



**Our mission:** *Families Speaking UP is a non-partisan grassroots group of people with intellectual and developmental disabilities (IDD), their families, friends and caregivers. We work to ensure that all voices are heard in the IDD debate. We share our knowledge and experiences, advocate for and include our loved ones with IDD in decision-making, serve as a unifying voice, and educate ourselves and policymakers. There is strength in numbers and our many strong voices must be heard.*

**Our vision:** *Through family support, networking, social media, word of mouth, and with the power of our numbers, we will seek to advocate for and influence Federal and State policy for all persons with IDD.*

## 2015 – OUR YEAR IN REVIEW

### MONTHLY SPEAKERS

- **Jane Gallivan**, Director, Delaware Division of Developmental Disability Services (DDDS)
- **Steve Groff**, Director Delaware Division of Medicaid and Medical Assistance (DMMA)
- **Thomas Cook**, Executive Director Delaware Association of Rehabilitation Facilities (DelARF)
- **Stacy Levitan**, Executive Director, Judith Creed Homes for Adult Independence (JCHAI), Phila.
- **Guy Alma**, Director of Development, Camphill Special School, Pennsylvania
- **Amy Lutz**, Mother, son with autism; Founder, Ending Aggression and Self-Injury in the Developmentally Disabled Foundation; Author, *Who Decides Where Autistic Adults Live?* The Atlantic, May 2015
- **Lisa Parles**, Esq., Mother, adult son with autism; Partner, Parles Rekem, LLP (disabilities law firm in NJ)
- **Krystal Odell**, sibling, Director of Supportive Services for Pennrose Management Company, one of the foremost developers of affordable housing in the Northeast and Pres./CEO of PennReach, a nonprofit serving the needs of families, seniors and special needs residents of low income housing.
- **Bryan Townsend**, Delaware State Senator
- **Melanie George Smith**, Delaware State Representative and Co- Chair, Joint Finance Committee

### FSU MEMBERS PARTICIPATE IN STATE IDD POLICY COMMITTEES:

- **Libby Cusack** -co-chaired the HCBS (Home & Community Based Services) Residential Services Committee that created the Residential Provider Self-Assessment
- **Teesie Bonk** - member of the HCBS Vocational Transition Committee. In addition, several of our family members also attended these weekly meetings from April - June 2015.
- **Gail Womble** - appointed to the GACEC (Governor’s Advisory Council for Exceptional Citizens)
- **Lisa Elias** – member SCPD (State Council for Persons with Disabilities)

## MONTHLY MEMBER ACTIVITIES

### February

- **FSU members** attend and testify at DMMA's HCBS Transition Plan hearing.
- **Micki and Lanny Edelsohn and Laurie Nicoli** visit A.J. Drexel Autism Institute in Philadelphia.
- **Micki and Lanny Edelsohn** present at UD's Osher Academy of Life Long Learning on the disabilities housing debate.

### March

- FSU members attend Disability Day in Dover and are given front row seats in the House Chamber and recognized by Representatives Melanie Smith and Gerald Brady. **Olivia and Libby Cusack, Maggie and Leigh Corrigan, Kate Lynch, Lisa Elias, Eric Sovde, Jehangir and Nilou Vevai, Ed Gootzait, Carol Kenton, Kevin Timm, Teesie Bonk, Robert and Micki Edelsohn**
- FSU members testify at Joint Finance Committee Hearing for DDDS, Dover, DE. **Mary Steppi, Libby Cusack, Andrew Edelsohn, Teesie Bonk, Pat Swanson, Lisa Elias, Gail Womble**

### April

- **Micki and Lanny Edelsohn, Laurie Nicoli and Pat Swanson** visit Drexel Autism Institute in Philadelphia.
- **Libby Cusack (co-chair) and Teesie Bonk (member)** are official members of the HCBS Transition Plan residential and vocational weekly meetings until June 11. Other FSU members also attend to observe.

### May

- **Libby Cusack, Pat and John Swanson, Laurie Nicoli and Lanny and Micki Edelsohn** visit Promise in Brevard, Florida and meet with founder Betsy Farmer to discuss their Intentional Community
- Drexel staff visits Delaware to tour Homes For Life group homes.

### June

- **FSU members** attend lecture on nationwide housing trends presented by Desiree Kameka from CCC (Coalition for Community Choice).
- **Pat Swanson & Micki Edelsohn** attend NJ Transition Plan and "Return Home NJ" in support of Lisa Parles, Esq. who testified. "Return Home" policy ultimately reversed!

### July

- **Micki Edelsohn and Pat Swanson** attend ACCSES Conference in Washington, DC .
- **Over 35 members of FSU** attend ADA 25th Celebration in Dover, DE.
- **17 FSU members** attend Road to Freedom bus in Rodney Square, Wilmington, DE.

### August

- **Micki and Lanny Edelsohn** visit JCHAI residential program in Philadelphia.
- **Micki and Lanny Edelsohn and Laurie Nicoli** visit New Jersey and meet with Lisa Parles and Krystal Odell on potential sites for residential communities there.
- **Michelle Dwyer, Jehangir and Nilou Vevai, Jan Capano, Karen Mackie, Ed and Susan Gootzait, Teesie Bonk, Libby Cusack, Lisa Elias, Carol Kenton, Pat Swanson** attend open forums for HCBS Transition Plan in Sussex, Kent and NC Counties and SPEAK UP on issues concerning their loved ones.

### September

- Several FSU members attend Direct Support Professional (DSP) luncheon to recognize those who give outstanding care to those we love.

### October

- **Gail Womble, Carol Kenton, Lisa Elias, Micki Edelsohn, Thomas Cook** and over 300 other people from our region attend EASI Foundation (Ending Aggression and Self-Injury in the Developmentally Disabled) Housing Conference in Philadelphia
- **Carol Kenton, Gail Womble, Lisa Elias, Thomas Cook, Laurie Nicoli, Pat and Katharine Swanson and Lanny and Micki Edelsohn** attend *Misericordia "Together for Choice"* housing conference in Chicago with 250 people representing 80 different agencies nationwide. This conference was a joint effort with the CCC (Coalition for Community Choice) of which FSU is a charter member.

### November

- **Laurie Nicoli and Pat and Katharine Swanson** visit First Place and SMILE Biscotti in Phoenix, AZ to discuss with founder Denise Resnik possible expansion of their model of bakery and residential ideas to Delaware.

### December

- **Micki and Lanny Edelsohn and Pat Swanson** make site visit to Madison House Autism Foundation and Madison Field Farm, Potomac, MD.

**To all our FSU members, we wish you a wonderful holiday season and look forward to seeing you and welcoming new families to our meetings in 2016!**

**UPDATED WEEKLY!**

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