



# reaching out

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## From the President of By Their Side, Martin Lampe

There are some very important aspects of the federal health care reform legislation that could tremendously improve services for people with developmental disabilities. Very few people seem to be aware of these changes, so here is a rundown.

**Community First Choice (CFC) Option.** Medicaid pays for most of the residential, supported employment and day services that people receive from Maryland's Developmental Disabilities Administration. People who meet certain disability criteria have an entitlement to Medicaid paying for their care in an institution, but the disability community no longer regards institutional care as necessary or acceptable. Medicaid also pays for residential, day and employment supports in the community, but it is not an entitlement. Each state decides how much money to put into these services, and after the funding is used up people go onto a waiting list, sometimes forever. There are 18,000 people on the waiting list now in Maryland. The disability community has been fighting to get services for all of these people on the waiting list, but without much success so far. The CFC Option, which is part of the health care law that was passed, gives each state the option to make Medicaid waiver services for people living in the community an entitlement (no waiting lists). Each state has to choose to opt in to this.

If they do, it would cost the state extra money, but there is a sweetener that might

convince states to opt in: the federal contribution to Medicaid would increase by 6%. This would apply not only to people with disabilities, but also to older people who could be taken care of in their homes rather than in nursing homes, and this could save Maryland a lot of money. It will be a major fight to convince Maryland to buy into the CFC, but it is our best opportunity to end the waiting list. Stay tuned, especially during the next legislative session; we and The Arc of Maryland may need your help to get this passed in Maryland!

The **CLASS Act**, also part of the health care law that was passed, will start a government-run long-term care insurance program in 2012. Premiums will depend only on age when a person joins the plan and his/her income, and there is no pre-existing conditions exclusion, so people with disabilities can join, as long as they are working and earning at least \$1200 per year. The premiums will be very low (about \$5.00/month) for people with low income. After five years of paying premiums, a person with a disability can begin collecting cash payments that they can use to pay for their residential, day and supported employment direct care services, but not for food, housing or medical expenses. There will be no income or means test, and the payments will not prevent people from also being eligible for SSI, SSDI, Medicaid, etc. The amount of payment will depend on the level of disability and has not been decided yet, but my understanding is it will be at least \$18,000/year. The payments may not be sufficient to cover all expenses, but they will go a long way.

(Cont'd on Pg. 2)



## Lifelong Advocates for Marylanders with Developmental Disabilities

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They can be combined with the existing Medicaid/DDA support, and this should greatly relieve the financial pressure on the state of Maryland. And perhaps most important, people (or their families) will have the freedom to choose their own caregivers and manage their own care.

**Medicaid expansion** is also part of the health care law that was passed. As of 2014, people will be eligible for Medicaid if their income is less than 133% of the poverty level (\$14,600 for individuals), and there will be no means test. This will make it much easier for people with disabilities to qualify.

The **ABLE Act** is legislation that is currently being considered. It has 167 sponsors in the House, from both parties, and is thought to have some chance of passing this year. This act would set up tax-free savings accounts for people with disabilities.

They could put their own money into the account, or family members or anyone else could put money in. Money in the account would not count toward the means test for SSI and Medicaid, so this would eliminate the problem of people losing their services because they have more than \$2000. The account could be a custodial account managed by a family member or someone else. After the person dies, Medicaid could reclaim money for support they provided. These accounts would serve largely the same purpose as special needs trusts, but with no lawyer required and minimal reporting requirements; the person could just go into a bank or other financial institution, and fill out a form, and the account would be opened instantly.

It is important for families to keep up with these changes, and take advantage of them as they go into effect. By Their Side will provide information as it becomes available.

## News from our Board of Directors

Board Committees were formed this year to focus on the various aspects of the program. Each committee is led by a member of the Board of Directors and membership is open to anyone interested in assisting the program.

**Education Committee:** The committee provides educational material to the membership and Board of Directors. The main focus over the past few months has been in the following areas: (1) Find out what the membership needs; (2) Work with the Arcs to provide information to our membership; (3) Educate board members with updated information regarding services in Maryland; (4) Prepare the newsletters; and (5) Plan the annual sponsors meeting. The committee has developed educational documents which can be found on the By Their Side website, including our latest FAQ sheet which answers many questions about the program.

**Finance Committee:** The committee's objective is to plan for and implement policies to achieve financial stability and growth and to protect reserves necessary to maintain programs during adverse periods. The committee, chaired by the Board's Treasurer: (1) Develops financial plans to support the program's operation; (2) Reviews and makes recommendations regarding the Investment Management Fund; (3) Maintains the membership fee schedule and fee schedules for services rendered; and (4) Prepares the annual budget.

**Membership Development Committee:** The committee's objective is to represent By Their Side and its mission to the public by developing promotional material, a prospect list, and establishing contact with all pertinent agencies or prospective sponsors through a newly formed **Speakers Bureau** of board members and volunteers. This year, the committee has (1) Distributed information to estate planning professionals; (2) Distributed information at the 2009 Maryland Special Olympics Summer Games; and (3) Developed the Membership Survey that is included in this newsletter. (We ask that you PLEASE RESPOND—We want to know your thoughts).

**Professional Advisory Committee:** The objective is to establish, maintain, and support the professional advocacy program and the staff by providing ongoing training and support to the Personal Advocates.

**Public Relations Committee:** The objective is to work with other By Their Side committees to promote/advertise our events and activities. This past year the committee has been working to get the word out that MTRC is now By Their Side and has completed the new website ensuring content is accurate and up to date. A **Facebook** group called By Their Side has been created. We hope everyone will begin to discuss their experiences with By Their Side on this social network page. The office is developing an email database so that pertinent information can be sent immediately to our families. The committee meets the fourth Wednesday of the month in the Annapolis area. If you can't come to Annapolis, conference calls can be considered for access. Remember to visit us on **Facebook**.

***By Their Side needs a constant flow of new members. Tell your friends about us, and join one of the committees or our Speakers Bureau. Call our office at 1-800-323-9407.***

### **Important Information for Families from the Developmental Disabilities Administration (DDA)**

People with developmental disabilities need services and supports, and these costs add up. Did you know that you may be able to obtain **Low Intensity Support Services (LISS)** to help cover some of your expenses? DDA has contracted with licensed providers to provide **LISS**, previously known as **Rolling Access Funds**. **LISS** is a statewide program for individuals eligible for DDA services. **LISS** works to assist individuals with developmental disabilities improve their quality of life, remain in their own homes, increase or maintain independence and participate in their communities.

To be eligible for **LISS**, the individual must meet all of the following guidelines: (1) be diagnosed with a developmental disability verified by an Individual Plan and/or a medical statement; (2) be a resident of Maryland as verified by documentation; (3) possess a social security card; and (4) not currently receiving any DDA funding for full residential services. **LISS** is the payer of last resort. **LISS** providers will first try to use other available resources to help meet the family's needs. After all resources have been exhausted, qualifying eligible individuals may access **LISS** funding up to \$3,000.

Contact your Service or Resource Coordinator for the regional **LISS** Provider for your area.

Join our group, **By Their Side**, on **Facebook** and invite all your friends to join. Check out our Website at [www.ByTheirSide.org](http://www.ByTheirSide.org).

Volunteer to help **By Their Side** by assisting one of the **Board Committees**. Call today, or email us at [info@ByTheirSide.org](mailto:info@ByTheirSide.org)

## **CONTRIBUTION UPDATE**

### **DONATIONS**

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John Gould, given by his sister,  
Susan Brome  
Michael Cashwell, given by Robert  
& Sue Davison  
Aric T. Greenberg, given by Edith &  
Norman Greenberg  
James Justice, given by William H.  
Justice  
Cindy Kolchin's birthday, given by  
Fred Kolchin  
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Richard Kolchin, given by Beatrice  
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Thomas Lechner  
Marie Markstrom, given by Marie  
Markstrom Estate  
Kadee Perry, given by Luanne &  
Bob Frebertshauser  
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Toni Pollin and David Kross  
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Esther Dorfman, beloved mother  
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Mr. & Mrs. Stephen J. Zaklan, by  
Dennis & Cynthia Zaklan

### **FOR PROMOTIONAL MATERIAL**

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Beverly Rill  
Summit Financial Services, Craig  
Hebert

### **CONTRIBUTORS TO THE ANNUAL MEETING**

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Edith Greenberg  
Mr. & Mrs. James Kao  
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Margaret M. Ulle  
Mr. & Mrs. Dennis Zaklan

**Thank you for your continued support by responding so generously to our Annual Fund Drive request last year. Your contributions mean a great deal to the success of our program. Please watch your mail in early December for this year's request. Your response is greatly appreciated by those we serve.**

## News from our Personal Advocates



The highlight of last year's Annual Sponsor's Meeting was our panel of By Their Side Personal Advocates. They shared different situations and issues that they helped our individuals resolve. We were able to put a face to the story with their presentations. The following are recent updates of our involvement with individuals:

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With follow up calls and support from our Personal Advocate to a transitioning youth's parent, his mother learned the provider selected for her son had not included a one on one funding request to DDA as expected. This was resolved with the provider and DDA before the deadline of handling funding requests so it did not become an emergency. At our suggestion, the young man's teacher made a videotape of successful ways to support him, for use by his new day program staff.

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By Their Side assisted a Trustee with the process of identifying a new service provider after the Trustee determined the current provider was not adequately addressing the needs of the individual. Frequent monitoring by our Personal Advocate, as arranged by the Trustee, had helped to identify the issues within the individual's Trust owned home and assure services were nevertheless provided.

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As requested by one individual's parents, By Their Side participated in a team meeting to address how a support service provider could most effectively use the individual's budget to more fully address their son's needs with less reliance on family support. Additional funding resources are now being explored by the Resource Coordinator, in anticipation of a future when the family will be less available to provide assistance.

By Their Side relies on the ability of our professional Personal Advocates to provide the excellent level of services our families expect from the program. We are pleased to introduce you to our new Personal Advocate, **John Iaquinta**. He will be working with families in the southern Maryland area, including Anne Arundel, Prince Georges, and Charles counties. John has been a Program Director at Langton Green for several years, providing residential case management and supervision to adults with developmental disabilities.

Meet the Staff  
Meet the Board

Join us on Saturday, **November 6, 2010**, for the  
**ANNUAL SPONSORS MEETING and LUNCHEON**  
The program will include information on Medical Decision  
Making. More information will be mailed in September

Enjoy the program  
Enjoy the FOOD!



Lifelong Advocates for Marylanders  
with Developmental Disabilities

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[www.ByTheirSide.org](http://www.ByTheirSide.org)

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