
**"UniteOurVoices" Newsletter # 142
January 30, 2015**

Dearest Advocates:

The National Resource Center for Participant Directed Services (NRCPPDS) at Boston College is currently looking to interview caregivers (meaning parents and/or individuals responsible for the care of their love ones with a disability). This study is part of a national look at participant (self) directed services and how they are helping caregivers get the necessary resources/services within the disability waivers in each State. In the State of Georgia, they are looking at specifically the NOW, COMP and CCSP waivers.

I spoke to Dr. Ellen Mahoney who is the Director of Research and she is very excited about hearing from our families. This is a way for the federal government to better understand the needs of the families and how to improve it!

I strongly suggest if you are a waiver recipient AND participate directed, please consider being a part of this study. It's easy. Contact Dr. Mahoney at 855-887-2555 or email ellen.mahoney@bc.edu to schedule a 30-45 min interview via phone. All information is confidential and you will be asked to sign an "informed consent form".

From this information, they will also be looking at setting up a resource center! Below is additional information as well. This is an easy way for us to get involved and make change happen! Have a great weekend.

Sincerely,
Heidi

"United - We Will Make A Difference"

Sincerely,
Heidi J. Moore

Parent Advocate for Children & Adults with Disabilities and Cancer

For more information and to see previous newsletters and disability information, please go to www.UniteOurVoices.com.

Join Heidi on Twitter at www.twitter.com/UniteOurVoices and Facebook Group at https://www.facebook.com/groups/435101099921721/?ref=br_tf

To follow Jacob's Journey with Leukemia, please go to: <http://www.caringbridge.org/visit/prayforjacobmoore> or www.teamjacob.org . To watch Jacob's Journey with Cancer video: www.youtube.com/watch?v=2GjPfmIZ76g

"Help The Children Now, So They Can Help Themselves Later!"

The material contained in this e-mail is for general information only. It is not intended in any way to provide or offer legal advice. To obtain legal advice, please consult with your attorney or a qualified legal representative.



Dear Caregiver,

You are invited to participate in a telephone interview about your experiences caring for a family member who is enrolled in a Self-Directed Home & Community Based Service Program. You are receiving this invitation because you are currently providing care to a participant in a self-directed program. We are researchers from The National Resource Center for Participant Directed Services (NRCPS) at Boston College. To learn how the program is working from the perspective of caregivers, we are conducting telephone interviews with caregivers like you.

We want to learn from caregivers, in their own words, about their views and experiences with this program. Your voice is extremely valuable in helping us understand the real impact of the program on peoples' lives, and especially in helping us learn what works best and where the program can be improved. Your thoughts will help identify ways to best serve caregivers and their families at home in the future.

We hope you will consider helping with this important research. To learn more about participating in a telephone focus group to discuss your experience with a self-directed program, please contact us toll free at <855-887-2555> or by e-mail to ellen.mahoney@bc.edu.

To learn more about NRCPS and our mission, please visit us at: nrcps.org

Thank you for your interest and help as we strive to learn about self-directed programs directly from caregivers who have a loved one enrolled in this type of program.

Respectfully,

Ellen K. Mahoney, RN, PhD
Director of Research

Boston College IRB
Approved

DEC 18 2014

Thru: Dec 17, 2015