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PARENT OUTREACH NEWS BRIEF

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Your Child's Medical Professional—A Vital Link To His/Her Well-Being

As a parent of a young child who has been diagnosed with developmental disabilities, you soon realize the importance of having the right medical care and good medical professionals involved in his/her life. For many years, you will play the key role in helping the professionals to understand your child's strengths and needs, and what services would be helpful. Below are some ideas on how to choose the best professional for your child and how to create a positive, satisfactory relationship with that person.

Choosing a medical professional: Look for someone who has special training, or a special interest in child development, and children with special needs. Ask other families who have children with disabilities who they go to. Question them about their level of satisfaction with the person. Other parents are most often a best source of good, reliable information!

Creating the Relationship: Show by example how you want to be treated and how you want your child to be treated. If you want to be listened to, then be a good listener, too. If you want the medical professional to be delighted with your child, then show your delight in your child.

Good Two-Way Communication is Key: Think of communicating with your medical professional as having a friendly, respectful conversation. That means it is two-way, and both of you should bring your questions, concerns, successes, and hopes to the conversation.

Have a Clear Understanding on the Best Way To Communicate: It is probably a given that along with your child's disabilities will come the need for increased medical care and possibly frequent medical emergencies. Find out the best way to get through to the medical professional both for general purposes and in emergency situations. Ask pointed questions and expect clear answers.

Getting the Most Out of an Appointment: To help cut down on waiting time, schedule the appointment first thing in the morning or right after lunch. If you have a lot of questions/concerns, let office staff know so that they can allow for a longer appointment time. Prepare for the visit by making a list of the important things on your mind. Prioritize your list. Offer to fax/email the list ahead of time as a means of helping the medical professional be well prepared. To help you remember the details of what is discussed, jot down notes, or ask someone who can do this for you to come along. If you don't understand terminology used, don't be hesitant to say I don't know what you mean!

Deciding to Change Doctors: Often parents are pleased with their child's medical professional. However, if you've given it your best, and the relationship just doesn't feel right, trust your gut. Speak with other families, contact local agencies, find the medical professional that is the right fit for you and your child!

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Save A Tree

Send Your Email
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To receive this news brief electronically, email at:
slawrence@councilondd.org
or call Susan at 584-1239



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A Metro United Way Agency



Health Care and Adults With Intellectual and Developmental Disabilities

Left Out in the Cold: “Health Care Experiences of Adults with Intellectual and Developmental Disabilities in Massachusetts” was published in 2008 by the ARC of Massachusetts. After hosting focus groups and health care professional interviews, the following needs were clearly stated:

- ◆ There is a clear **lack of knowledge** of medical professionals regarding people with disabilities.
- ◆ **Communication Issues:** Quality of care is adversely affected by negative attitudes, and interactions with people with disabilities.
- ◆ **Access:** There is a vital need for adults with disabilities as with all people to access timely preventative and as-needed medical care for the most positive, healthy result.
- ◆ **Insurance:** There is a lack of adequate health coverage, and poor consumer knowledge of the health insurance system.
- ◆ **Care Coordination of Services:** Is not a standard practice for patients with ID/DD, but needs to be.

Those interviewed came up with five key recommendations:

1. Increase health care professionals’ and staff members’ knowledge and experience.
2. Expand residential staff members’ and care providers’ knowledge.
3. Increase patients’ self-determination.
4. Provide formal care coordination.
5. Improvement reimbursement rates.

It’s also clear from the report’s summary that both state legislators and health insurance providers who were interviewed lacked knowledge of the medical needs of individuals with ID/DD and of the difficulties that they experience when accessing medical care. (to access full report go to www.arcmass.org)

There’s no doubt from this report and from our own experiences as families with adult children who are disabled that there needs to be advocacy work done at all levels of government and with our medical profession-

als! As our population of adults with disabilities lives longer, the need becomes more evident. Many ARCS and Family Advocacy groups throughout the states are working to improve this situation. Only when those making our national, state and local decisions on health care and medical training are pushed to look at these issues will changes occur. *If you are interested in getting involved at the local and state level, the Council on Developmental Disabilities has a “Governmental Affairs & Disability Policy” Program. You are encouraged to email Donovan Fornwalt at: dfornwalt@councilondd.org or call at: 584-1239.*



Finding a Physician When Your Child Becomes an Adult

One of several major challenges that families face as their children reach the age of 18 is that of finding a physician who will oversee their health care needs as adults.

Sometimes their pediatrician will reluctantly continue to see them for a number of years. This is probably only a “band aid” solution to the problem. However, facing the challenge of finding a physician who will accept Medicaid, have a background of experience and/or training with people who are disabled, and willing to give the extra time and increased communication that will be needed is not an easy one!

Two very good ways of finding the right physician are to talk with families who have already needed to find one for their adult child, and calling agencies who work with people with disabilities to learn from them names of family or staff recommended physicians. Perseverance will pay off and the right physician will be found!

Please take a few moments to fill out and mail in the physician form on the next page. It will be of great help in keeping up to date our information to share with families !

Physician Information Form

Do you have a physician for your adult child with whom you are satisfied? Please share this information so that we may in turn share it with the families who call the Council. If you have more than one, please feel free to copy this page!

Child's Age and Disability	
Does your child have significant medical issues? If so, please describe.	
The type of insurance coverage your child has.	
Is discomfort or fear in a medical situation an issue for your child?	
Physician's Name	
Physician's Specialty	
Address	
Phone	

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Does the physician have training/knowledge specific to developmental disabilities?					
Are you satisfied with the physician's attitude towards your child?					
Does the physician allow for additional time necessary to adequately meet the need of your child?					
Are you able to get in contact with the physician in a reasonable amount of time when it is needed?					
Is office staff respectful and courteous to you and your child?					
Would you recommend this physician to another family who has a child with disabilities?					

Additional comments:

Please send by mail to: Council on Developmental Disabilities, 1151 So 4th St, Louisville, KY 40203, Attention: Susan Lawrence, or scan & email to: slawrence@councilonddd.org

Thanks to you for taking time out of your no doubt overly busy life to share this information. Down the road, it will help another tremendously!

***Sometimes when we are generous in small, barely detectable ways it can change someone else's life forever.** Margaret Chao



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Our Mission:

To initiate positive change on behalf of individuals with developmental disabilities by voicing their needs to the community; creating new choices for living, learning, and participation; and, ensuring the highest quality of life possible.

Our Vision:

A society that includes, values, and empowers children, youth, and adults with developmental disabilities.

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HealthCare.gov

The U.S. Dept. of Health & Human Services has announced a new website called HealthCare.gov. This new tool lets consumers take control of their health care by connecting them to information about quality, affordable health care coverage. The site offers a central database of health coverage options—from Medicare to the new Pre-Existing Conditions Insurance Plan. It also answers questions that relate to people with disabilities and health care, and has information about insurance plans and community services in every state. ***For more information visit this link: http://www.disability.gov/health/news_%26_events.***