



## Table Topics: KAND in Adulthood

Speakers: Janie Desmond & Betsy MacMichael

August 17, 2019

# Leaning In To Possibilities

**KAND in Adulthood**



Jane Desmond & Betsy MacMichael

Kif1A Family & Scientific  
Engagement Conference

New York City

August 2019

# Who are we?

- Every child is different, with both challenges and gifts
- Every parent/couple/family is different
- What does the future hold?
  - Getting out and about?
  - Communicating with others?
  - Eating on one's own?
  - Telling jokes... playing games.....graduating preschool....
  - Sleeping through the night?
  - Moving away? College? One's own neighborhood? Work?

Janie at two years old





Janie at 8



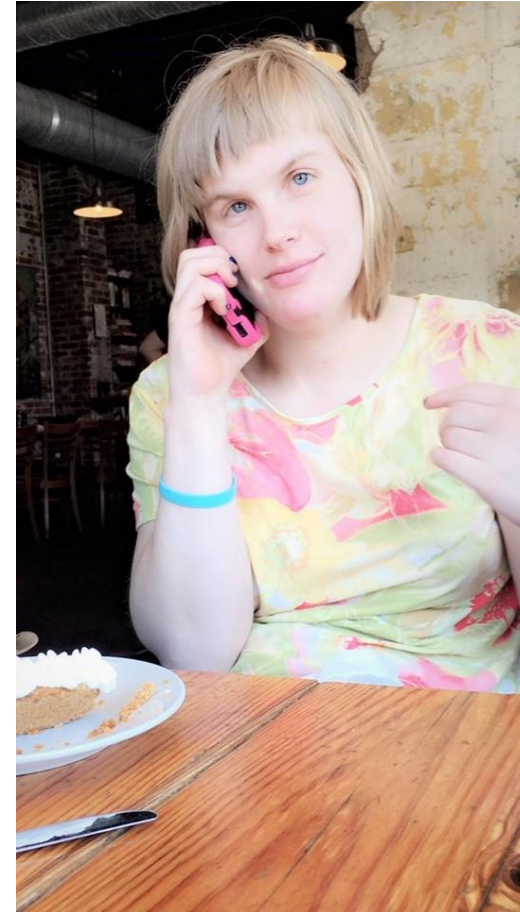




Jane at 23

# What happened in between?

- Person first
- Anger > understanding about others
- Our mantra
- Sense of humor (whose?)
- Think of abilities in different terms



- Whole person, not medical condition
- Perspective
- Contribution





What next?









the dignity of risk





Mom dreaming (or awake) at 3am



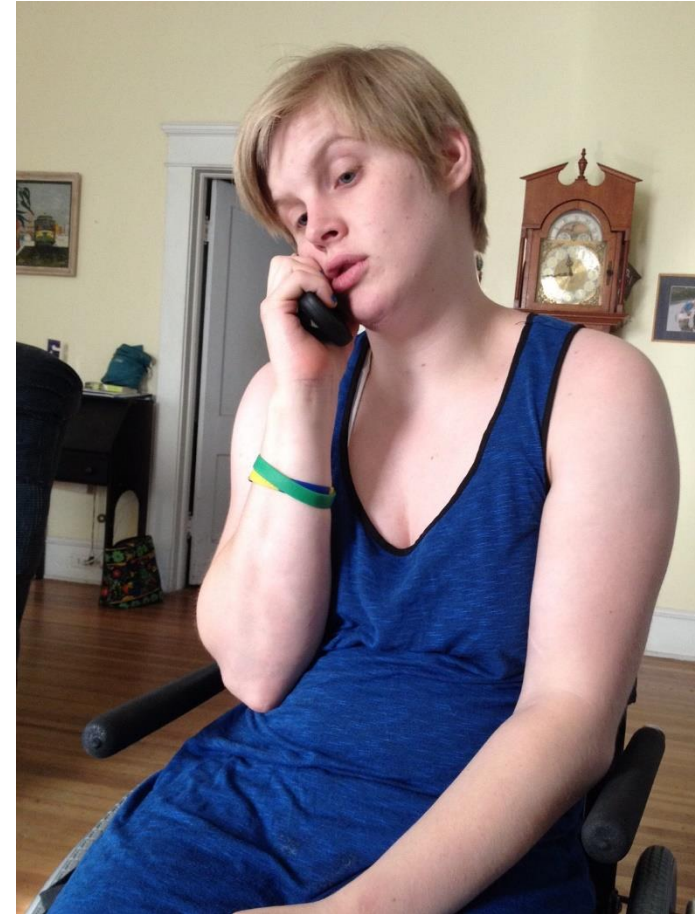
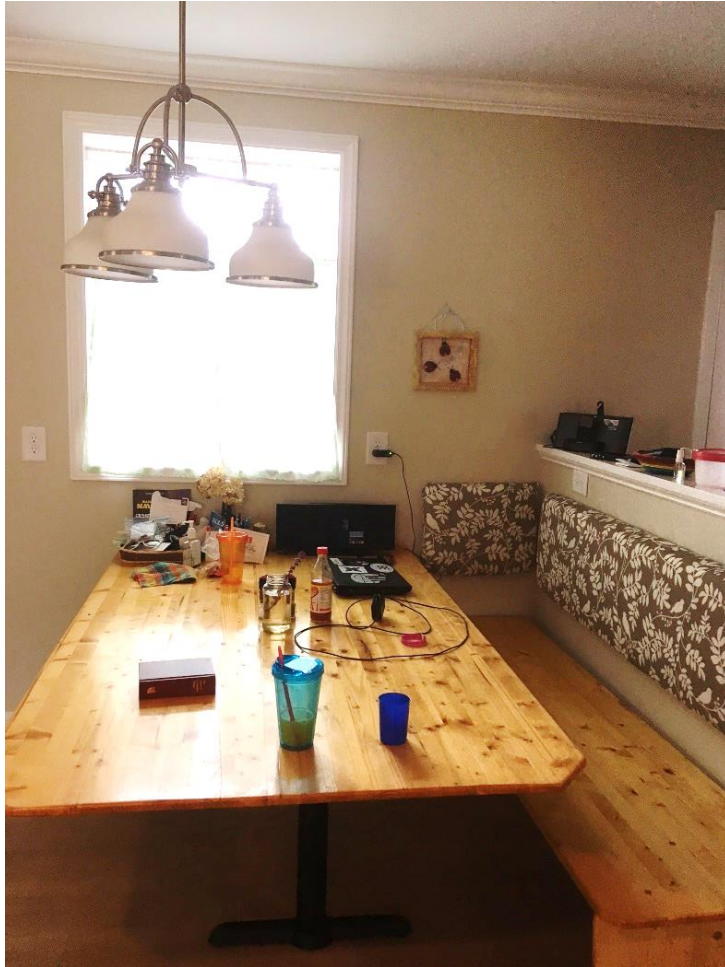
Supported decisionmaking > Informed choice



Empowerment with a buffer



# Immediate, emergency type choices

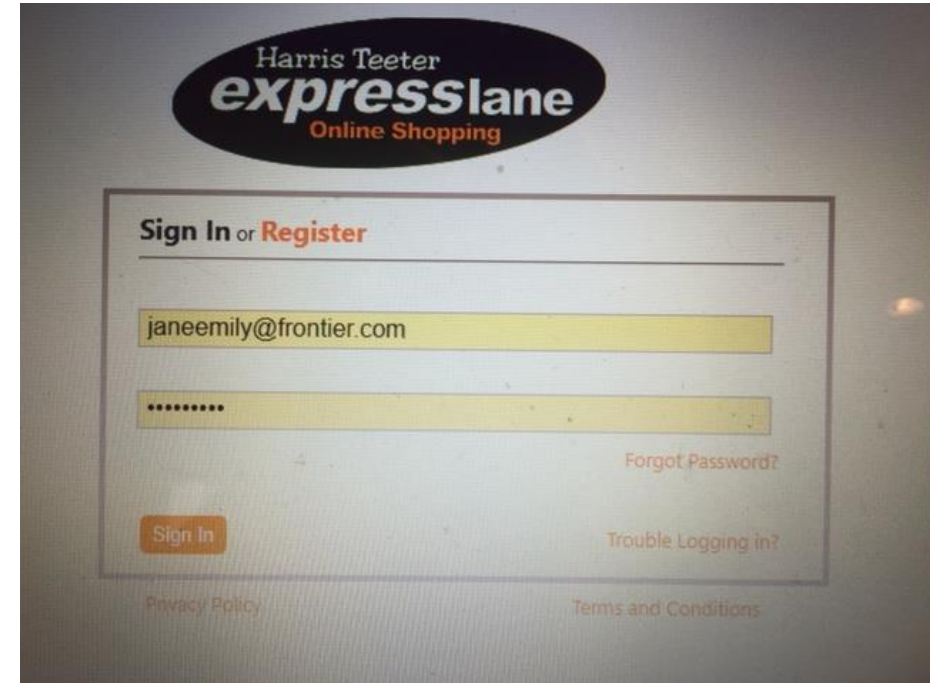
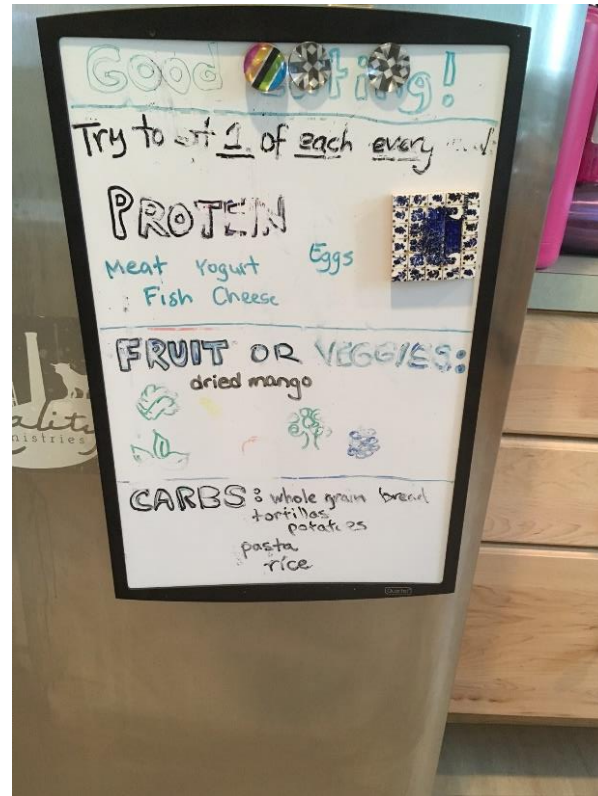




# daily choices, daily compromises....

Food shop, daily meal choices..

Parent's, staff, roommates choice or *my* choice?



# Keeping some autonomy from roommate





# Janie in 2011



# J&S in 2019

<https://www.youtube.com/watch?v=qEZBBKxJ2qY>





- Excerpt time permitting from:

- <https://www.youtube.com/watch?v=qEZBBKxJ2qY>

# Smart technology and apartment living



## Six Key components to making this work:

1. Neighbors, friends, family who are physically nearby
2. Good roommate
3. Opportunities to grow through Risk and experience





4. Trusted advisors to help make decisions
5. City environment full of things to do
6. Some privilege and advantages



# Leaning in to Possibilities

