peace of mind of having health care that is always there.
- It outlaws the current insurance practices of excluding people with pre-existing health or disability conditions, or of jacking up your rates if you get sick or disabled.
- It forbids insurance companies from picking only the lowest-risk individuals and families, and rejecting others.
- It builds on today's private insurance system, which is primarily employer-based, while making insurance more affordable

for the self-employed and subsidized for the unemployed. As a result, no one will wind up uninsured, even if they or members of their family experience a disability, injury or sickness.

- It offers a nationally uniform and comprehensive benefit package -- in contrast to some of the other legislative proposals -- that includes a range of preventive services, doctor and hospital visits, outpatient rehabilitation, home health care, durable medical equipment (including orthotic and prosthetic devices and training in the use of those items), mental health services, and many other essential services.

- It includes long-term care reform by expanding home- and community-based services for people with severe disabilities, regardless of age or income. With a projected three million people with disabilities and their families benefitting from this new program, it represents a major expansion of long-term supports for people to live in their own homes, or with their families where appropriate, and to enjoy fuller and more satisfying lives.

- It adds significant civil rights protections in the enjoyment of health care benefits, consumer involvement in the design of the new state programs for Home and Community-Based Services for Individuals with Disabilities, and health care "report cards" so that families can assess which health plan best fits their needs and reward that plan with their membership.

While incremental improvements can be made in the years to come, now is the time to guarantee health security for our children, our children's children and ourselves. But to paraphrase a famous essayist, this is not a case of doing something simply for posterity; we are definitely doing something for us, too! Without secure health coverage, too many of us are not free to change jobs, or move to a different location, or venture from disability rolls to payrolls. Without that security, employers may be reluctant to hire the person with a disability or a person with a family member who is disabled.

These basic concerns unite us. So let us tell our personal stories and give the need for health care reform a human face.

Early in my son's life, a physical therapist who had dedicated her long career to helping young children with disabilities shared with me the words of the poet, Joseph Addison: "Everyone must have something to do, someone to love, something to hope for."

I am constantly reminded of those words not only for Hamp, but for the people with whom I've worked with and worked for. In your quest to empower people, we must ask at each stage in life "what do they have to do?"

For the young child, is a preschool program or other early intervention available? For the school-age child, is school relevant, safe and effective? Are our schools and transitional programs teaching not only how to make a living but how to live? And for adults, is there a job or day activity or voluntary service that provides a niche? As President Clinton said in Memphis in November: "I do not believe we can repair the basic

fabric of society until people who are willing to work have work. Work organizes life. It gives structure and discipline to life. It gives meaning and self-esteem to people who are parents. It gives a role model to children." He went on to say: We cannot, I submit to you, repair the American community and restore the American family until we provide the structure, the value, the discipline and the reward that work gives." Those powerful thoughts are equally, if not more apt, for our citizens with disabilities who too often experience high rates of unemployment and underemployment.

What do they have to hope for? And what do we who love them as their parents have to hope for? Linda Charlton, a mother of a two-year old daughter with Down's syndrome, recently described her goals for Katie before a superb and productive meeting of the President's Committee on Mental Retardation in these moving

terms:

"First, we want her to feel loved...to give her a sense of high self-esteem so that she can experience life with confidence. She is a very social child and while I think she has the capacity to make many friends, I wonder how other children will accept her. We envision her attending public schools, at least for the most part, and one day we hope to see her graduate from high school.

There's even a part of us that hopes she'll continue her education after that...but we'll have to wait and see, and we'll also have to see what it is that Katie wants to do. I wonder if she'll ever get married...if she doesn't, I hope at least she has a companion to enjoy life with. And if we could, we'd like to see her remain as happy as she is today...Our Katie -- who loves people, music, dogs, rain, sunshine, swings, cookies, apricots, baths and the color red."

These are the dreams and feelings to which any parent can relate. For me, part of them were fulfilled when my son Hamp was asked last year by the members of his graduating class to give one of the commencement addresses at his high school. I will never forget that moment, nor will Hamp. Here was the young man who as a baby we were told would not survive or would have to be institutionalized. But Hamp defied those odds, lived at home, and went on to attend school with his non-disabled peers. This is the speech that he wrote, on his own, politely declining his mother's offer of help by saying that this was his speech to give.

"Hello, my name is Hamp Rasco. I am pleased to share with you what attending Hall High has meant to me.

I enjoyed the pep assemblies and the band. I enjoyed talking with friends in the cafeteria, and going out into the community with my CBI CLASS.

After graduation I plan to find a job in the community where my social skills can be put to use. This is important to me because I want to make new friends with all kinds of people.

I would like to encourage other students with special needs to never give up, work hard to do a good job and be proud and happy about what you do at school.

I want to thank Dr. Anderson and the Vice Principals for their support of my program. I want to tell Ms. Chapman and Mr. Smith how much I appreciate all the work they have done on my behalf and all students with special needs. And I also thank Ms. Yates. And, finally, I especially want to thank my parents for believing in me and always encouraging me to be all that I can be.

I really hate to leave all my friends at Hall, but I must move on.

Thank you. Good evening."

Like Hamp, we all must move on. From health care reform to education reform, from safer streets to safer transitions to adulthood, we all have great challenges ahead. But from the White House to your house, we need to work together. We need to reassure all of the Hamps of this country that they will always have health insurance, that they can have jobs, and that they are included in the life of our communities.

Health security frees up a family for hopes and dreams, safer streets help free children and young people to test their wings. People at every age need something to do, someone to love, and something to hope for to be whole and part of whole communities.

I believe a new day is dawning for America's citizens with disabilities and for all our people. We won't always succeed and we won't always be able to do everything that you would want.

But I can promise you this: we will never relent in our effort to give every person a chance to develop -- fully.

Because at the end of Bill Clinton's second term at the dawn of the third millennium, I want to be able to say to Hamp Rasco and Mary Margaret Rasco and to all of America, with a clear conscience and a full heart: We did our best. And I want all of you at this meeting to join me in being able to look at one another and say: We did our best.

Thank you very much.

Carol H. Rasco is the Assistant to the President for Domestic Policy. In this capacity, she is the chief domestic policy adviser and coordinates the staff of the White House Domestic Policy Council. She is the mother of Mary-Margaret Rasco and Hamp Rasco, who has various disabilities.

* This article is a revised and expanded version of remarks
delivered by Ms. Rasco to the Arc Governmental Affairs Seminar,
held in Washington, DC on March 21, 1994.

MEMORANDUM TO CAROL H. RASCO

FROM: Stanley S. Herr
SUBJ: School to Work Opportunities
DATE: May 4, 1994

1. Re the consultation concerning Hamp, Jay Klein left me a message that he is not the "expert" in this field, but that a colleague, Carol Tashie [REDACTED] is. They have a project called "Turning Point" and I have a call in to learn more about their transition program in general.

I had previously given you the name and number of Bill Kiernan, whom I would rely on for advice. For easy reference, [REDACTED]
[REDACTED]

2. Re the School to Work Opportunities event, one of the trainees who sat behind the President is a person who seemed to have multiple disabilities. I spoke briefly with "Kirsten" who is blind and perhaps cognitively limited. I know you will be pleased to know of this inclusion of a person with disabilities in such an event and program. Based on a list of participants, her name may be Kirsten Davidson from Bethesda, working with a program called "TransCen, Inc" in Rockville. I may try to find out more information on this program, and see if the enrollment of persons with disabilities is typical or exceptional.

3. Although you probably already have a copy of the enclosed glossy brochure School to Work Opportunities: an Owner's Guide, I draw your attention to its claim on page 1 that this initiative "helps all youth achieve high standards" (emphasis added), and will "enhance the employability of all youth." (ditto, p. 4). Page 2 also states that it "creates well-marked paths students can follow" to move from schools to first jobs or continued education and training. As you know, for kids with disabilities in most places, those paths are hard to find. Perhaps correcting this condition can be one of the agenda items for our meeting with Judy Heumann next week as we discuss transitions among other things.

THE ARC GOVERNMENTAL AFFAIRS SEMINAR

MONDAY, MARCH 21, 1994

(end of June,
late April 15
May -

Thank you.

①

I am very pleased, honored but somewhat overwhelmed to be in front of you today. As I reviewed the roster of participants and topics for this ~~conference~~ conference, I saw the names of individuals that have looked at me from pieces I have read and studied - ~~often at the suggestion of my boss over our 12~~ years together - and I saw names of people to whom I have listened, with whom I've discussed the ~~youth of our country~~ ^{disability issues, partic. health & ed.} the conditions facing our families and their needs and hopes. And that's where the overwhelmed part comes in...What can I add to what has ~~been~~ ^{been} and will be said?

I come to you to add my strong commitment and that of the administration as well as to reflect with you on the challenge before us. I might add that if you're like me, a luncheon speaker after a morning packed with stimulating, sometimes provocative thoughts, well a luncheon speaker is sometimes a nuisance...you want to TALK about what you've heard, or assimilate it before moving on to the afternoon agenda...so I'll try to add to that assimilation, be quick, and allow you to continue your conversation with one another.

or recuperate from what you've heard.

You and your peers in the field, be they ~~volunteers~~ ^{volunteers} (the capacity in which I worked exclusively from my son's until he was 7 and a half), ~~center~~ administrators, ~~center~~ workers, and so forth daily create the success stories in family's lives like my own - you help to enable our determination, our capacity to ~~take~~ ^{take} on responsibility and teach responsibility - and above all you care.

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~~A recent headline in the Ark. Democrat / Gazette which profiled me as one of the Arkansans making the move to DC stated something to the effect that "son's life leads local woman to White House. And indeed it has.~~

I want first to discuss an overview of domestic policy closing
I bring to the Domestic Policy Council what is seen by some as a simple statement of purpose: All children shall be empowered to develop to their fullest potential. You and I know that the only way children can do so is if each of us as human beings are given that ongoing opportunity - and it is in that context I both speak today and carry out the daily tasks entrusted to me by President Clinton.

w/ health care.

I am reminded inwardly on a constant basis of what an elderly physical therapist who had dedicated her life to young disabled children told me early in my son's life...she said, "Carol, I don't know a lot of philosophy or theory about programs for children like Hamp, but I think the best thing I can tell you as a parent is to remember the words of Joseph Addison, an essayist, poet "Everyone must have

Something to do

Someone to love

Something to hope for."

And how right she was and is in the case of not only Hamp,
but people with whom I've worked with and worked for....and
so at each age of life in our quest to ^{empower people} ~~prevent how we~~
~~approach the problems of the urban poor~~ we must ask

What do they have to do? If a young child, what is the
preschool program available? Can they play, dance, sing, and
soar? If a child, is school relevant? Is school safe?

Are we teaching not only towards
how to make a living but also how
to live?

You know -
the key phrase I learned

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in an otherwise inadequate higher educational experience designed to prepare me to teach elementary school...I was taught there are two educations, one should teach us how to make a living and the other how to live. We do too far little of heeding that maxim.

And for adults: What do they have to do?

As President Clinton said ~~a little over a week ago~~ ^{recently} in

Memphis... "I do not believe we can repair the basic fabric of

had already
w/ reg 86

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society until people who are willing to work have work. Work organizes life. It gives structure and discipline to life. It gives meaning and self-esteem to people who are parents. It gives a role model to children.

Further...we cannot, I submit to you, repair the American community and restore the American family until we provide the structure, the value, the discipline and the reward that work gives.

- these quotes are equally if not more powerful in terms of citizens w/ disabilities

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my daughter doesn't want to miss school, my son

Number 3: Something to hope for... ~~My daughter who didn't~~

~~want to miss a day of the eighth grade today, has many hopes~~

~~and I both thrive in that gleam of hope in her eyes constantly~~

~~look for ways to nurture and keep that sparkle present... help~~

help

me, help our administration look for ways to create that hope

for all citizens of this great country. Health security frees up

a family for hopes and dreams, safer streets help free children

to look at what education can be for them...but untreated ear

infections, uncorrected vision problems, lack of immunizations,

school buildings in AMERICA where children must wear their

coats in order to be warm enough to even begin to pay

attention...and we wonder where hope has gone?

wants to make it to well on Kim I thrive on the gleam

To put things bluntly, it isn't often ^{enough} we see in a community
whether a block, a zone, in the power centers of a large city,
in the boardroom, public or private...it's not often we find
social workers, health care outreach personnel, early
childhood and K-12 front line educators, government workers
and ~~big~~ "business" types sitting down together...each has had
their own niche and seldom the twain have met. I submit to
you that until each side - human development and economic
development are willing to sit at a common table - real
reinvention of government for ^{citizens of disabilities} ~~families~~ will not occur. We can
make application procedures simpler for ^{individuals} ~~families~~ seeking help,
we can legislate incentives and tax credits, we can give health

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security, we can write more meaningful standards for our students... all on the one side known as human development and we can talk about investments, deficits, inflation, job creation, etc. on the economic development side but until we recognize that giving people at every age

(1) something to do;

(2) someone to love; and

(3) something to hope for

are all a part of a mandatory whole just as people and families and communities are both parts and "whole" entities" ...

we will not have accomplished the task before us.

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In closing I am reminded of two pieces that haunt me, motivate me in this area of thought. One, in my freshman philosophy course at Hendrix College in Arkansas, Dr. Ellis repeatedly pounded the table in his quest to motivate us to go out into the world and face the adversity necessary to make positive change, admonishing us to remember that saying from THE PRINCE: "There is nothing more difficult to take in hand, more perilous to conduct, or more uncertain in its success than to take the lead in the introduction of a new order of things." We have not a choice, we must take this moment in time to introduce a new order for ^{all citizens} ~~our families~~.

For as Governor Clinton said back in 1987 as we closed our year's work on MAKING AMERICA WORK:

America won't work if Americans can't work, or learn, or believe in the promise of tomorrow.

~~Thank you~~

^{I believe} At last, a new day is dawning for America's ~~children and~~ ^{people - all people} ~~their families~~. We will work together with you. We won't always succeed, and we won't always be able to do everything that you-- and we--would want.

But I can promise you this: we will never relent in our effort to give every ~~child~~ ^{child} a chance to develop--fully. Because at the end of Bill Clinton's second term, at the dawn of the third millenium, I want to be able to say to Hamp Rasco and Mary Margaret Rasco and to all ~~the children~~ of America, with a clear conscience and a full heart: We did our best. And I want all of you at this ~~summit~~ ^{meeting} to join me in being able to look at one another and say: We did our best.

Thank you very much.

A large, stylized handwritten signature, possibly 'Bill Clinton', is written on the right side of the page. It is accompanied by several scribbles and a circled number '15' at the top right.

E X E C U T I V E O F F I C E O F T H E P R E S I D E N T

04-May-1994 04:59pm

TO: Stanley S. Herr

FROM: Carol H. Rasco
 Economic and Domestic Policy

SUBJECT: Thank you!

Thanks for the Addison quote..I love it!

EXCEPTIONAL PARENT

PARENTING
YOUR
CHILD
WITH A
DISABILITY

1994 EDITORIAL CALENDAR

Month	Editorial Theme	Article plus Product Directory
January	National Directory Issue	Associations, Organizations, Products & Services
February	Early Intervention	Seating and Positioning
March	Mobility	Wheelchairs, Cushions, Camp Directory
April	Summer Fun	Cycling, School Directory, Hotels, Travel
May	Recreation ()	Racing Wheelchairs, Adaptive Sports Equipment
June	Computer Networking/Telecommunications	Augmentative Communication
July	Teens	Driving Aids
August	Health	Incontinence, Bathroom Aids
September	Education	School Directory
October	Holidays	Home Access, Ramps
November	Technology	Environmental Controls
December	Religious Education	Vans and Lifts

2 week
(April 8th -
May 5th)

Month	Editorial Theme Descriptions
January	Directory information, 1993 index of articles.
February	Early intervention: Articles focusing on programs, products and services for children zero to three years of age.
March	Mobility: Articles focusing on the purchase, use and maintenance of wheelchairs and related mobility aids. This is our 5th annual mobility theme issue.
April	Summer fun: Articles focusing on family travel, vacation ideas, vacation destinations and specialized or integrated camps for children with disabilities.
May	Recreation: Articles focusing on fun activities (sports, drama, dance, community activities, etc.) for children and teens with disabilities.
June	Computer networking/telecommunications: Articles focusing on the use of computer networking and telecommunications by parents, organizations, schools and individuals (children and adults) with disabilities.
July	Teens: Articles focusing on teenagers with disabilities and their families. Topics might include driving, sexuality, employment, college, peers and family issues.
August	Health: Articles focusing on health, dental health, nutrition and incontinence.
September	Education: Articles focusing on the social, legal and psychological aspects of education for children with disabilities. This is our 22nd annual education theme issue.
October	Holidays: Articles focusing on gifts including adaptive toys and children's books. Additional articles on ways to include children with disabilities in family holiday activities.
November	Technology: Articles focusing on innovative uses of technology by children with disabilities. This is our 12th annual technology theme issue.
December	Religious education: Articles focusing on religious education with an emphasis on helping children with disabilities become part of their families' religious congregations.

On-going Departments:

Parents Search & Parents Respond:	In Parents Search, parents look for information on various aspects of raising a child with a disability. In Parents Respond, parents answer questions raised in previous editions of Search.
What's Happening:	Short current news items of interest to families.
Fun stuff:	Articles on fun activities to do with children with disabilities.
Media:	Reviews of books, videos, software.
Children's Page:	Short pieces by children with disabilities and/or their siblings.
Letters to the Editor	
Editor's Desk:	Notes from Stanley D. Klein, Ph.D., Editor-in-Chief and magazine co-founder.

New Departments:

Fathers' Voices:	A column focusing on the special needs and concerns of fathers of children with disabilities.
Role Models:	Stories by or about successful parents or individuals with disabilities.
Point Of View:	Opinion pieces.
Corporations	Short pieces honoring large and small corporations that are working to create greater opportunities for people with disabilities.
Who Care:	

Ad Closing Information

The close for ad insertion is the 1st of the prior month.
The close for ad material is the 15th of the prior month.

Exceptional Parent Offices

Publishing Office	Editorial Office	Advertising Office
120 State Street Hackensack, NJ 07601	209 Harvard St. Ste 303 Brookline, MA 02146-5005	120 State Street Hackensack, NJ 07601
Joseph M. Valenzano, Jr. President/Publisher 201-489-0871 Phone 201-489-1240 Fax	Stanley D. Klein, Ph.D. Editor-in-Chief 800-852-2884 Phone 617-730-8742 Fax	Kerry J. Cannon Vice President Sales 800-E PARENT Phone 201-489-1240 Fax

EXCEPTIONAL PARENT

PARENTING
YOUR
CHILD
WITH A
DISABILITY

AWARDS

Exceptional Parent and Dr. Klein have received numerous awards, among them:

National Parent Network on Disabilities, 1992

"Special Recognition Awards for outstanding leadership on behalf of people with disabilities and their families."

Boston Institute for the Development of Infants and Parents, 1992

Award for Excellence to Dr. Klein "to acknowledge your many contributions in the field of child development over the years and to honor your outstanding work."

New Jersey Developmental Disabilities Council, 1991

"Special Recognition Award for 20 years of helping families and their children with disabilities."

The National Down Syndrome Congress, 1989

"National Media Award"

The President's Committee on the Employment of the Handicapped and the American Association of Disability Communicators, 1986

"...in recognition of outstanding contributions to public understanding of disability issues."

Massachusetts Early Intervention Consortium, 1985

"...for outstanding contribution to early childhood intervention...."

Association of Retarded Citizens/Massachusetts, 1983.

Distinguished Citizen Award to Dr. Klein

EXCEPTIONAL PARENT

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- **BARBARA J. SEABURY**, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
- **HOWARD SHANE**, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
- **CAROL TINGEY**, Ph.D., Parent, Psychologist, Western Rehabilitation Hospital, Sandy, UT
- **HAROLD TURNER**, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA
- **IRVING KENNETH ZOLA**, Ph.D., Professor and Chairman, Dept. of Sociology, Brandeis University, Waltham, MA

Stan. FYI

SR

Special Article

The Challenge of Communicating with Parents

STANLEY D. KLEIN, PH.D.

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Although working with parents is a critical aspect of pediatric care, the training of pediatricians, like the training of colleagues in other pediatric health care disciplines, rarely includes specific content about the doctor-parent relationship or the role of the family in health care.¹ Rather, it is as if it is assumed that working with parents in a clinical setting will develop in each clinician "naturally" and that neither concepts nor techniques for interacting with parents need to be learned.² One area of clinical literature in which parents are likely to be mentioned is in reference to children with disabilities.

This paper presents specific concepts about the health care professional(s)-parent(s) relationship and the communication of information, often called patient-education information, to parents. My goal is for the skilled clinician to be able to integrate these concepts and techniques into his or her day-to-day work with parents in ways that fit with the personal style of the clinician, the demands and constraints of the health care setting in which the professional practices, and the needs of the parents.

ATTITUDES TOWARD PARENTS

Many health care professionals view parents negatively: as nervous, guilty, anxious, depressed, and/or overprotective. Such negative stereotyping by professionals seemingly begins to develop as inexperienced clinicians in training observe parents in health care settings. These clinicians seem to ignore the fact that the sample of behavior they observe is not representative of any parent's everyday adaptation to parenting; rather, it is an observation of parents under significant stress brought about by concerns for a child's health and the potentially frightening implications of any health care assessment. As a result, after observing many parents under the stress of seeking health care for a child with a "problem," health care professionals, as they gain

more experience with children as patients, can conclude that all parents are anxious, inept, inadequate, troubled adults all the time.³

In addition to observing parents under the stress of clinical care, most health care professionals have these clinical learning experiences at a developmental stage in their own personal lives, as young adults, during which they are in the process of establishing themselves as independent individuals—a time when it is common for young adults to blame their own perceived inadequacies on their parents' lack of parenting abilities. Thus, the stage specific "complaints" of young adults in reference to their own parents serve to confirm their observations of their young patients' parents.³ Parenthetically, although I advocate personal psychotherapy, I suspect that young professionals who are in psychotherapy may be particularly vulnerable.

Finally, "pop psychology," as reported by the public media as well as by a considerable body of professional literature continues to blame parents, especially mothers, for the problems of children and, retrospectively for the problems of adults, thereby "validating" the personal and clinical experiences of the developing professional. For example, in a review of 125 articles in reference to psychological disorders of children, "mothers are held responsible for 72 different kinds of psychological disorder."⁴ Despite increasing research and clinical evidence of the role of constitutional characteristics in the development of both physical and mental illness, stigmatizing of parents continues in professional literature.⁵

The unfortunate result of all these kinds of experiences in the lives of developing health care providers is that many professionals unwittingly bring negative stereotypes (prejudices) about parents to their encounters with parents, which interfere with their perceptions of parents and their ability to communicate constructively with them.⁶ Seligman and Darling,⁷ in their wonderful book, *Ordinary Families, Special Children*, review many studies regarding the negative attitudes of professionals toward parents of children with disabilities and illustrate the destructive impact of such attitudes.

To actively counteract the factors that create negative stereotypes about parents and contribute to blaming parents, developing professionals need opportunities to discuss their perceptions and attitudes and to be willing to learn from

This paper was adapted from a presentation at Creating Family-Professional Partnerships: Educating Physicians and Other Health Professionals to Care for Children with Chronic and Disabling Conditions, Pittsburgh, PA, May 21, 1992.

Index terms: professional-family relations, parents, children, exceptional, patient education, education, medical.

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parents via a variety of teaching formats. These formats can include parents as lecturers and panelists as well as professionals participating in home visits and respite care. Unless brought to consciousness and addressed, these prejudices may be passed on as clinical wisdom to new generations of health care providers.⁵

Parents as Experts and Partners

A far more appropriate perspective in reference to the parents of young patients is to learn to appreciate that (1) parents are experts about their child and can serve as teachers to professionals,^{8,9} and (2) parents can be partners in the diagnostic and treatment processes. This view is clearly articulated in recent federal legislation in the United States that seeks to establish early intervention and family support programs for families that include an infant or toddler with a disability or serious medical condition.^{7,10} (See Public Law 99-457 Education of the Handicapped Act Amendments, U.S. Congress and related regulations prepared by the U.S. Office of Education, 1986.)

One illustration of parental expertise is research that demonstrates that when parental abilities to assess a child (such as estimating their child's developmental levels in specific areas) have been studied, parents do as well or better than professional "experts."^{11,12} However, the concept of parents as experts can be troubling for some clinicians. Although professionals expect parents to provide information, they are often unlikely to expect parents to take an active role in decision making.¹³ Rather, parents may be expected to be passive and cooperative, prepared to agree with professionals.¹⁴ As described above, mothers in particular have been blamed for all sorts of childhood psychological problems. In addition, historically, mothers of children with disabilities have been misperceived by professionals (mostly men) as hostile and demanding and probably psychopathological. In contrast, more recent literature on female development makes clear that when women speak out on behalf of the needs of loved ones, they are asserting themselves in a psychologically healthy, appropriate fashion.¹⁵

The partnership concept is particularly relevant in the pediatric care of children with disabilities because most clinical problems require long-term day-to-day management and care, usually delivered or supervised by parents.¹⁶ In the literature on models of the doctor-patient relationship, the mutual participation model is considered most appropriate for "chronic" conditions because the doctor and the patient (and/or parents) work together toward mutual goals.¹⁷ This model is likely to be effective when there are common goals, common understanding of the problem, and a common plan for treatment.¹⁸ This model is not appropriate in acute illness situations in which the doctor tells the patient (or parents) what to do and/or administers the treatment directly to a relatively passive patient.¹⁶

Studies of patient compliance support this collaborative model although the term "compliance" suggests an authoritarian approach by the provider.¹⁹ In a pediatric setting, Korsch and Negrete²⁰ demonstrated that the key factors in parental (mother) cooperation with physicians and in successful health outcome for the child included the mother's perceptions that the doctor praised her as a mother, an active

exchange between doctor and mother, the physician's expression of concern for the mother's feelings, and mother's satisfaction with the visit. Similarly, in special education settings, it has been found that parental satisfaction is related to having adequate time and input from professionals, being involved in the discussion, and not being blamed.²¹

From a practical point of view, this means that the process of meeting the health care needs of a child will be enhanced when the health care professional believes that the interaction with the child's parents will be one of active reciprocal learning—parents and professionals learning from each other how best to help the child. In his recent book, Greenspan²² notes: "It should go without saying that the parents are the true integrators of all that relates to the child, as they are with the child the most hours of the day. They not only need to benefit from the insights of all the professionals who work with the child, they need to provide feedback to the professionals about what works and doesn't work at home, as well as the emotional climate there."

In learning, the self-esteem of the learner is critical. In fact it has been shown that when parents feel more competent, they become more effective.²³ Therefore, to facilitate learning (and teaching) by parents, the professional needs to clearly demonstrate respect for the expertise of parents and to explicitly acknowledge their role as active partners.

Brazelton poignantly illustrated how the professional's approach to a parent can affect parental self-esteem and thereby facilitate participation. He described how pediatric residents were distressed by the fact that the teenage mothers had no questions for the residents after an initial physical examination of their new babies. When the residents followed Dr. Brazelton's suggestion that they begin their contact with a positive comment about the mother and her new baby, the mothers had many questions (Brazelton, TB, personal communication).

CONCEPTS AND TECHNIQUES FOR COLLABORATION

Setting

It is assumed that it is usually important for the health care professional(s) to meet with parent(s) separate from the young child/patient (see below in reference to older children). The setting in which such a discussion of the child's history or the clinical findings occurs conveys a mutual participation model of communication when it encourages an active give and take among adults of equal status.³ Practically speaking, this means: (1) each participant seated in an equally comfortable chair, (2) each seated adult's eyes on the same level, (3) each seated at a conversational distance from the others, and (4) each being able to take notes comfortably.²⁴ Accordingly, a separate office (or seating area) with a desk and adult-sized chairs is more appropriate than using an examining room (along with nearby medical equipment), a classroom, or a playroom with furniture designed for young children. In addition, parents are entitled to uninterrupted privacy according to a prearranged schedule that respects the value of their time as well as the professional's and allows sufficient time for

discussion with an opportunity to continue, if necessary, at another time.¹⁹

When children are 10 to 12 years old, meeting with parents separately is not likely to be constructive because it creates the impression that parents and the professional(s) are on the same "side" at a time in the child's life when he or she is likely to need the health care professional as a supportive ally or advocate "against" the parents. Because such separate meetings also create the impression that the clinician is communicating something different to parents than to the child, meeting with the parents and the child together (while at the same time providing an opportunity for confidential doctor/patient communication for the child) will be more constructive as long as the professional, by words and by action, focuses attention on the child and the child's health care needs.³

Include Dad

Whenever possible, we need to encourage the child's father to participate. All too often, despite recent cultural awareness of sexism, "mother" is expected to attend meetings in reference to a child's health as if she were at home with nothing else to do while her traditional husband's work is too important to be interrupted by such trivial matters. In that same scenario, the mother is expected to report to the father so that he can provide his stamp of approval and pay the bill.³ In a study of hundreds of Individual Education Planning Committee meetings regarding special education assessments, both parents were present in only 9% of the meetings.⁹

Involving the father, which may still require a special invitation to counteract stereotypical male behavior, communicates that he too has an important parenting role. Involving fathers is especially important when parents are expected to carry out or supervise compliance or participate in a treatment program at home. Even when divorced fathers do not share in child custody, they can participate.

Traditionally, fathers have not been actively involved in the educational and health care needs of their children. By involving fathers from the start (including fathers who may not be living with their children), clinicians demonstrate to children as well as their parents that fathers are important. It is not unusual for a boy to get the idea, based on his observation of his mother and most of his teachers (usually women), that school is girl's work. At the same time, fathers, when confronted with a child who is awkward and/or somewhat disappointing, are more likely than mothers to withdraw their efforts to be with their son. This unfortunate cycle of disappointment, frustration and withdrawal can be altered by involving fathers from the beginning and letting fathers know just how important they are. Fathers are usually very responsive to this approach, often reporting that it is the first time they have not felt left out by health professionals.⁶

Fathers of children with disabilities are beginning to get attention. "Families and professionals now have the chance to build new bridges, to dramatically construct a vision that gives fathers of children with disabilities recognition and understanding, and most importantly, substantive programs—not add-ons—that speak to dads' unique concerns."²⁵

How Many Professionals?

In some multidisciplinary settings, clinical findings and recommendations are presented to parents at a "team" meeting in which every health care professional involved in the assessment of a child is present and has a turn at presenting the findings of his or her area of speciality. Some school systems convene similar mass meetings when the special education assessment of a child is completed because it is erroneously believed that the federal law regarding special education and related services mandates such meetings. Although the federal law actually states that three professionals must attend every meeting (along with parents) at which individualized education plans are created, Cruickshank et al⁹ found that an average of five professionals attended, and sometimes as many as 10 to 12 attended. Greater numbers were usually related to greater severity of a child's disability.

Most parents report feeling overwhelmed when the number of professionals exceeds the number of parents. Many professionals believe meetings that include many professionals tend to contribute to a fragmented approach to the child and family rather than the integrated approach such meetings are supposed to facilitate.

For most parents, smaller meetings with one or two key professionals are preferable. One of the professionals present should be prepared to be involved in follow-up communications. All such meetings require thoughtful preparation: the more professionals in attendance, the more complicated the planning process. Some parents find the participation of a trained parent advocate very helpful.²⁴

Planning and Preparation

Whenever possible, it is helpful for professionals to communicate with parents in advance (for example, by telephone or mail) about structural details such as meeting time, both starting time and finishing time; meeting place (how to get there, where to park, etc.); names and functions of participants; and agenda. Parents can have an invitation to modify the agenda.

The professional team needs to prepare themselves for meeting with parents. One person needs to be identified as the leader, the person who will assume responsibility of introducing (or reintroducing) each team member to parents, for keeping the meeting focused on the agenda, and for appropriate follow-up with the family. The team needs to agree on the key messages they wish to convey and to prepare who will and how to present them so the meeting can proceed without anyone being rushed. Ideally, the team can learn to model such interpersonal skills as attentive listening, mutual support, respectful give and take, and the ability to help one another communicate clearly.²⁴

Parents/Professionals "Partnership"

Inasmuch as parents may have served only as informants in previous relationships with health care providers, the importance of their active participation as observers and experts will need to be stated early in process. In situations such as at the diagnostic center, when parents have provided a case history to another provider or at another setting, it is helpful to apologize for the repetitiousness and to explain

the purpose of a case history in the current context. In addition, to counteract the common parental experience that a case history is like a courtroom interrogation in which parents are on trial, the health care professional can make clear that parents are not being judged on the basis of whatever they did or did not do and that it is unrealistic to expect parents to remember developmental details for each child. Parents need to hear that they are not being blamed. Rather, one purpose of the discussion is for parents to share their observations as well as their questions and concerns.³

Another technique to address parental worries about being judged is for the health care professional to explicitly state his or her empathy with the parents by acknowledging that parenting is always difficult and that parenting a child with a disability can result in the parents feeling upset, frustrated, angry, and discouraged (other human feelings are also possible). Similarly, the clinician can clarify in a supportive manner that parents probably would like to enjoy parenting more.²² Via such specific empathic comments, a clinician conveys understanding of parental dilemmas and addresses the common complaint of many parents that health care providers do not really appreciate the day-to-day challenges of caring for children with health problems.^{6,20,24,26,27}

By acknowledging the "negative" feelings parents experience, the clinician helps the parents become more active because in the doctor's office many parents believe they are expected to be "mature," "objective," and stoic.

To do this, parents are likely to actively suppress their feelings of frustration and worry. This process takes a great deal of psychic energy which is then unavailable for active participation in the diagnostic process. The clinician begins the process of freeing up this energy and thereby facilitating communication and understanding by providing parents with an opportunity to talk about their feelings and by responding with empathy and attention rather than with implied or explicit criticism, or impatience to get on with the procedures.

The clinician's goal is not to cure parents of their frustrations. Rather, as parents have an opportunity to express their feelings to the doctor and to each other, new energy for the task at hand becomes available, energy previously expended on keeping these feelings hidden. In a sense, the parents' emotional block to talking and learning is being treated. During such discussions, parents need to be assured that they are the most valuable people in their child's life and that they can be invaluable in all efforts on behalf of their child.⁶

A useful technique for actively involving parents is to inquire about parental observations, in everyday interactions, of the child's development in areas relevant to the particular health concerns (such as hearing, language, motor skills, memory, intelligence, reading, social skills, etc.) that the clinician will be objectively and subjectively assessing during the examination. This process also enables the professional to explore parental expectations in relation to the child's "problems" and their remediation and sets the stage for connecting parental observations with specific clinical findings after the examination of the child.^{6,18,28} By linking parental observations to clinical findings, the establishment of shared treatment priorities by the parents/professional "partnership" is facilitated.

In discussing clinical findings, health care professionals need to speak in understandable language. Few parents, including well-educated people, understand technical medical and educational terminology. Professionals tend to overestimate the level of understanding of adults. For example, Alpert and Wittenberg^{9,18,28} found that adult patients actually understood only 29 of the 50 medical terms their physicians had thought appropriate for conversations with patients.

When such treatment priorities require parental involvement with their child in a program at home, the mutual participation or partnership model can help prevent the professional team from establishing unrealistic expectations likely to lead to noncompliance. For example, although a particular therapy program may require 30 minutes per day of a parent and a child working together, the professional can review how much time is actually available within the constraints of everyday family life and begin with smaller, more realistic increments of time. In this way, both parents and child can begin the process by feeling successful rather than feeling inadequate to the task. Gradually, the "partners" can decide to increase the demands.³

DELIVERING BAD NEWS

Communicating clinical findings indicating that a child has a serious medical problem or developmental disability is a challenging parent education responsibility. There is no way any practitioner can make the sad news about cerebral palsy, mental retardation, or cystic fibrosis sound like good news.²⁸ Instead, the professional can have the critical clinical goal of providing parents with an opportunity to begin to mourn the loss of the healthy, "perfect" child they had anticipated and of facilitating the parents' active participation in parenting.^{29,30} In this way, the clinician can continue to be "a healer despite his failure [to maintain health] . . . He can initiate the healing process in the patient's deep psychological wound."³¹

One reason the task of delivering bad news can be especially difficult for a health care clinician is that it contrasts so dramatically with health care situations that the practitioner finds gratifying, e.g., successfully treating an acute medical crisis.^{32,33} In the bad-news situation, the doctor, as well as the parents, can experience the situation as a tragedy. This is especially likely when there is little the provider can do to immediately improve the child's condition. It is helpful for clinicians to appreciate their own feelings of frustration, disappointment, and sadness when they are unable to do what they do best. When unable to "fix" the problem, the clinician may erroneously believe that there is nothing that he or she, as a health care practitioner, can do to help the family or the child.²⁹ This is an unfortunate error because, even as parents are faced with the inevitability of a child's terminal illness, there is a great deal the practitioner can do to help the child, parents, and other family members. "Helping patients deal with loss is one of the most difficult and delicate tasks we face . . . all the more so because our training places a premium on 'doing something to the patient rather than talking or listening. Emotion is discouraged in favor of objective objectivity."³³

For some professionals, particularly some medical subspecialists and clinicians at diagnostic centers, delivering bad news to parents can be an everyday, relatively routine, task. In dramatic contrast, for individual sets of parents, hearing the bad news for the first time will be an experience never to be forgotten. Etched in parental memories and painfully reviewed again and again in the years to come, this first encounter will influence parental perceptions of professionals, sometimes in irreparable ways.

Because of the magnitude of the impact this encounter can have on parents, professionals must approach the challenge with sensitivity and appreciate that the process will take time. It cannot be carried out in a constructive fashion when it is presented by a standing professional with one hand on the doorknob poised to go on to the next "case." Rather, it requires a step-by-step discussion with everyone seated.

It is crucial to acknowledge that some professionals are unable to set sufficient time aside to be with parents for this difficult interaction; others do not feel up to the task temperamentally. Under such circumstances, the parents will need a capable substitute who is prepared to take charge of communicating the findings on behalf of the team.

Starting during the Case History

The time to prepare for the presentation of bad news is during the case history. Ordinarily, during the case history, the clinician knows quickly the probability that the child has a serious problem. It is particularly important to explore parents' ideas about the etiology of various symptoms to learn about the parents' understanding of the body and how it works and to be prepared to correct misconceptions later.

Step-by-Step Presentation

The bad news will be upsetting no matter how it is presented. However, the practitioner can present the findings in a thoughtful step-by-step manner that takes into account the parents' predictable shock and distress and provides appropriate parent education information.

By beginning with a review of the parents' observations and concerns voiced during the case history, followed by the clinician's observations that confirm or clarify those of the parents, the clinician gradually can move on to the diagnosis and prognosis. For example, with a 1-year-old infant with cerebral palsy and a hearing impairment, the clinician can review the parents' observations about the child's delayed motor development or apparent inattentiveness. He or she can then describe examination findings that support the parents' observations. Then clinical findings (such as reflex abnormalities and electroencephalography results) that go beyond parental observations can be described, beginning to explain the internal, systemic conditions that cause the child's observable behaviors. One principle of parent education is that the clinician begins with externally observable behaviors, then takes the parents "inside" the child's body, and explains the relationship of internal processes to observable behavior in lay terms, without using the specific diagnostic terminology. The reason for not yet using the specific diagnostic term is to facilitate

the maintenance of the parents' attention while linking parental observations with clinical findings.²⁸

The clinician must present the specific bad news in the form of technical diagnostic terminology. Some practitioners, wanting to "protect" parents from the pain and distress likely to be associated with diagnostic terminology, may communicate via euphemisms or postpone using clinical terms.^{34,35} However, as parents usually are aware that something is amiss and are worried about it, avoidance of direct discussion by the practitioner is not helpful: it leaves parents fearful and uncertain.

More specifically, without the specific terminology, parents are cut off from three valuable sources of information. First, the clinician, by speaking openly about the diagnosis, can more easily discuss the possible future problems and how to cope with them.³⁶ Second, parents will be able to educate themselves via parent education materials, which are categorized by diagnostic terms. Third, because parent support groups are likely to be organized according to diagnosis, parents without diagnostic information cannot learn from other parents with similar children.³⁸

When parents have heard the diagnosis, the clinician must take the time to explore the parents' reactions, worries, and fears. Diagnostic terminology is loaded with emotion and mystery. Professionals need to listen to parental worries about the terminology and take the time to explain the meaning of the terminology for the specific child being discussed.²⁸

Parental Distress

When faced with the information that a child has a disability or serious illness, the average, mature, mentally healthy parent will be very upset. Distress is an understandable, healthy reaction. However, parents and, unfortunately, sometimes the clinician, may feel that parents' emotional distress, fears, and concerns about the future are not relevant subjects for the doctor-parents' encounter. Parents and/or the doctor may believe that the "healthy" way for parents to react is to suppress feelings and act in a stoic fashion.²⁸

As described earlier, when parents suppress fears and distress, a great deal of psychic energy is consumed.²⁶ A parent, working hard to keep feelings and worries inside, has very little energy available to pay attention, listen, and learn the vital information about the child's condition that the health care professional can provide. Instead, the practitioner now has a parent with a temporary learning disability caused by emotional stress. Because the parent is upset and preoccupied with inner distress in regard to the child's diagnosis, he or she is unable to learn whatever the clinician wants to teach. A valuable technique at this stage is to say to the parents, "cerebral palsy is a frightening term." A statement of this kind provides explicit permission for parents to be frightened.²⁸ It communicates to parents that it is a normal, human reaction to be frightened by technical terminology and especially terminology that suggests a child has a serious problem.³⁷ Without explicit permission and encouragement, a parent may feel embarrassed by the way he or she feels, silently suppress feelings, and pretend to understand the doctor's educational presentation when, in fact, he or she is unable to pay attention.

This critical step of acknowledging parents' probable reactions gives parents the opportunity to talk about shock, fears, sadness, and even anger at the clinician providing the diagnosis. Parents need a chance to voice fears, worries, and questions to a clinician who conveys that it is acceptable to be upset and to say so. This enables parents to begin the emotional reaction to loss: the mourning process.²⁸ "For most sad patients, you accomplish a major therapeutic act by simply allowing the patient to release feelings . . . you fulfill your professional role by simply providing a setting in which the patient can comfortably express and reflect."¹⁹

It is important to keep in mind that parents' upset, confusion, anger, and questioning behavior (such as questioning the doctor's competence and repetitive questions about the diagnosis itself) are all primary manifestations of anxiety rather than hostility. Accordingly, it can be productive for the clinician to say, "I can appreciate how frightening it is to hear this news about your child." Or to say, "I can appreciate that you must have all kinds of feelings, including very angry feelings about getting this news."²⁸

By empathic comments, the clinician explicitly informs parents that strong feelings are permissible and acceptable; the clinician validates parental emotions. Parents need to hear that, under the circumstances, it is normal to have many troubling feelings at the same time: fear, sadness, anger, hopelessness. Parents also need to know that the practitioner is willing to listen patiently and will not criticize any emotional reactions.³⁶ After parents describe their feelings, the clinician gradually can provide the educational information parents need to understand the diagnosis, to reduce the level of distress, and to begin proper action to meet the needs of the child and the family.²⁶

By encouraging parents to discuss their emotional reactions, the clinician helps parents begin to mourn.³³ It is helpful to explain to parents that they are likely to experience a wide range of emotions because they will be going through the mourning process. At the same time, by manner and words, the clinician communicates that "I will stay with you and, over time, help you learn everything you can to facilitate your parenting." The phrase "over time" is critical as the mourning process does take time. Giving lip service to a mourning process does not bring it to an end. It will take time, during which parents will need continued attention and concern, preferably from the clinician who delivered the bad news.²⁸

Highly trained health care professionals dedicated to improving health and addressing acute health care problems may have difficulty with the approach described above and with parents who are upset. Often, talented professionals perceive parental distress and feel upset themselves by the magnitude of the parents' situation. As a result, they cope with their own personal discomfort and believe they are meeting parental needs for information by immediately presenting a thoughtful "lecture" to parents about the diagnosis and prognosis. In this way, the professional is likely to feel better because he or she is in control and reassured of his or her expertise. The clinician also may assume that as a result of the valuable information conveyed, parents will understand the child's condition and feel better as well.

Instead, parents suffer quietly and say little. They feel embarrassed about being upset—and additionally embarrassed for not understanding the "lecture." Surely, parents need a great deal of information; the issue for the clinician is the dosage and timing.²⁸

Denial and Anger

Denial is part of the mourning process; denial is a reaction to anxiety. If a clinician pushes harder to make a point that a parent denies, the parent's anxiety, as well as the denial, will increase. The more effective technique is to address the cause of the denial itself; namely, to talk more with the parent about how frightening and upsetting the bad news can be.²⁸

By specifically encouraging the parent to talk about feelings of anger about the bad news, the clinician helps prevent the clinical depression that can occur in parents as they try to cope with the birth or the initial diagnosis of a child with a disability or serious medical condition.^{28,38} When angry feelings are turned inward because there is no opportunity to express them outwardly, depression can result.³⁹ By addressing parents' feelings, the clinician also has an opportunity to help parents regain their self-esteem and thereby help them remain active participants in the treatment process.

The professional also can help the parents by explaining the value of verbalizing to one another the wide range of feelings each parent is likely to experience in the months to come—including the feeling that they are "going crazy." Parents need to know that experiencing such feelings is part of the mourning process and that it is in their own best interest to be able to speak openly about their reactions with their loved ones, as well as with caring professionals. At the same time, as a way of preparing parents to be understanding of each other, it can be helpful for parents to be reminded that individuals in mourning can be difficult to be with and may act or speak in troubling ways.²⁸

Touching

Although some advocate physical touch as a technique for comforting, I suggest caution for three reasons. First, it is unlikely that we will be cognizant of specific familial and cultural styles and meanings in relation to touch. Second, because inappropriate touching by psychotherapists, physicians, clergy, and other authority figures has received a great deal of publicity recently, I believe that touch in a clinical setting is now more likely to be misinterpreted. Third, more and more clinical literature indicates that many, many adults have been physically and sexually abused and, therefore, they too may be vulnerable to well-intentioned touching. Instead, I suggest we put our messages into words; via empathic language we can "reach out" in very meaningful ways.

Support Groups

The professional team also has the responsibility of explaining that parent support groups can provide emotional support and practical information very effectively, often far more effectively than any professional. By becoming a participant in parent groups, parents no longer feel isolated, can

share their grief, and can learn practical solutions to everyday challenges.

To connect parents with groups, professionals need to be knowledgeable about appropriate local and national groups. As experienced parents have pointed out, professionals may be asking too much when they expect upset parents of a newly diagnosed child to have the energy and courage to contact a group. Rather, with parental permission, the team can have the group reach out to the parents (Greer M, personal communication).

Written Reports

Under the best of circumstances, well-intentioned, intelligent parents are unlikely to remember everything communicated verbally by the health care professional.¹⁸ Encouraging parents to take notes or to audiotape meetings can be helpful, but a more effective approach is to prepare a written report (using language understandable to lay persons) for parents summarizing the discussion in the meeting, including the clinical findings, the diagnosis, and specific recommendations. Beside helping parents (and clinicians) remember the discussion and thereby preventing the normal distortions in memory that occur, such reports often can be more valuable than technical clinical reports for other professionals unfamiliar with discipline-specific jargon.

TRAINING

Although it has been said that "the ability to deal with and communicate bad news . . . should be studied, practiced, and critiqued no less than the more technical skills,"¹⁸ few health care settings actually provide opportunities for systematic practicing of oral or written communication skills. Whereas meeting parents and interacting with them in a classroom or clinical seminar is valuable, there is no substitute for practice for learning specific techniques.

I have used actors and actresses playing parents to provide practice, instant replays, and immediate feedback to student clinicians. Individual students are videotaped delivering bad news, and the tapes are reviewed and critiqued in small group discussions. People with acting training are likely to be uniquely perceptive about the details of an interpersonal encounter and able to respond to content as well as process.

Discussing the proper dosage of information and the best sequence in which to present it is another useful exercise. Trainees need to sort out the information considered crucial and determine how to present it in a thoughtful, understandable manner. They may need to be reminded that the "lecture" method is not the most useful format for "teaching."

Writing to educate parents (or patients) also requires practice. Although we may require students to write referral

letters to colleagues or clinical reports for medical recordkeeping, I am not familiar with any specific efforts to train professionals to write for parents. My observations, based on forcing students to write letters to patients they have "seen" via video, indicate that some of our well-educated students have learned to write very complicated, lengthy sentences and paragraphs that are difficult to comprehend. Others write as if they have never had to write complete sentences. Modern word processing equipment with good memory can facilitate efficient report writing, but I am very concerned about the need to teach professionals how to "input" their knowledge in an understandable fashion.

Finally, one of our greatest challenges for training is to appreciate the powerful messages conveyed by modeling in the clinical setting. In the current health care context, where so many external factors can detract from good care, each of us can try to maintain high quality care and understanding for parents and be as clear as we can to our students about the compromises we may make.

CONCLUSIONS

I have presented teachable concepts and techniques for communicating with parents. Unfortunately, selling the need to teach and practice such content continues to be an uphill struggle. In closing, let me share a list written by a parent about what parents need from professionals, a list of principles that we can try to teach:

- A supportive relationship over time that allows for changing needs, strengths and external realities as well as recurrent feelings of helplessness and not-knowing.
- A wide view—but one that is also concrete and focused and provides information and tools (practical and emotional) to make the immediate more workable and the future more predictable.
- Validation for current feelings along with the recognition and assurance that they will not always be the same.
- Respect for a parent's courage to experience and withstand enormous fears, pressures and unknowns however these are being expressed.
- Willingness on the part of the professional to find out and not assume or label where a parent is.
- Help in sorting out feelings and fears about how things will be from the facts or possibilities that may be fuller or different.
- Help with and ongoing reworking of hopes and expectations that is both challenging and supportive, grounded in reality, yet leaves room for feelings and dreams.⁴⁰

Acknowledgment. Preparation of this article was supported in part by a donation to Children's Hospital by Thomas and Barbara Lee.

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RESOURCES

Ordinary Families, Special Children by Milton Seligman and Rosalyn B. Darling, Ph.D. New York, Guilford Press, 1989.

This book does an outstanding job of reviewing the literature on families that include a child with a disability and discussing clinical applications within a family systems framework.

Exceptional Parent magazine, 1170 Commonwealth Avenue, Boston, MA, 02134.

Since 1971, this magazine has published many articles by parents. Clinicians can request a free waiting room subscription by writing to the address above.

The Medical Home Project of the Hawaii Medical Association. Calvin Sia, M.D., Principal Investigator, and Margo I. Peter, M.Ed., Project Director. The Medical Home Project, Hawaii Medical Association, 1360 South Beretania, Honolulu, HI, 96814.

This project has produced educational materials for physicians working with young children with disabilities and their families that includes valuable suggestions for communicating with parents.

Families, Physicians, and Children with Special Needs: Collaborative Education Models by Rosalyn B. Darling, Ph.D. and Margo I. Peter, M.Ed., Westport, CT, Greenwood Publishing Company, in press.

This book covers the proceedings of the conference "Creating Family-Professional Partnerships: Educating Physicians and Other Health Professionals to Care for Children with Chronic and Disabling Conditions" at which this article was presented.

Breaking the News. The Institute for Families of Blind Children, P.O. Box 54700, Mailstop 111, Los Angeles, CA, 90054-0700, \$10. Videotape.

Four ophthalmologists discuss their feelings, experiences, and style when conveying a serious diagnosis to patients and parents.

How to Break Bad News: A Guide for Health Care Professionals by Robert Buckman, Johns Hopkins University Press, Baltimore, MD 1992.

This excellent new book, a collaboration by an oncologist and family psychotherapist, presents a protocol for breaking the news to adult patients. Issues raised as well as protocol and examples are applicable to communication with parents.

Your Child's Recovery—A Parent's Guide for the Child with a Life-Threatening Illness by Barbara A. Dailey, New York, Facts on File, Inc., 1990.

"An excellent resource for families . . . rich resource for trainees in pediatrics, child psychiatry, nursing, and social work . . . teachers" (see book review on page 200).

Are There Good Ways to Give "Bad News"? by Gloria L. Krahn, Ph.D., Ann Hallum, Ph.D., and Cetrelia Kime, M.A. *Pediatrics*. 91:578-581, 1993. Mothers and fathers of 24 infants with a recently diagnosed disability were interviewed regarding their preferences for how to be told the "bad news." Recommendations for how to present "bad news" can be concisely drawn from the findings.

EXCEPTIONAL PARENT

PARENTING
YOUR
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DISABILITY

EDITORIAL MISSION

To reach out to parents

of children with disabilities and special health care needs, so they can participate in a network of caring parents throughout the world.

To empower mothers and fathers

by providing practical information and emotional support from other parents, knowledgeable people with disabilities and thoughtful professionals, enabling parents to:

- Appreciate that they are the most important experts in the lives of their children;
- Embrace the exhausting and often thankless job of parenting, always remembering that the child with a disability is, first, a child;
- Develop parenting skills to cope with the day-to-day challenges and joys of nurturing a child with a disability, and prepare to meet the challenges to come;
- Become confident advocates for the needs of their children and their families;
- Learn to be informed consumers, able to collaborate with professionals in selecting the best possible products and services;
- Prevent burnout, by also attending to their personal needs.

To energize parents

to join local, state and national organizations dedicated to active community participation for children and adults with disabilities, and their families.

To share ideas and experiences

so that parents, professionals and other advocates can learn from one another and better collaborate to serve all children and families.



Stanley D. Klein, Ph.D.
Editor in Chief

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READERS' NEEDS

Activity	Child Needs	
	Some Help	Complete Assistance
Toileting	26%	57%
Eating	38%	34%
Bathing	29%	60%
Grooming	30%	63%
Dressing	30%	58%
Communicating	41%	40%
Mobility	28%	30%
Travel	26%	67%

Source: Human Services Research Institute Cambridge, Mass.

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IMPORTANT DEMOGRAPHIC STATISTICS

- *Readers saving ALL issues*.....66%
- *Average household income*.....\$56,000+
- *Require special aids and equipment*.....65%
- *Own personal computer*.....48%
- *Own vans*.....21%
- *Own home*.....85%
- *Purchased adaptive aids for their auto*.....24%
- *Made home adaptations/alterations*.....37%
- *Purchase special health foods*.....31%

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PRESIDENT'S STATEMENT

Child-rearing is a vital and difficult task; unrecognized and unsung perhaps because it is so universal. Even more vital and much more difficult is the task of raising a child with a disability.

Exceptional Parent magazine provides straightforward practical advice, emotional support, and useful information stripped of professional jargon. Our editorial focus is on information that is useful, sensitive, and compassionate . . . in essence, "information that matters from people who care".

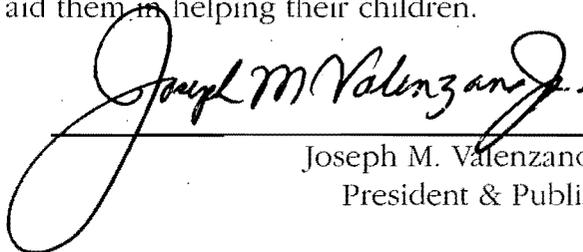
The child is our main concern. The disability is secondary. Because of this, we are careful about vocabulary.

We believe that parents are the key experts on the lives of their children. Our focus is on real people with real problems and real concerns . . . people like our readers.

We concentrate on what parents can--not should--do, presenting differing opinions objectively without taking sides. Many articles are written by parents or people with disabilities, illustrating how "exceptional" people cope with extraordinary challenges.

Exceptional Parent approaches advertising as information important to its editorial content. It is an added value to our publication and its editorial message.

Our readers know they can rely on *Exceptional Parent* to respond directly to their needs, whether that's by networking with other parents, following important trends and issues, or learning about products and services that can aid them in helping their children.



Joseph M. Valenzano, Jr.
President & Publisher

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Co-founder, Editor-in-Chief

Stanley D. Klein, Ph.D., is Co-founder, Editor-in-Chief of *Exceptional Parent*, the magazine Ann Landers has called "must reading for all those with a handicapped child."

Dr. Klein, a clinical psychologist and educator, founded *Exceptional Parent* in 1971 with two colleagues. Dr. Klein is Professor of Psychology and Director of the Counseling Service at the New England College of Optometry in Boston. He also serves as a Research Associate in Medicine at Boston's Children's Hospital where he teaches pediatricians about working with parents of children with disabilities.

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Dr. Klein is married and is the parent of two children.

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President & Publisher

Joseph M. Valenzano, Jr., has spent over 20 years in the publishing industry, holding senior executive positions at McGraw-Hill, Elsevier, Thomson and Medical Economics. He is a former Chief Financial Officer, as well as a line operations officer in charge of manufacturing, distribution, information systems, marketing and circulation. Mr. Valenzano has served as a consultant to several leading publishing, communications and health care companies in the areas of mergers and acquisitions, divestitures, financial systems, manufacturing and production, and strategic and tactical business planning. In addition to launching publications, he has worked with several well-known investment banking firms specializing in IPO's and other financings for the publishing and health-care industries.

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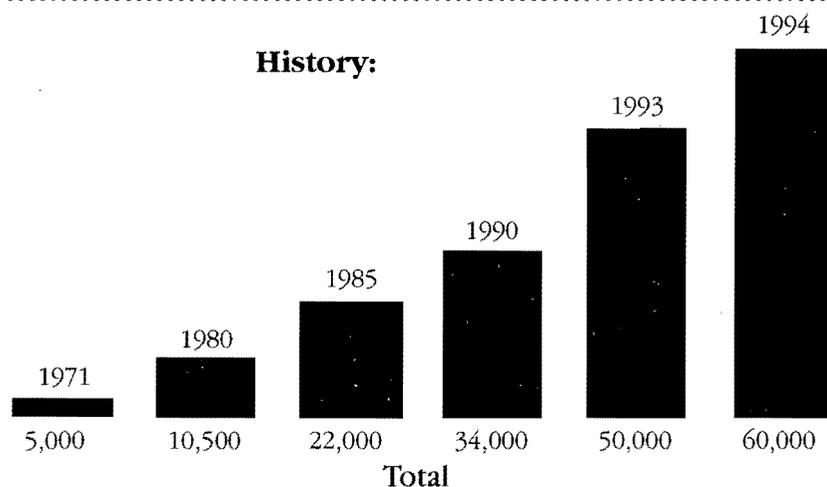
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