Dear Disability Rights Advocate:

These are exciting days. We are writing to you about what may be a pivotal chapter in our efforts to obtain family support for families of children with disabilities. And we are writing to tell you how you can help turn this dream into a reality.

For the past year, families of children with disabilities from all over the country, together with the Consortium for Citizens with Disabilities, have worked to develop recommendations for federal legislation on family support for children with disabilities. The U.S. Senate Subcommittee on Disability Policy, which is part of the full Senate Committee on Labor and Human Resources, this spring plans to introduce federal legislation that advocates for family-centered and family-directed systems of support. If ultimately adopted and signed into law, this bill would send a clear message in Federal law that families are the primary resource caring for children with disabilities.

As you may know, reaching this point with any government body is an extensive process that involves many complex discussions and negotiations. And successful passage of this bill will require not only further discussions and negotiations, but the commitment of individuals and families like yours who are willing to make your voices heard.

The packet you have in your hands contains information and tools you may use to support your cause. It is designed to simplify the process of contacting your elected officials to express your support for this legislation. The packet also is designed to help you contact members of the news media to encourage them to write about the problems created by the present system, problems that this legislation can help solve.

Let us be clear — this will be a long process, very likely several months in length. Success will neither come easily, nor quickly. But if we cast our efforts together and make our voices and wishes heard by those we have elected to represent us, then we are hopeful that we will succeed in our quest.

The attached sheet describes the materials in this packet and includes some recommendations on how you may proceed. If you have any questions, you may call either of us, or the public relations team working with Colleen Wieck in Minnesota.

We wish you the very best in your efforts and encourage you to seize this truly exciting moment in our history together.

Sincerely Yours,

Mr. Allan I. Bergman

Director of State-Federal Relations United Cerebral Palsy Associations 1522 "K" Street NW, Suite 1112

allan A. Berguan

Washington, D.C. 20005

Phone: 1-800-872-5827

Ms. Fran Smith

Consultant

2574 Sheldon Drive Richmond, CA 94803

Fran Smal

Phone: (510) 222-2999

Family Support Legislation Packet Contents

Your voice can play a crucial role in the passage of this legislation. To support "The Families of Children With Disabilities Support Act," we are recommending that you consider taking any one or all of the following actions:

0	Contact your Senator by phone or mail to express support for this legislation. Since the legislation has not yet been introduced in the House, we are limiting our action to only the Senate at this time.	
	Call your Senator's office and ask for a copy of the Bill. This will help them tally interest in this issue.	
	Contact members of the Senate Labor and Human Resources Committee to thank them for taking on this challenge and introducing this legislation.	
	Contact members of the national news media to encourage them to write about the need for this legislation.	
	Encourage other families and individuals you know to take these same steps by circulating these materials to them.	
To assist you in this effort, here are the materials we are providing to you:		
	"The Family Support Act: Realities, Principles and Focus" — this is a three-page summary of the focus and provisions of the bill. You may use it for background, or make copies for the news media and your partners.	
	"The Case for Family Support" — This one-page fact sheet contains important statistics that can help present the need for this legislation.	
	"Saving Families, Saving Money" — This one-page fact sheet demonstrates how the state of Minnesota increased its services to children with disabilities by adopting a family support focus.	
	Sample letter and phone scripts for contacting your elected officials on this issue.	
	Background information and guidelines on how to phone, write and work with your Senator and other elected officials.	
Q	Guidelines on how to approach the news media, along with addresses and phone numbers of key national news media likely to have an interest in this issue.	

If you have any questions or need assistance, don't hesitate to call any of the individuals and phone numbers listed in this material.

Family Support Legislation Key Messages

When speaking to elected officials, media representatives, support groups or others interested in this issue, it is important to focus your discussion on what you would consider to be your main points or "key messages" that you would want someone to most remember. It is most effective when each key message or main point is stated individually and then backed up either with statistical information or real-life examples that demonstrate why that statement is important.

Here are three key messages you may want to consider using as you begin forming your ideas on what you might say in support of this legislation. As you contemplate these, consider how you would support each with statistical information or real-life examples.

	There is a need for statewide, comprehensive, coordinated, interagency systems of family support that are family-centered, family directed and easily accessible.
	(For an example of supportive information, see for instance "The Case for Family Support" information sheet.)
	Establishing a family-centered, family directed system of family support such as described in "The Families of Children with Disabilities Support Act" would result in a more efficient and cost-effective system.

(For an example of supportive information, see for instance the "Valuing Families, Saving Money" information sheet.)

Children and families would directly benefit from a family-centered, family directed system of family support — families would be strengthened, communities would be enriched, and ultimately, a greater number of people in need would be served.

(For an example of supportive information, see for instance the "Valuing Families, Saving Money" information sheet.)

The Family Support Act: Realities, Principles & Focus

The Families Of Children With Disabilities Support Act advocates for family-centered and family-directed systems of support that meet the real needs of families caring for children with disabilities. Following are some of the societal realities, policy principles and areas of focus that have guided the development of this bill:

<u>The</u>	Realities	
٥	Children benefit from enduring family relationships in a nurturing home environment.	
Q	High financial outlays and significant physical and emotional challenges limit the ability of many families to meet the special needs of their children.	
ū	Financial disincentives are currently forcing some families to make unwanted out-of-home placement of their son or daughter.	
0	Supporting families to care for their children with disabilities at home is both efficient and cost-effective.	
	There is a need in most states for statewide, comprehensive, coordinated, interagency systems of family support that is family-centered, family directed and easily accessible. These systems should avoid duplication, use existing resources more efficiently and prevent gaps in service.	
The	<u>Principles</u>	
0	Families should be supported in determining their own needs and in making decisions concerning necessary, desirable and appropriate services. They should play decision-making roles in developing policies and programs that affect their lives.	
ū	Family supports must focus on the needs of the entire family. Family needs change over time, and family support must be flexible.	
	Supports must be sensitive to the unique needs, strengths and cultural values of the family.	
	Family support must be proactive and not solely in response to crisis.	
٥	Families should be supported in their choice for integration and inclusion of their children within the community. Family support should promote the use of existing social networks, strengthen natural sources of support and help build connections to existing community resources.	

The Case For Family Support

The U.S. system of services for people with disabilities is often described as a patchwork quilt. Unfortunately, that quilt is ridden with holes and provides little shelter for families struggling to care for a child with a disability.

The current focus on achieving independence for people with disabilities neglects members of their household. The people who share a household with (and care for) a person with a disability carry a difficult burden, one which strains both their pocketbook and their spirit.

	More than \$17 billion a year is spent on disability services, benefits and programs. This money maintains a system that is frought with overlapping segments, conflicting eligibility criteria, and inconsistent regulations.
	(Source: Braddock, D., et. al., Institute on Disability and Human Development, University of Illinois at Chicago, 1994)
	The money spent on disability services by government agencies is highly weighted toward costly out-of-home care and tends to encourage dependence, rather than independence, by not helping people obtain the skills and resources they need for life in the community.
	Only one cent of every dollar allocated by the U.S. government to help individuals with disabilities goes to help families support their child at home. The other 99 cents are spent on out-of-home care.
	(Source: Knoll, J., et. al., Human Services Research Institute, 1990)
Q	There is a national trend toward de-institutionalization, but the allocation of support is lagging behind. In 1977, 91,000 individuals under age 21 with mental retardation lived in public or private institutions. That number fell to 60,000 in 1982, and to about 48,500 in 1987. Despite this significant shift, family support services have reflected a relatively small corresponding increase.
	(Source: Birenbaum and Cohen, American Association on Mental Retardation, 1993)
	Substantial cost savings can result from redirecting resources to family-based care. Typical family-based support programs average between \$7.00 and \$15.00 per child, per day. Conversely, out-of-home placement costs can approach \$250 per child, per day, and rarely are below \$100.

(Source: Minnesota Disability Law Center, United Cerebral Palsy Associations, 1993)

For more information, contact Greg Smith, Colle & McVoy Public Relations, at (612) 851-2555, or Brian Kane, Colle & McVoy Public Relations, at (612) 851-2644.

Valuing Families, Saving Money: A Minnesota Model

The state of Minnesota began a significant redirection of resources for disability-related services in the 1980's. The state systematically defined public policy with a value declaration that all children, regardless of severity of disability, have a right to grow up in a family home and that families should be supported rather than supplanted in their primary caregiving responsibility for children with developmental disabilities.

The Minnesota experience from 1980-90 demonstrates how increasing family support gives relief to both families and government budgets.

In 1980, Minnesota spent \$20.4 million on services for children with developmental disabilities.
Out of that \$20.4 million, 830 children received services out of the home, separated from their families. Only 50 children benefitted from family-

In 1990, following a decade-long redirection of resources, Minnesota spent \$24.3 million (a 20 percent increase) on residential services for children with developmental disabilities.

directed subsidies.

\$10.8 million was spent to provide services for 219 children in facilities away from home.

\$13.4 million was spent for 1,827 Minnesota children to receive family support services in the home.

THE BOTTOM LINE: Over a decade, the number of children receiving state support in Minnesota increased by 240 percent, while spending increased in that 10-year period by only 20 percent.

If Minnesota had not enacted this change of focus, it would have had to allocate more than \$44 million to serve the same number of children (830) who in 1980 received out-of-home services for just over \$20 million.

Most importantly, this redirection of resources has allowed the state of Minnesota to drastically expand the number of people receiving support (to 2,046), serving both the individuals with disabilities and their caregiving families.

The Minnesota experience offers evidence that sound social policy and sound economic policy can add up to a win-win for everyone involved.

(Source: Minnesota Disability Law Center, United Cerebral Palsy Associations, 1993)

For more information, contact Greg Smith, Colle & McVoy Public Relations, at (612) 851-2555, or Brian Kane, Colle & McVoy Public Relations, at (612) 851-2644.

How to • • • Work With Your Elected Officials

- Be fair and be informative.
- Be understanding of the pressures being applied to elected officials by others whose views are different from yours.
- Be friendly and maintain contact; don't wait until a crisis to seek them out.
- Be reasoned and reasonable in presenting your arguments.
- Be charitable (up to a point) about delays in their response or action.
- Be constructive and cooperative. Try to present alternatives.
- Be realistic and persistent, but recognize that politics is the art of compromise.
- Be practical and offer sound arguments.
- Be a good opponent. Fight the issue, not the person.
- Be informed and loyal to your position.
- Be trustworthy.
- Be calm and evaluative.
- Be generous in giving credit where credit is due.
- Be visionary, realizing you may still win the war after losing a battle.
- Be willing to work at your arguments and through your contacts.

How to • • • Call Your Senator

- ♦ Telephone numbers (in Washington, D.C.) for U.S. Senators on the Senate Subcommitte on Disability Policy and on the Senate Committee on Labor and Human Resources are included in this packet.
- Identify yourself to the person who answers the phone. Be sure to say that you are a a constituent in your senator's state. If the senator is unavailable, ask for his or her aide on Disability Policy issues.
- If you are not a constituent, but are calling a Senator who is a member of a key committee, you can appeal to the Senator's role as a statesperson and explain that you are urging him or her to vote on behalf of <u>all</u> families.
- ♦ Tell the Senator the issue or bill number you're calling about. Give your position and the reason for your position.
- ♦ Briefly explain the likely impact of a bill on your family and on the senator's constituents in general.
- ♦ If the senator is unavailable, give the aide or staff member your message. Congressional staff are very good at relaying messages.
- Be polite. Keep party politics out of the discussion.
- Say "thank you" for the senator's consideration of your views.

Sample Phone Scripts

Hello, my name is	I am a parent caring for a child with a	
disability, and I'd like Senator/Repr	resentative to know that I	
	Vith Disabilities Support Act currently under consideration	
in Congress. Families such as mine	e are currently faced with inadequate systems of support	
that rarely meet our individual need	s and often contribute to the breakdown of families. The	
Families Of Children With Disabili	ties Support Act is an important first step in ensuring that	
my family and families like mine ca	an obtain the support we need in order to provide for our	
children and keep our family intact	Thank you for your consideration.	
Hello, my name is	and I'm calling to urge Senator/Representative	
to si	apport legislation that works to establish better systems of	
support for families caring for child	ren with disabilities. The Families Of Children With	
Disabilities Support Act does just the	nat. As a parent of a child with a disability, I have learned	
firsthand about the limitations and	nadequacies inherent in current systems. I want support	
that allows me to both determine m	y family's needs and contribute to decisions concerning	
desirable, necessary and appropriat	e services. Senator/Representative	
can help my family and the	usands of other families like mine gain supports that are	
sensitive to our individual needs.	Thank you.	
Hello, my name is	It's time to give individual states the guidance	
	amilies caring for children with disabilities. Currently, too ed and too many families are suffering because of it. The	
Families Of Children With Disabili	ties Support Act will help set states on a more fiscally	
	th. We need a serious redirection of philosophy and	
resources. Senator/Representative	can help make this a reality by	
supporting The Families Of Childre	en With Disabilities Support Act. Thank you.	

How to • • • Write to Your Senator

Elected officials care about what you say. A logical, courteous, personal letter carries weight: it can change a senator's mind, particularly when the senator is wavering on an issue.

It is important that your message be written as effectively as possible. Here are a few pointers:

- ♦ Be sure to say that you are a constituent in the senator's state.
- ♦ Limit the letter to one subject.
- ♦ Be as brief as possible (no more than one piece of paper), but don't sacrifice clearness and completeness.
- State your purpose at the outset and use the remainder of the letter to expand your views.
- ♦ Letters about a particular bill should include its name, bill number (if you know it) and subject matter, because there may be several bills concerning the same topic. If your senator or representative is an author of the bill, acknowledge that.
- Explain in your own words how you feel about the need for (in this case) The Families With Disabilities Support Act.
- Issues you write about may be emotion-laden; be factual rather than emotional.
- ♦ Legislators want to know how votes actually affect constituents. Give Facts and illustrations.
- Don't assume that a legislator is as well-informed as you about a problem. Explain the situation, what you think and why.
- A polite, positive-sounding letter is more likely to impress than one that is negative, rude or threatening.
- Be certain that your name and address are on the letter.
- Send a note of appreciation if your legislator supports your issue.
- ♦ To obtain the file number or a copy of the "The Families of Children with Disabilities Support Act," call your Senator's office and ask for the senate number of the Bill and a copy, if you desire one.
- Finally, always close by asking for a written response.

Sample Letter To Senator/Representative

DATE

The Honorable Edward M. Kennedy SD-428 Dirksen Senate Office Building Washington, D.C. 20510-6300

Dear Senator Kennedy:

I am writing to urge you to support "The Families Of Children With Disabilities Support Act," which will provide incentives to states to develop and enhance statewide systems of support for families caring for children with disabilities. I urge you to lend your support to this bill.

My family has a personal stake in this issue. (Briefly describe your family's experience; for example, our son/daughter was born with (_______), which has left him/her (describe condition). In seeking to provide for his/her needs, we have encountered numerous obstacles, such as (_______) and (_______). We want to care for our child in our home and keep our family intact, but are prevented from doing so by a system that is difficult to access and which places incentives on out-of-home care.)

Parents like me/us across the country face similar obstacles as we strive to keep our families functional and intact. Your support of "The Families Of Children With Disabilities Support Act" will provide thousands of families like mine with an opportunity to shape our own destiny and experience the freedom that many other Americans have come to take for granted.

I will look forward to receiving a letter from you that indicates your intention regarding "The Families Of Children With Disabilities Support Act."

Thank you for your consideration.

Sincerely,

Your Name Your Address Your Phone Number (optional)

Senate Committee on Labor and Human Resources

SD-428 Dirksen Senate Office Building Washington, D.C. 20510-6300 PH: 202/224-5375

Majority Members

Senator Edward M. Kennedy, D-Mass. Committee Chairman SR-315 Russell Senate Office Building Washington, DC 20510-2101

PH: 202/224-4543 FAX: 202/224-2417 TDD: 202/224-1819

Senator Jeff Bingaman, D-N.M. SH-110 Hart Senate Office Building Washington, DC 20510-3102

PH: 202/224-5521 PH: 202/224-1792

Senator Christopher J. Dodd, D-Conn. SR-444 Russell Senate Office Building Washington, DC 20510-0702 PH: 202/224-2823

Senator Tom Harkin, D-Iowa SH-531 Hart Senate Office Building Washington, DC 20510-1502 PH: 202/224-3254 TDD: 202/224-4633

Senator Howard M. Metzenbaum, D-Ohio SR-140 Russell Senate Office Building Washington, DC 20510-3502 PH: 202/224-2315

Senator Barbara A. Mikulski, D-Md. SH-709 Hart Senate Office Building Washington, DC 20510-2003

PH: 202/224-4654 FAX: 202/224-8858 TDD: 202/224-5223

Minority Members

Senator Nancy Landon Kassebaum, R-Kan. Ranking Minority Member SR-302 Russell Senate Office Building Washington, DC 20510-1602 PH: 202/224-4774 TDD: 202/224-1165

Senator Dan Coats, R-Ind. SR-404 Russell Senate Office Building Washington, DC 20510-1403 PH: 202/224-5623 TDD: 202/224-9449

Senator Dave Durenberger, R-Minn. SR-154 Russell Senate Office Building Washington, DC 20510-2301 PH: 202/224-3244 TDD: 202/224-9522

Senator Judd Gregg, R-N.H. SR-393 Russell Senate Office Building Washington, DC 20510-2904 PH: 202/224-3324 FAX: 202/224-4952

Senator Orrin G. Hatch, R-Utah SR-135-Russell Senate Office Building Washington, DC 20510-4402 PH: 202/224-5251 FAX: 202/224-6331

FAX: 202/224-6331 TDD: 202/224-2849

Senator James M. Jeffords, R-Vt. SH-513 Hart Senate Office Building Washington, DC 20510-4503 PH: 202/224-5141

Senate Committee on Labor and Human Resources

SD-428 Dirksen Senate Office Building Washington, D.C. 20510-6300 PH: 202/224-5375

Page 2

Majority Members

Senator Claiborne Pell, D-R.I. SR-335 Russell Senate Office Building Washington, DC 20510-3901 PH: 202/224-4642

TDD: 202/224-6564

Senator Paul Simon, D-Ill. SD-462 Dirksen Senate Office Building Washington, DC 20510-1302 PH: 202/224-2152

TDD: 202/224-8180

Senator Paul David Wellstone, D-Minn. SH-717 Hart Senate Office Building Washington, DC 20510-2303 PH: 202/224-5641

Harris Wofford, D-Penn. SD-521 Dirksen Senate Office Building Washington, DC 20510-3803

PH: 202/224-6324 TDD: 202/224-1063

TDD: 202/224-4754

Minority Members

Senator Strom Thurmond, R-S.C. SR-217 Russell Senate Office Building Washington, DC 20510-4001

PH: 202/224-5972 FAX: 202/224-1300

Guidelines for • • • Talking With News Media

	Identify yourself and explain that you are a parent of a child with a disability, and that you are actively pressing for national legislation on family support issues.
0	Ask the person on the phone if they are the right person for you to be talking with.
0	Once you have the right person on the line, ask that person if they are aware that there is national legislation in the Senate that would provide family support to families caring for children with disabilities.
o	Be prepared to answer their questions on 1) what family support is, 2) how does the current system fail to provide appropriate support, 3) what problems you have dealt with in the current system, 4) the name of the Act (and bill number) that addresses this situation.
a	Always try to give your main point first in your answers, such as by telling the person that the current system fails to provide proper support for families like yours and that national legislation is necessary to correct current hardships, inequities and disincentives.
0	Be brief in your responses to the reporter's questions; include only what is necessary.
0	Be specific, using examples, statistics, personal stories as illustrations.
0	Be personal; refer to your children by names, give details on yours and their emotional reactions to your situation.
٥	Be persistent — will they do a story on the need for the legislation and the problems it addresses? What other information do they need? How can you help them?
a	Don't let the reporter get you off track; emphasize that you are specifically interested in the need for family support and national legislation to correct the current system's shortcomings.
	Realize that your phone call alone may not be enough to get an immediate response; but that it may take several phone calls from several people just like you to make the difference.

If you have any questions about this part of the process of supporting this legislation, you may call Alian I. Bergman, President, UCPA at (800) 872-5827, Fran Smith at (510) 222-2999, or the public relations team of Greg Smith and Brian Kane at either (612) 851-2555 or (612) 851-2644.

Contacting The News Media

The following national news reporters and media representatives regularly write about national policy issues and have, on occasion, written about issues that are related to caring for children with special needs and government support for families in need. Many of these individuals also have previously received correspondence regarding the need for Family Support for families caring for children with disabilities.

Just as you urge your elected officials to support The Families of Children With Disabilities Support Act, please consider contacting these representatives of the news media to 1) call their attention to progress on The Families of Children With Disabilities Support Act, 2) express your struggles under the present system, and 3) express your desire to see The Families of Children With Disabilities Support Act adopted.

The more calls and letters these representatives receive from individuals and families like yours, the more likely they will be to acknowledge the problem and look into developing a story on the need for national legislation.

Also, if the person you call turns out to no longer be with the organization or has changed assignments, ask for the name and number of the person who would be interested in a story that involves national policy changes to support families caring for children with disabilities.

The following media representatives, (including <u>US News & World Report</u> reporter Joe Shapiro, who wrote the book <u>No Pity</u>, and his editor David Whitman), should be considered for contact first.

David Whitman, Senior Editor US News & World Report 2400 North Street NW Washington, D.C. 20037 PH: (202) 955-2030 Fax: (202) 955-2713

Joseph Shapiro, Associate Editor US News & World Report 2400 North Street NW Washington, D.C. 20037 PH: (202) 955-2374 Fax: (202) 955-2478

Angelia Herrin USA Today 1000 Wilson Blvd. Arlington, VA 22229 PH: (703) 276-4581 Fax: (703) 247-3290

Carol Castenada USA Today 1000 Wilson Blvd. Arlington, VA 22229 PH: (703) 276-3648 Fax: (703) 247-3290 Cage Ames, Family Editor Newsweek 444 Madison Avenue New York, NY 10036 PH: (212) 350-4408 Fax: (212) 421-4993

Michelle Ingrassia Newsweek 444 Madison Avenue New York, NY 10036 PH: (212) 350-4928 Fax: (212) 350-4121

Richard Lacayo, Associate Editor Time Magazine Time & Life Building Rockefeller Center New York, NY 10020 PH: (212) 522-4242

Ursula Nadasy
Time Magazine
Time & Life Building
Rockefeller Center
New York, NY 10020
PH: (212) 522-2407
Fax: (212) 522-0323

Media To Contact Page Two

Other media representatives to contact regarding The Families of Children With Disabilities Support Act:

Paul Haskins National Assignment Editor

New York Times 229 West 43rd Street

New York, NY 10036-3959

PH: (212) 556-1234 Fax: (212) 556-4603

Barbara Vobejda Washington Post 1150 15th Street, NW

Washington, D.C. 20071-0002

PH: (202) 334-7430 Fax: (202) 334-1008

Marcia Van Dyke, Family Producer

CBS This Morning

CBS News

524 West 57th Street

Suite 44

New York, NY 10019

PH: (212) 975-4739

Antoinette Machiaverna, Producer

Today **NBC** News

30 Rockefeller Plaza

Suite 304

New York, NY 10112 PH: (212) 664-4571

Victoria Duncan, Producer

Today NBC News 30 Rockefeller Plaza Suite 304

New York, NY 10112 PH: (212) 664-4571

Giselle Fernandez, Correspondent

CBS Evening News 524 West 57 Street

Studio 47

New York, NY 10019 PH: (212) 975-3691

Fax: (212) 457-4385

Janice Horwitz Time Magazine Time & Life Building Rockefeller Center

New York, NY 10020 PH: (212) 522-3840

Fax: (212) 522-0323

Randy Barone, Special Projects Producer

Good Morning America

ABC News

147 Columbus Avenue New York, NY 10023 PH: (212) 456-5900

Lauri Beecher, Segment Producer

Good Morning America

ABC News

147 Columbus Avenue New York, NY 10023 PH: (212) 456-5900

Julia Hartenstein

"American Agenda" Producer World News Tonight

ABC News

77 West 66th Street New York, NY 10023 PH: (212) 456-4040

Kathy Moore, Producer CBS Evening News 524 West 57th Street

Studio 47

New York, NY 10019 PH: (212) 975-3691

Fax: (212) 457-4385

Cheryl Gould

NBC Nightly News 30 Rockefeller Plaza

New York, NY 10112-0002

PH: (212) 664-4971

For more information on working with the news media, contact either Greg Smith or Brian Kane of Colle & McVoy Public Relations in Minnesota at 612-851-2555 or 612-851-2644.