

## LIFE AFTER SDMNY: MORE GREAT WORK, A WEDDING (ACTUALLY TWO), AND A NEW BABY!

Many of you will remember Matthew “Hezzy” Smith, our knowledgeable, committed, and talented first Project Coordinator. His personal and professional connections to the Disability Rights community, and especially to the I/DD community and self-advocates were invaluable as we built the foundation for SDMNY, and ensured that we involved people with I/DD at every stage of our work. Hezzy left us and moved to Massachusetts after four incredibly productive years, and, needless to say, we were not happy at losing him.



*The first wedding, in Massachusetts, with Deacon Tony Phillips officiating*

The good news is that although he is now doing great work at the Harvard Project on Disability (HPOD) he never entirely left SDMNY. He has stayed on as a Senior Advisor and has been invaluable in a number of initiatives, from conducting focus groups with self-advocates on our “Principles for SDMA Legislation”, serving as both a facilitator and a mentor, to working with the new mentors in our current OPWDD grant (Good News [9/1/2023]). We’ve been meaning to catch up with him on how he’s doing, and sent him a few questions which he’s been kind enough to answer.



*Bhargavi and Hezzy celebrating the second wedding in Chennai, India*



### **1. What is your new job and what does it entail (What is the POD? What's your role?)**

Harvard Law School Project on Disability (HPOD) is a disability law and policy center that works to support civil society to advance the human rights of people with disabilities around the world. At HPOD, I direct our advocacy initiatives, which means that I try to use our expertise and resources to highlight pressing disability rights issues. Currently, HPOD is actively working to promote disability-inclusive climate action and research, to visibilize persons with disabilities in the global peace and security agenda, and to advance efforts to develop an international human rights treaty for older persons.

Also, because of my own passions, a lot of my focus is on supporting self-advocacy work. I'm lucky enough to get a lot of support from our Self-Advocacy Associate, Anne Fracht, who has decades of experience both in Massachusetts and nationally in the self-advocacy movement. In the past few years, in trying to leverage the best of Harvard's institutional heft and prestige, I've been developing inclusive research projects—research projects that include self-advocates as researchers in various ways.

One effort that I'm proud of was a study that was recently accepted by the *Journal of Policy and Practice in Intellectual Disability* where I supported Anne, and two other self-advocates, Tony Phillips and Diana Mairose, to interview group home residents with intellectual disabilities in Massachusetts about their experiences during the COVID-19 pandemic. Although the study's scope was modest, we heard about self-advocates' stories of resilience, in terms of coping with personal losses or finding remote work amid lockdowns, as well as more disappointing stories, where group home staff's avoidable failures to follow safeguards or to respect the self-advocates' own safety preferences appear to have caused them to contract COVID-19.

Listening self-advocates interview each other about their experiences made these stories especially powerful, and I'm excited for the other inclusive research projects we have underway. For so long, people with intellectual disabilities have been the subjects of research done on them by people without disabilities, and I'm grateful for this opportunity to flip the script and apply my SDMNY facilitation skills to giving self-advocates opportunities to apply the notion of "nothing about us without us" in the rather intellectual arena of research from which they've been too long excluded.

### **2. How, if at all, does the work you're doing now incorporate SDM?**

One way in which I've gotten to make my interests in SDM intersect with my efforts to promote inclusive research has been in a research project on transfer of rights. This was a research collaboration between the Institute for Community Inclusion at UMass, which is a University Center for Excellence in Developmental Disabilities (UCEDD), and two self-advocacy groups, Massachusetts Advocates Standing Strong (MASS) and Self-Advocacy Association of New York (SANYS).

As part of this project, we interviewed 21 groups of parents, youth with intellectual disabilities, and school staff in Massachusetts and New York. We heard a lot of interesting stories, but what we did not hear was much evidence of the "school-to-guardianship" pipeline that has in a very short time become something of gospel in some SDM circles. Instead, we heard a lot more nuance—parents being more influenced by their peers or health care professionals or service providers, for example, than by school staff. In fact, several parents complained a bit about how they felt that school personnel were too hands off in explaining their transfer of rights options to them, and that they would have wanted more directionality from those discussions, which is not what we expected to hear. While we had found there to be limited empirical evidence of the "school-to-guardianship" pipeline in a literature review that we published in the *Journal of Special Education*, it was nevertheless surprising not to detect a strong sentiment that schools were heavily influencing parents' and students' decision-making around the age of majority among the 21 triads we sat down with.

What *was* interesting, however, and something that only our self-advocate researchers would have been able to find authoritatively, was that it was pretty clear that these parents consistently overrated how involved students were in transfer of rights discussions. Since we interviewed each person in each these groups of three individually, we were able to triangulate a bit, and the students consistently reported being less involved in these discussions than the parents did. It's hard to know whether that's due to social desirability bias, wishful thinking, or just different perspectives, but that was a great example of how self-advocates bring so much to the table in terms of both collecting and analyzing data as part of inclusive research teams.

### **3. Fond memories or thoughts about SDMNY?**

Recently, I've had the pleasure of reviewing some of the case law on SDM from New York that has emerged since your path-breaking *Dameris L.* decision. It's incredible how many SDM-related decisions have been published by New York courts in comparison to other states, including those states that have had SDM statutes on their books for the better part of a decade. I was especially gratified to see SDMNY get a specific call out in *Matter of Grace J.* and to learn that Grace ultimately did follow through on the Surrogate's suggestion and got started on the path to her own SDM agreement. I've described some of these cases in an upcoming article for TASH's *Inclusive Practice* online publication that I've co-written with Anne and Chester Finn. It was humbling to bear witness to the extent to which you individually and the SDMNY project more broadly (I'm thinking of Diana Ross and the Supremes as an apt analogy) have contributed to a something of a jurisprudential renaissance in New York around the topic of legal capacity that I haven't seen from any other state. There's so much that New York and SDMNY have to teach the rest of the country and the world about how to make SDM a reality in the daily lives of people with disabilities (my piece with Anne and Chet is titled "Giving SDM 'Teeth'") and I'm looking forward to sharing some of those lessons with TASH's community of progressive advocates, providers, and families together alongside two incredible self-advocates.

### **4. Personal details**

Since moving up to Massachusetts and joining HPOD, I've had some big changes in my personal life! I married the wonderful Bhargavi Kamakshivalli outside of Boston, and we had the one and only Deacon Tony Phillips officiate. We had so much fun with that wedding that we decided to get married again in Chennai, India! That ceremony was extra special for me, because in their tradition, the groom's sister has an important role in literally tying a knot in a thread placed around the bride's head, and my sister Emily was on hand to do us the honor. We also recently welcomed into the world Shakti Kamakshi Smith and we couldn't be happier. We're immensely grateful for all the warm wishes and generosity we've received and we've already begun our disability rights indoctrination program by making sure she has prominently placed in her nursery one of the lovely, handcrafted wooden Judy Heumann pull toys made by LARK Toys in Minnesota. I'd highly recommend them for anyone starting a new family!

**CONGRATULATIONS, HEZZY AND BHARGAVI, AND WELCOME, BABY SHAKTI!**