



# A Grassroots Approach to Addressing the MCH Workforce Crisis

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Received: 2 November 2021 / Accepted: 3 March 2022 / Published online: 28 March 2022  
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**Abstract** Following predictions of a dramatic drop in the developmental-behavioral healthcare workforce by 2023 due to retirement and/or burnout, much has been written about ways to replenish or sustain needed personnel. To date, we continue to have a crisis of not enough new clinicians being attracted to the field to replenish the third of the workforce that is expected to retire. Recent concerns about increased clinician mental health problems and burnout in the wake of COVID-19 and other societal stressors add further complexity and urgency. This crisis will not be solved solely by a top-down focus on intensive graduate training or marketing to newly licensed professionals. Through the lived experience of three fellows from the Leadership Education in Neurodevelopmental and related Disabilities (LEND) program, this paper offers a “grassroots” approach to supporting people with disabilities (PWD) to weather this rebuilding period by increasing (a) their material wealth through entrepreneurship and (b) capacities for self-

determination through thoughtful mentorship and considered changes in institutional culture.

**Keywords** Self-determination · Neurodevelopmental · Healthcare workforce · Persons with disabilities · Empowerment

In anticipation of one-third of the developmental-behavioral healthcare workforce retiring by 2023 (Bridgemohan et al., 2018), considerable energy and available resources have been rightly directed toward attracting new clinicians-in-training to the field and finding ways to mitigate against burnout and other factors that might accelerate or increase these predicted losses. Recommended strategies range from pragmatic efforts to make working conditions as comfortable as possible (and thereby lengthen the time-to-retirement) for an older, part-time workforce (Coker Group, 2019) to re-evaluating the “viability” of developmental medicine as currently practiced, inclusive of suggestions for significant restructuring of existing models-of-care and re-defining who will be served (Leslie et al., 2018).

As a Leadership Education in Neurodevelopmental and related Disabilities (LEND) program, we are committed to the principle of leadership at any level of training, whether one is a non-disabled healthcare professional or a person with disabilities (PWD) whose compelling personal story moves a legislator

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to advocate for a critical disability-rights bill (e.g., Burks-Abbott et al., 2021). Here, we make the case for a “grassroots” approach to cultivating the Maternal Child Health (MCH) workforce, because we cannot solely focus on advanced clinical training, graduate-level education, etc. as a top-down, high-cost solution to a widespread need that has only grown larger with each passing decade (e.g., Zablotsky & Black, 2020). In practice, this requires both a) the development of an MCH workforce that is inclusive of PWD and b) increasing opportunities and pathways for PWD to gain employment—no small feat with imperfect systems that have been stretched all too thin by the enduring effects of the pandemic. Toward this twofold end, we seek to empower PWD and their allies to take care of themselves and each other *during the workforce’s rebuilding period*. This paper is ultimately written for policymakers, legislators, mentors and employers in the disability space; realizing our vision necessitates their creative problem solving and historical willingness to invest in promising-but-uncertain futures. We will also rely on our colleagues-in-advocacy for PWD to spread this message to their constituents and to those who mentor PWD to instill a renewed sense of self-sufficiency and self-determination into their teaching. In the following sections, we offer three alternatives to the traditional doctor-patient model for supporting PWD.

### **Mentorship (Albert Milne, PWD, in Conversation with Adriana Mallozzi, Leslie Maxwell, and Jason Fogler)**

As a youth, I had Muscular Dystrophy, but because I could walk, people were confused [about the extent of my needs as a PWD]. I went to elementary school in the late ‘70’s and early ‘80’s, when there just weren’t the services available for PWD that there are now. I was a pretty shy kid all through high school, but in my 30’s, [I received] a lot of support—counselors, support staff, my [late] mother—that motivated me to speak up to others. I attended the Self-Advocate Learning Series, which helped me to be assertive. I met other people like me; we supported each other. My mother taught me how to speak my mind without being aggressive or mean—taking other people’s opinions into account—and a case manager told me that it was “ok to speak up as long as you’re not aggressive about

it.” I spoke up about needing support, wanting to live on my own, [and] have choices.

On hearing this, Adriana reflected on her own experience as a PWD: “As a teen, there’s all this pressure to fit in. As you get older, you realize that it doesn’t matter what people think, you start embracing your identity (inclusive of disability), understanding who you are – and a big part of that is having role models and being around other people who are like you.

“Every milestone of my educational career was questioned – labeled with stale and passive ‘impossibles’ – and I successfully passed each one.”

Al continued: It takes time and courage to speak up for yourself. There was a first-time advocate in the self-advocacy group that I chair: She didn’t want to speak. I thought, “That’s [how I was] back then.” PWD are afraid to say something that will make people mad, people in authority, like group home staff; but if you don’t say something, people won’t know what you need. I want to encourage her [to open up]; when people grow, I feel really proud. In our group, we encourage each other, make each other feel at home, [and] get work done too. There’s a lot of issues today that we *need* to speak up on: social issues, economic issues, we’re at a crossroads in our society.

### **Community Partnership, Universal Design, and Full-Inclusion (Leslie Maxwell, LCSW, Licensed Clinical Social Worker and Adoptive Mother of Three Neurodiverse Children)**

As a LEND fellow, I had the unique opportunity to spend an academic year working with a small organization specializing in serving families who have children with autism or related social disabilities. I drew from both my clinical experience as well as that of being a mother of three adopted neuro-diverse children who have experienced trauma in their short lifetimes. Both professionally and within my local community, the pandemic made it more clear than ever that parents are displeased with how their school districts handle their children’s education. With children learning from home entirely or in hybrid programs, parents and caregivers were in many cases hearing what was being taught and observing whether

their child was engaged with or understanding the material. Parents' voices grew louder: *They are not understanding the complexity of my child's needs. After all of the IEP meetings, emails, goals and objectives, and progress reports, they are not applying what is taught in 1:1 or small group SLP or OT into the general classroom environment or within the life of the school in general.*

With the support of LEND and the organization's interdisciplinary team, I was able to think deeply about how to strengthen opportunities for children with neurodevelopmental disabilities to develop pro-social and functional life skills—skills needed to be effective in the workforce and adult life more broadly. School should be providing foundational skills for PWD, but in both my own life, and that of my clients, the resounding cry is that the schools *just don't get it*. The services of a SLP, OT, BCBA or Social Worker/Counselor are rarely coordinated or thoughtfully integrated throughout the child's day. Without embedded support and comprehensive plans, children may make progress in areas, but learning seldom generalizes across environments. What happens when these learners are outside of the classroom or outside the four walls of the therapist's office?

The agency's clinicians provided relational support to families outside the clinic hour—sending encouraging text messages on the morning of their IEP meetings, offering time to debrief—which enhanced productive collaboration and working alliance. Great efforts were taken to understand parents' and children's values, goals, strengths, and preferred activities so that clinical advice would be more personally meaningful and impactful. Families felt heard and cared for, and the clinicians felt more personally invested in their work.

Just as we have learned through ample research that siloed approaches to medical care are not as effective as those where multiple disciplines are integrated or where there is truly a centralized medical home (Male et al., 2020; Ogundele et al., 2020; Zajicek-Farber et al., 2015), I believe the same holds true in the education of children with neurodevelopmental disabilities. For taught material to be learned and then put into action, the environment must closely mimic or, better still, *be* a true natural environment and safe space that is free from judgment and negativity. For true learning to take place, the child cannot be seen as their disability alone, but rather as a whole person,

with unique gifts and skill sets to contribute to the world, without pressure to conform to exactly what is expected or even demanded in a typical educational environment. Creating such an environment is no small task: While advanced training in the needs of PWD is certainly important, staff need to intuitively embody the belief that all voices around the table need to be heard (with encouragement if necessary) and respected, that behavior is communication, and that children do well if they can.

**PWD Entrepreneurship (Adriana Mallozzi, Founder and CEO of Puffin Innovations: [puffinno.com](http://puffinno.com))**

You learn from the adults around you, both ways to navigate and succeed in the world and, unfortunately, antiquated language like “wheelchair-bound” and “special needs.” In the advocacy world, words—the framing of one's narrative and message to constituents, supporters, and potential allies—are *everything*. When I was a young adult up through my mid-twenties I used terms that are now considered antiquated and inappropriate because that is what I heard from nondisabled adults around me. It was only when I entered and immersed myself in the disability/advocacy space that I began to understand the importance of language by being around older, more experienced PWD and advocates (e.g., Oliver, 2021). While social media can be a painful source of cyberbullying or exclusion, it can also bring PWD *closer* to supportive communities and high-profile role models such as Judy Heumann and Alice Wong.

In a time when our country has plenty of problems to solve, imagine if any major resource at our disposal was going unused? The population of PWD in the United States is a massive group of individuals who know how to adapt to change and iterate on new solutions in ways most people don't have exposure to (Ingram, 2020). In the U.S., approximately one in four people are classified as disabled, and more than \$150 billion is lost in tax revenue annually due to the limited utilization of PWD in the workforce. *Talent* is one of our greatest resources, yet people with disabilities don't have a viable way to hone these insights and skills or collaborate with others that identify with the experience of being disabled. Inclusion in the innovative workplace won't be possible until opportunities to

level-up in the gig economy, entrepreneurship, or tech-trade are available on an equal playing field. As we know, growth isn't only reflective of hard STEM skills, which is why any growth-nurturing plan for a different world needs to include emotional support as much as technical.

The goal of our project is to provide PWD access to entrepreneurial opportunities and a tailored, wellness-promoting curriculum. While numerous accelerators and incubators have flooded the market to assist entrepreneurs, none address the unique needs and challenges of entrepreneurs with disabilities. We will create an innovative hub—initially digital and, aspirationally, brick and mortar by 2022—that will benefit both active and aspiring innovators with disabilities. In partnership with experts in the intersectionality of mental health and disability, this platform will include tools relevant to starting and/or growing a business, mentorship, self-care, and peer-to-peer support. These aspects of our program are designed to fulfill an unmet need for a marginalized group, comprising 15% of the world's population (The World Bank, 2021). In 2019, 27% of working-age people with disabilities lived in poverty, more than twice the rate of their nondisabled peers (National Disability Institute, 2019). Furthermore, a startling 60.5% of households containing a person with a disability were considered “asset poor,” meaning they did not have enough resources to live at the federal poverty level for three months (National Disability Institute, 2019).

PWD are two times as likely to have past-due medical bills at a time when 20% of White, non-Hispanic PWD and 35% PWD of color lost their jobs as a consequence of the COVID-19 pandemic (National Disability Institute, 2020); PWD are also twice as likely to forgo medical care because of costs. Disability and poverty are oftentimes conflated as a cause-and-effect relationship. PWD often do not have the support they need to lead economically prosperous lives, which in turn makes them more susceptible to vulnerable conditions. What if we could change that? What if we could change the narrative society has about people with disabilities so that a disability becomes synonymous with innovation, creativity, and grit?

As the gig economy continues to grow, entrepreneurship and self-employment are clear paths toward health equity and financial independence for PWD. While PWD have recently turned to exploring

entrepreneurship opportunities, societal stigmas create barriers to entry, investment opportunities, and growth that non-disabled counterparts may not face. Instead, consider that the entrepreneur is commonly seen as an innovator—a designer of new ideas and business processes. PWD are inherent problem-solvers and innovative in their approach to the most mundane of daily tasks, unknowingly (or at least unconsciously) building the skills to be future, successful entrepreneurs. By starting their own businesses and achieving ownership, people with disabilities are able to create employment opportunities customized to their needs, abilities, and expertise, while also contributing to the job market to support fellow PWD. Furthermore, an unexpected positive of the COVID-19 pandemic was how working on Zoom removed so many of the usual logistical barriers to in-person collaboration for PWD. For many, working in close-up neutralized the effects of implicit bias from seeing a person in a wheelchair or struggling with other physical limitations (Loftus, 2021).

The technologies originally designed and developed for the disabled community—voice recognition, texting, home automation, etc.—have emerged as optimized solutions for both disabled and non-disabled people. This elevation of accessible and inclusive technology has made it easier than ever for PWD to forge their own paths through entrepreneurship. “Disability” is a minority group that anyone can become a part of at any time and find themselves in need of services. Our solution for better-supported infrastructure and growth conditions is ready for PWD who currently experience the void in our program marketplace and those who may experience this reality in their lifetimes.

We acknowledge that the solutions outlined herein are multifactorial with effects that, for now, may not be easily measured beyond the single-case/qualitative experience of individual PWD. We also appreciate that these are far from “one size fits all” solutions: While technology might create more options for one set of disabled individuals, it may not be the preferred choice for those who struggle with cognitive impairments or executive functioning challenges. To see wider spread effects, we will need policies that, for example, support PWD entrepreneurship or promote a quality improvement approach to training self-advocates and frontline providers—and vetting technologies that are truly customized to individual needs. The

real-time adjustments embedded in the quality improvement approach can help to identify, fine-tune, and accelerate growth-promoting programs and processes.

### Discussion: Themes and Proposed Solutions

This paper was written in direct response to the looming “workforce crisis” in developmental medicine (Bridgemohan et al., 2018) and is targeted primarily to those who might be able to invest needed time and resources into improving the collective health and well-being of PWD during what is anticipated to be a long—and potentially prohibitively long—rebuilding period. We also appeal to our direct colleagues, the readership of this journal, to consider this message seriously, operationalize it in their programming, and research these aspirational new programs’ efficacy so that they will be better able to promote them to their elected officials and potential investors.

The above examples suggest ways to improve the lives of PWD outside of the healthcare system—largely through increasing their (and their families’) capacities to self-advocate in important life domains and, in the case of entrepreneurship, *material* impact on themselves and their communities. Waitlists for qualified clinicians are prohibitively long, complicated by insurance considerations, logistical barriers, and the socio-politico-economic forces that perpetuate health disparities in our country. PWD need to find ways to support and sustain themselves between healthcare visits—ideally *improving* their life circumstances so as to mitigate the effects of stress and allostatic load on their health during the healthcare workforce’s rebuilding period. We appreciate that these are heterogeneous voices and thus represent very different paths to success and fulfillment. Remedying the workforce crisis will not be “one size fits all.” We leave it to the reader’s interpretation—be they a clinical coordinator, legislator, or prospective investor—about how best to meet the needs of PWD as suggested by our three vignettes (among a multitude of possible examples). As one example of many, we have written elsewhere about the strain on seeking employment and opportunities to increase income imposed by the current policy limiting assets of PWD to \$2,000 to

receive social security benefits (Burks-Abbott et al., 2021).

All three vignettes featured organizations that consciously created “seats at the table” for PWD, taking extra effort to cultivate personal as well as clinical/service–provider relationships, and supporting empowerment-through-mentorship. Soliciting participation from PWD is key, especially for those who are new to advocacy and unaccustomed to asking for what they need. While at “the table” we must ask: What is important to you? What do you want to achieve? How can I help you be successful? Having PWD role models and control of the terms with which we define ourselves are essential to this empowerment process. When PWD learn to turn a perceived “societal weakness” into their greatest asset, this new internalized perspective not only supports individual development but also serves as an example to change the way society at large perceives disability. We recommend that close attention be paid to supporting emotional functioning, monitoring stress levels, and encouraging networking and mentoring for both PWD and their service providers.

While technology offers the best possibility for supporting all of these activities from a distance and leveling the playing field between PWD and non-disabled people, any program targeting the developmental-healthcare workforce needs to be pragmatic, low-cost, and stakeholder-driven. An ideal program would:

- (a) Take an *individualized strengths and needs assessment* of every PWD seeking to be matched with opportunities that worked to their strengths and talents *and* provided the necessary scaffolding and protections to which they are entitled so that they can reach their full potential within their chosen field or position. Such an ambitious goal requires taking sufficient time to cultivate rapport with the PWD, elicit and uncover the PWD’s talents and aspirations (including those the PWD may not have considered—or allowed themselves to consider—as a consequence of systemic or internalized psychological barriers), and take a *growth mindset* approach to cultivating those skills before and during placement in an educational or vocational setting.

- (b) Have a *scalable and portable framework*, such as Universal Design (UD; see e.g., Burghstaler, 2021), that can be applied to any individual's set of circumstances, any community, and/or any resource network. A program designed according to the principles of UD would set the standards of that program's development (at its inception and over time), and the principles of UD would in turn serve as the criteria by which to measure the program's ongoing efficacy, accessibility, and *fidelity* (both to its core principles and those served by the program). UD is intended to be an adaptive framework, shaped by input from its users (CAST, 2018), and thus an optimal framework from a theoretical and practical perspective to underpin our vision.
- (c) Have the ability to *flexibly adapt to individual training/development needs and local ecosystems*. This flexibility would enhance the training of all people going into the field as well as continue to develop and educate people already in the field, thereby involving PWD in all facets of the program and promoting a flexible mission and workplan.

Bridgemohan and colleagues predicted a dramatic reduction in the developmental healthcare workforce by 2023, and this was not accounting for the deleterious effects of the COVID-19 pandemic on the current workforce's mental health and morale. Our three-point aspirational vision offers the possibility of bringing more people—with and without disabilities—into the workforce in a creative, time-and-cost-effective, individually tailored, and less “pipeline-dependent” fashion. The theoretical—at least empirical—underpinnings of our vision are Universal Design, Growth Mindset, and Rapid Cycle Quality Improvement (Schurman et al., 2015). All of these theoretical schools have at their core the idea of iterative and measurable improvement at any level—individually and systemically. We hope to inspire further conversation and program development in this critically needed space.

**Author's Contribution** All authors were equally involved in the conceptualization, writing, and editing of this manuscript, with Dr. Fogler taking the senior and corresponding author role in organizing team efforts and submitting the manuscript. All

authors freely consented to participate in the writing of this manuscript and consent to be published in MCHJ.

**Funding** This work is in part supported by HRSA Grant Number T73MC00020 (LEND, Boston Children's Hospital).

#### Declarations

**Conflict of interest** The authors have no relevant disclosures or conflicts of interest related to this manuscript submission.

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