

## **Mayor's Council on Disability Issues**

October 12, 2022 - Meeting Minutes

Zoom

### **I. Meeting called to order at 4:01 p.m.**

### **II. Roll call:**

**Members:** Alexander, Barber, Childress, Colebrook, Cox, Jenkins, Landfather, Lowe, Maxwell, Mull, Nesmith, Shimmin-Orr, Ross, Simmons, Spangler, Villanueva, Welch

**Resignation:** Andrea Briggs

**City of Knoxville Staff:** Cook, Dziubak

**Present:** Alexander, Childress, Barber, Briggs, Cox, Landfather, Lowe, Maxwell, Nesmith, Shimmin-Orr, Simmons, Spangler, Welch

**Absent:** Colebrook, Mull, Ross, Villanueva

**Guests:** Missy Zolecki and Robert Miller with the National Fragile X Foundation, and Samantha Brown, Sydney Phillips, Madison Lamon, Kennedy Toney, Zoe Pryor, Samantha Richards, and Julia Cortazzo with UT Class RSN430 Management and Therapeutic Recreation

Interpreters: Jessica Brackeen, Haile Stewart

### **III. Approval of September Minutes**

Welch motioned to approve September minutes, Cox seconded, none were opposed, motion passed.

### **IV. Presentation: National Fragile X Foundation, Missy Zolecki and Robert Miller**

A. Mission Statement: Our mission is to serve the entire Fragile X community to live their best lives by providing the knowledge, resources, and tools until, and even after, more effective treatments and a cure are achieved.

- Robbie Miller, Director of Clinic and International Relations, shared his background and that he has worked with the organization since 1999 and is

working with the CDC to provide/improve the number of people being referred and diagnosed with Fragile X syndrome.

- Missy Zolecki, Director of Community Empowerment, shared that she is a parent of a 21-year-old with Fragile X syndrome.

B. Fragile X is an inherited genetic disorder affecting the X chromosome in both males and females. This mutation can lead to:

- Fragile X syndrome
- Fragile X-associated tremor-ataxia syndrome (FXTAS)
- Fragile X-associated primary ovarian insufficiency (FXPOI)
- Other premutation carrier issues
- Characteristics of Fragile X syndrome
  - Physical Features
  - Behavioral Characteristics
  - Cognitive Abilities
  - Disposition Characteristics
  - Medical Issues
- How Common is Fragile X in Tennessee?
- Autism and Fragile X
  - Approximately 1/3 to 1/2 of all children with Fragile X syndrome have some degree of autistic behavior.
  - For between 2% and 6% of children with classic autism, the cause of their autism is Fragile X syndrome.
  - Autism is a behavioral diagnosis while Fragile X (FXS) is a medical diagnosis. It is not uncommon for a child to initially be diagnosed with ASD and later to receive a diagnosis of FXS or vice versa.

- For More Information: <https://fragilex.org/our-research/treatment-recommendations/understanding-asd-fxs/>
- How is Fragile X diagnosed?
  - Genetic Testing for FMR1 DNA test (Fragile X DNA test)
  - Printables are available concerning different testing for providers to order on the website.
  - The providers need to work with the insurance companies to determine the coverage, as it varies based on a number of different criteria.
- Why is Diagnosis important?
  - Can lead to multiple immediate and extended family members learning they may have or are at-risk for developing a Fragile X disorder.
  - Will lead to specific Fragile X evidence and consensus-based treatments including therapies, special education, counseling, and medication.
  - Allows for families to make the reproductive decisions best for their family (Many families have 2, 3, or more children with FXS).
  - Allows for families to be part of the global Fragile X community of families and professionals. (The NFXF has parent-led groups in almost all 50 states).
  - Allows for those that are interested to become part of the Fragile X research project that can benefit their child, themselves, and millions throughout the world.
- National Fragile X Foundation Programs include:
  - Promoting Advocacy
  - Providing Education
  - Advancing Research

- Improving Treatment
- Resources Available
  - All resources can be found at [fragileX.org](https://fragileX.org) or by emailing [treatment@fragilex.org](mailto:treatment@fragilex.org)
- What is the Fragile X Clinical & Research Consortium (FXCRC)?
  - The FXCRC is a group of over 30 Fragile X specialty clinics at hospitals throughout the US and overseen by the NFXF. (It also includes international clinics).
  - Fragile X clinics provide medical services, including medication evaluation and consultation, supervised by a physician, and supported by the latest medical, educational, and research knowledge available. Services, such as genetic counseling and occupational, speech, language, and behavioral therapies are also available either at the clinic or by referral.
  - Many of the clinics participate in collaborative research efforts.
- Where are the clinics located?
  - <https://fragilex.org/our-research/fragile-x-clinics/>
- Presentation questions and comments included:
  - Cook asked a question about funding available for genetic testing
  - Cox shared personal comments about her friend that has this condition

## **V. Member Advocacy and Information**

- A. Cox shared that she went to a TVHRA (Tennessee Valley Human Resources Association) meeting and learned about the prevalence of stigmas relating to people coming out of incarceration, how many of them have disabilities, and the disadvantages that people can face after incarceration.

- B. Landfather shared that in recent travels he has noticed inaccessibility for wheelchair users. Cook shared how she prepared for a trip a number of years ago knowing she would not be able to access the lavatory. There have been some changes that are being made by the airlines since then, and Cook will research that and share with the CODI members. Simmons shared that there were wheelchair accessible bathrooms on the Airbus A330 in 2009, but that was very specific to that plane design.

## **VI. Committee Reports**

A. Bylaws – did not meet

- Dziubak wants Bylaws to meet by this time next month to discuss possible changes brought up at the last retreat.

B. Membership – did not meet

- Dziubak wants Membership to look back at previous candidates as CODI will need new members after recent resignations. Landfather asked how we are with ratios, and Dziubak stated that we are okay, but need people with disabilities to apply to keep the number of members above 50%. Cox asked if she can submit people, which Dziubak encouraged, so long as the nominee is aware of the time commitment of 4 to 5 hours per month and are okay with that as well as live or work in the Knoxville area. Dziubak mentioned to the guests that they are encouraged to nominate folks as well.

C. Transportation –

- The Greyhound bus stop has been moved but is not in a better spot though it is a mile away, the new stop has additional seating, though not much more, and there will be porta-potties available. Dziubak shared that Greyhound is selling off their properties and focusing on the UK.

- As the cities are contracting for stops, there has been some discussion with Knox Transit but as of now no agreement has been reached.
- Welch shared that Maxwell informed the group that they are in the phase of the draft plan of the KAT Reimagined program. The green trolley went from a detour route to a fixed route. They have the stop on Gleason and now there is a bench inside West Town Mall, which is an update.
- Advance Knox had public meetings and Welch will share a community choices survey from this with everyone.
- Updates on Northshore Drive: they are on Phase 3 regarding pedestrian walkways and greenways and will be finished next year.
- Transportation spoke about electric vehicles and advancements, and Landfather mentioned that Ford Motor Company will be creating 6000 jobs in the Memphis area, and that they have three different business models regarding electric vehicles.

#### D. Community Engagement –

- Facebook needs more posts and to encourage CODI participation in this, we will be creating a calendar to have each member choose a week to contribute articles or links to Dziubak, including verbiage for the posts.
- CODI did not participate in Parking Day this year, but several members were downtown during the event. Landfather asked how it went and Barber shared that only 5 or so parking spots were included and there was not a lot going on. Landfather feels like the industries of construction and architecture are slammed right now.
- Community Engagement will be helping the Livability sub-committee with implementing and conducting the accessibility checklist.

- It was reported that the Wheelchair Tennis Community Expo has been rescheduled for some time in the Spring.
- Cook mentioned an AARP round table discussion about affordable housing and she will share that with members of Community Engagement.

## **VII. Strategic Plan Reports**

### **A. Livability –**

- Discussed the intangibles that are hard to put a number to but if a location is disability friendly overall how we should rate them, this will be discussed at the meeting on November 8<sup>th</sup> (which was moved to accommodate more time to get additional accessibility checklists completed).
- Dziubak assured members that a window cling is being sent to South Press as they did score “very good to excellent” on the checklist.
- Landfather asked for an explanation for our guests about what the accessibility checklist is and why we are doing it.
- Cook pointed out that we can certainly tweak things regarding the checklist, but that means Dziubak will have to rework the digital version of the checklist and that we have 2 tablets available. Dziubak confirmed that there are several potential changes that have already been discussed and while making a different version accessible will mean starting over on the accessibility of the document, she does not mind.

### **B. Universal Design – did not meet**

## **VIII. New Business**

- A. Cook welcomed our guests and encouraged them to attend next month and the month after, and mentioned that we like to encourage engagement with students.

## **IX. Announcements and Public Forum**

- A. Landfather shared he is on the board for Metro Drug Coalition, and they just opened the Gateway, and that he is sharing as there is overlap between the communities that both groups focus on. Landfather shared a link to Gateway with the group.
- B. Cook shared that on October 25<sup>th</sup> from 4:00 to 6:00pm at the City of Knoxville Public Works Service Complex at 3131 Morris Avenue off Middlebrook, KAEC (Knoxville Area Employment Consortium) is having their 20<sup>th</sup> year anniversary celebration. In addition to the reception, there will be an opportunity to celebrate Disability Employment month, and an award ceremony at 5:00pm.
- C. The mayor went to Spark today and made a proclamation for White Cane Awareness Day this Saturday, and declared the month of October as being Blind Awareness and Achievement month. It was a good turnout and connecting people with disabilities to the government is always great.
- D. Welch shared that the Office on Aging has their annual workshop Aging: A Family Affair is at Rothchild's banquet hall on November the 10<sup>th</sup>.
- E. Dziubak told our guests that they are free to reach out to anyone in the group with questions. Nesmith shared that he is a current UT student, and he can share his contact information. Madison Lamon asked if we could introduce our main people, Dziubak introduced herself and Cook, Landfather, Barber, Lowe, Welch, Nesmith, and Simmons introduced themselves.
- F. Dziubak will share the strategic plan with everyone.

## **X. Meeting adjourned at 5:17pm**

Respectfully submitted by: Karen Lowe, secretary and Misha Dziubak, CODI Liaison