

Request For Assistance: Self Directed Youth Transition Community Of Practice

At the [Beach Center on Disability](#) we are getting an increasing number of requests from families from around the country who have sons and daughters with significant intellectual disabilities who are transitioning from high school or who are young adults.

These families very much want to create innovative supports that will enable their son or daughter who needs extensive and even pervasive support to access funding that will enable him or her to have their own home, have a real job, have friends, and have preferred places to hang out in the community. I am sure that this request is very familiar to you and the DD Council network.

We are in the process of developing a Community of Practice that will involve finding "pioneer families" who have "beat the odds" in setting up the supports for their son or daughter to have a joyful, inclusive, and productive life. As a first step, we want to find the pioneer families, hear their stories, learn what has worked, and organize information on a website that will be readily available to families coming along behind them.

We very much need help from the UCEDD network in locating the pioneer families. We are hoping that you might put us in touch with families who meet the following criteria:

- * Has a son or daughter with a significant intellectual disability who is over the age of 18.
- * The son or daughter, along with support from the family, has control over at least a portion of his or her Medicaid budget and is able to decide whom to employ and how much to pay each employee.
- * Has found creative solutions to the complexities of community living associated with having a home, job, friends, places to hang out, and/or transportation. The person does not have to have all of these things in place but must have at least some component of their life that has worked especially well and from which other people can derive a vision and some "nuts and bolts" for learning how to do it.

If you know of any families who meet this description, we are hoping very much that you will do two things. First, would you help us by contacting the family and asking if you can share their name and contact information with us? If the family agrees, would you email that information back to me? It would be helpful if you could provide several sentences describing why you think that they have a particularly helpful story to share.

Another option is that you could ask families who may be interested in being part of this network to contact us themselves.

Our goal is to arrange a convenient time to have a telephone conversation and perhaps email exchanges with the family. We will communicate with them in whatever way would be most convenient for them.

We welcome your ideas of how we might do the best job in organizing information that will be helpful to families in your state.

Thank you so very much for being the "eyes and ears" for us in putting us in touch with pioneer families. We at the Beach Center are exceeding grateful to you for considering this request and hope very much to hear from you with the names of one or more families.

If you have any questions, please feel free to contact me by email (turnbull@ku.edu) or phone (785-864-7608).

Cordially,
Ann Turnbull