

FACTS:

The Process/ Access

The System

On-going
communication and
updates



I don't know who it is, but the author of these "easy-to-assemble" instructions should be ***severely punished!***

Future Limited . . .

- By what's available
- Reforms that “tear-down” without “building” other options first
- Lack of understanding about what needs to be fixed – from the parent / family / consumer perspective
- What's really new?



“Consumer Driven” is different
from *planned*
in a “*Person Centered*” way

- Who controls the money?



- Legislation / Regulations do NOT support seamless transitions

Fear

- A future without an understanding of all of the adjectives that define our family members
 - Lack of a life that has everything that YOU want... relationships, safety/security, opportunity to contribute, choices and not based solely on someone else's definition of your needs



SO, WHAT DO YOU
PREFER TO BE CALLED?
HANDICAPPED?
DISABLED? OR
PHYSICALLY-CHALLENGED?

"JOE"
WOULD BE
FINE.

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THE MOST APPROPRIATE LABEL IS
USUALLY THE ONE SOMEONE'S PARENTS
HAVE GIVEN THEM.

Transition from the perspective of aging parents



Mary Beth is a young
(ok, early middle-aged) woman with

- Remarkable gifts and talents
- Very complex needs
- Very ordinary needs
- Good days & bad ones
- Likes and dislikes
- Interests and desires



Just like you and me!

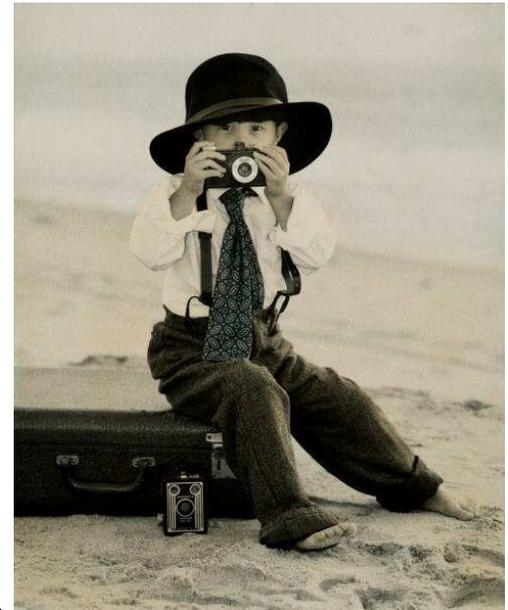
Mary Beth...

- Daughter
- Sister
- Granddaughter
- Aunt
- Teacher
- Neighbor
- Friend
- Patient
- Customer and much more!



Transition from HS

- LEA was very caring but focused on
 - Learning skills used in day programs
 - Getting her “placed” into a day program
 - Guardianship / residential living
- Our family’s concern
 - Happiness, good health and comfort
 - Belonging, community and friends
 - Meaningful ways of spending her time
 - The same hopes and dreams that we have for her sister



At age 21 Mary Beth “transitioned” into an ICF-MR level group home

- We learned a lot....
 - Her Father, Sister and I did not die, although it felt as though we might.
 - Mary Beth did not die either.
- We learned that getting her there was pretty easy.
- We learned it was nearly impossible for her to direct her life there.



The system's "rules" dictated everything

- There was no flexibility:
- Pre-selected meals prepared on any given day of the year whether the "residents" liked the food or not to.....
- How long a "resident" could stay in a bath,
- Day placement requirement,
- The temperature in the house,
- Who could visit her and when,and so on
- Staff determined music, outings, detergents, etc.

*That system was not designed to provide a home where people are supported to live **their** lives, rather it was designed to house 6 people*

After 2 months Mary Beth moved back home to....



- Opportunities to make personal choices
 - She has the choice to eat food that she likes and can take a bath as long as she wants.
 - She turns on her lights if she wants to.
 - She participates in her community.
 - She has friendships and natural opportunities.
- Supports designed for her to live as independently as possible

*In her home, on an ICF-MR level,
supported through Medicaid Waiver program*

As an aging couple with an aging adult at home, we need....

- More sleep!
- Opportunity to pursue OUR interests, dreams
- Time to care for ourselves and our aging parents



As an aging couple with an aging adult at home

- We recognize that we will need to use the system again and...
- We will need a plan that supports Mary Beth to transition into an environment that respects, understands and supports her uniqueness and individual needs.



When we walk to the edge of all the light we have known and we take a step into the darkness of the unknown, we must believe that one of two things will happen....

There will be something solid to stand on or we will be taught to fly! ~S. Martin Edges



My parents always had a dream for my brothers and sisters for when they grew up, but nobody had a dream for me, so I never had a dream for myself. You can never have a good life if nobody ever has a dream for you, unless you learn to have a dream for yourself.”

~Connie Martinez

