

Disability Awareness Panel

March 29, 2018 | Miller Auditorium

The panel was organized by Topaz Hooper, coordinator of Diversity Programs and Multicultural Affairs, as part of Disability Awareness Week. Unfortunately, the panel was scheduled on an evening before a day when the College was closed for a holiday, which meant only a handful of people attended. Nevertheless, Topaz and the panelists went ahead with the presentation.

Panelists included:

Asher Edelson, a USF student with Tourette's Syndrome (motor, vocal, and mind tics), who at one point was the Vice President of the Democratic Disability Caucus of Hillsborough County (divinums@yahoo.com)

Olivia Babis (BAY-bis), a peer mentor with the Suncoast Center for Independent Living in Sarasota and currently a candidate for Florida Senate District 23, was born without arms (congenital double amputee). (peermentor@scil4u.org)

Karen Clay, mother of a 37-year-old man who requires total physical care (born with most severe form of spinal muscular atrophy) but who graduated from high school with a 5.0 GPA. (mikesmom31@mac.com)

Topaz's questions and a summary of the responses:

What disabilities do you have and how have you worked with them?

Panelists all spoke of finding their own ways of learning to adapt, sometimes in spite of well-meaning therapists and those looking to "fix" them. Babis uses a motorized chair, learned to use her feet to perform tasks most people do with their hands, and has earned a master's degree. Asher needed and used accommodations in K-12 (scribes, note-takers, AT) and has found ways to alleviate some symptoms but mostly has learned to live proactively in spite of the tics. DragonSpeech and other voice-to-text apps don't work because of the vocal tics. Karen's son has become a pioneer in the use of assistive technologies that allow him to communicate and to be a writer/photographer and Emmy-nominated documentary creator.

How has advocating for disabled people impacted your life?

Panelists spoke of:

- "having to fight for everything from diagnosis on"
- "being *allowed* to attend regular classes" regardless of cognitive ability (conflation of physical impairment with mental impairment)
- not being tested for gifted programs because teachers had low expectations
- "the look" when applying for jobs (but can't prove discrimination based on "the look")
- dilemma of having to stay in poverty in order to qualify for Medicaid waivers when could be holding paying jobs
- relatives only recently approved to be paid as caregivers with Medicaid funding; have to choose between better paying jobs or providing care

- organizations supposedly serving people with disabilities only having token employees with disabilities
- C-14 certificates that allow mainstream employers to hire people with disabilities but to pay them less than minimum wage
- cycle of exploitation where organizations get funding to build shelters or provide work but then don't actually do what they say they will do
- cannabis has helped manage ties but that means employment drug tests are out
- dating an issue
- has learned to be own advocate as an adult

How does the current political/social system impede or help you? What would you recommend?

Panelists spoke of:

- litigation driving changes (“sometimes have to put it in dollars and cents terms”) but also of the problem with frivolous lawsuits creating resistance to change. Florida and California have the highest number of frivolous lawsuits . . . to the point that Florida passed legislation limiting law firms’ ability to “shake down small businesses” for ADA violations.
- people with disabilities who could be employed but then the health-care costs to employers would be prohibitive and/or the disabled person would lose Medicaid health care. Massachusetts and Arkansas have both expanded Medicaid to alleviate this problem. Need to uncouple SSI from Medicaid.
- guardianships being promoted by lawyers who prey on parents’ fears about what will happen to their disabled child if the parents die, which then does not allow the child to grow up -- “perpetual children”; same concerns regarding sexuality and sexual relationships.
- policies being driven by stereotypes and misconceptions.
- need more legislators and in advisory positions with disabilities at all levels. Sen Tammy Duckworth lost both legs in war and is first female senator to be pregnant (often seen as a disability) while in office; one New York town has a council member with Tourette’s.

What does “allyship” and “justice” look like to you?

“Allyship” speaks to people without disabilities who, for various reasons, advocate for people with disabilities.

Babis, questioned “allies” whose motives are to “give a voice to someone who doesn’t have one,” asking why they think people with disabilities don’t have voices. Babis noted she is the only person with a disability on an advisory board for people with disabilities . . . but there are lots of parents on the board. Parents want to protect disabled children but end up holding them back.

Clay felt the disability community’s voice is hampered by the political system. Some allies are appointed by the governor, so they may be afraid to speak out against the status quo. Some organizations depend on state/federal funding so are afraid of losing funding

if they speak out too strongly. Unlike the LGBTQ community, which has become more cohesive, the disability community does not have a cohesive message or political voice. Edelson defined an ally as one who has empathy and said there is always room for allies, but more participants should be people with disabilities. Not all allies have the same experience or the tools needed; but, regardless of political stance, they should be welcomed.

In terms of justice, Babis spoke of having things like para-transport not crossing county lines. So when she needs to go to the airport, she has to make arrangements for and pay fees to two transit companies (double the cost of what it should be). Helping people see problems from the perspective of disability is, she felt, paramount. Clay said “justice for all” has to mean ALL.

Question from audience:

What are we doing right?

Edelson mentioned the fact that, in the U.S., we have ADA, Medicaid, and SSI speaks about us as a country, compared to other countries around the world. Need to remember the positives but can't be too content.

Clay spoke about the technological developments and medical progress that have taken place over the last few decades.

Babis noted that she sees simultaneous progress and regress, two co-occurring, contradictory events. For example:

- Eugenics (selective abortion/sterilization) and more effort regarding job placement
- Institutionalization of people with disabilities has dropped dramatically but with little corresponding increase in community services so the jails and prisons have become the institutions -- 50% of female inmates have cognitive disabilities

What counties in Florida are better at providing services?

Clay and Babis responded by saying Florida is one of the worst in the nation in general (46th), but some counties are better than others with St. Petersburg and some other larger cities in the top 10-20 in the nation. Babis noted there is an active Tampa Mayor's Alliance advisory/advocacy group with a page on the City's website (<https://www.tampagov.net/accessibility/mayors-alliance>). She also advocated for having an ADA coordinator, not just an HR person.