

January 13, 2020

"People with Intellectual Disabilities and Autism, Their Family Caregivers, and Support Staff Must Not Be Forgotten in Philadelphia's Vaccine Distribution Plan."

If the COVID-19 pandemic taught us anything it was that family is everything, especially for people with Intellectual Disabilities and Autism (ID/A). We cannot forget people with ID/A, their families or those that provide their care in the Philadelphia Vaccine Distribution Planning. On January 5, 2021 during a press conference, Dr. Farley, the city's Health Commissioner announced that at the current rate, it will take 12 months or longer to vaccinate the entire city of Philadelphia. There is still no meaningful place for this population in the next round of distribution.

This is unacceptable and concerning. The Philadelphia Vaccine Distribution plan must ensure that people with ID/A, their family caregivers, including many aging caregivers, and Direct Support Professionals who are providing care in people's homes, group homes and the community are <u>not only included but prioritized to receive the vaccine</u>.

While those living in congregate settings such as nursing homes are being included, <u>more than</u> <u>86% of people in Pennsylvania with ID/A live in the community with predominately aging family</u> <u>caregivers</u> with their own increased risks for COVID-19 facing disastrous rates of exposure, complications, and death due to COVID-19. <u>People with ID/A are at higher risk for COVID-19</u> <u>regardless of where they live</u>. Philadelphia has had an alarming and disproportionate number of cases and deaths due to COVID-19 for this population.

<u>Vision for Equality (VFE)</u> based in Philadelphia has been on the forefront of ensuring that people with ID/A, their family caregivers and Direct Support Professionals are not forgotten. For 25 years, people with ID/A and their families have counted on VFE to support families by ensuring inclusion within our community. Families need to know they can count on the Department of Public Health and Philadelphia leaders to ensure they are not forgotten in the vaccine distribution plan for our city.

Recently Vision for Equality and members of the <u>Philadelphia Support Groups (PPSG)</u>, a longstanding family to family support program, urged city leaders to ensure family caregivers and their loved ones are not forgotten. Families called and wrote letters sharing their stories of why this matter to them.

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PPSG represents eight family Support Groups across Philadelphia whose sons and daughters with disabilities live at home. They represent families in every neighborhood in the city and are committed to helping them have the best quality of life. Additionally, PPSG represents all Philadelphia families including those in predominately Black, Brown, and Latino communities that are often further disenfranchised and have endured a history of systemic racism, barriers, and medical inequity. The city has an obligation to not only include these communities but repair the trust that has been broken and ensure that the vaccine plan is mindful and restorative so that all communities are not only included but supported to participate.

Many of PPSG's members are single parents who are struggling with just existing, some with food insecurities, medical issues of their own and many are elderly. Family caregivers lovingly have taken over all the total responsibilities of caring for their loved ones including personal care since last March when their services shut down due to the virus. They are struggling just to exist. Family members have been sheltered at home, for the most part, without any assistance struggling daily to get through the day. Many of them cannot go out into the community to essential places like Doctor's offices and even Hospitals will not allow them in because they are not able to wear masks because of their disability and are often vulnerable because of their underlying conditions which often comes with having a developmental disability.

People with ID/A, their family caregivers, and support staff must not be forgotten and be included in the next round of distribution. When they receive the vaccine, it will not only protect them but help them eventually to have a fuller life in the community.

The Department of Public Health recently shared this statement on <u>Twitter</u>, "Our Health Centers see everyone: insurance or no, citizen or no, no English? We'll translate. Remember You. Are. Welcome." Therefore, the Department must be held accountable to carry this mission and principal to their vaccine planning and distribution, especially for those with ID/A immediately.

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