Problem:
People with intellectual/developmental disabilities (IDD) should be able to make decisions about how they want to live. While, in theory, disability services allow people to have autonomy, the rules for state assistance is very limiting. These rules often don’t include the voices of those with lived experience and can restrict the choices that we want to make about our future.

While many of the rules have purposes, the collective effect of these policies is that our rights are being slowly stripped away. One way to ensure that we can advocate collectively is to have at least one advocate on the team that is working to pass a certain bill to a law.

Without advocates with lived experience on the team that effect disability policy, experts will claim that they know what is best. However, if nobody on the team has a disability, we can expect to have the same issue of experts claiming to know how to serve disabled people based on what scientists tell them. While scientists have good intentions, people with disabilities are people. They deserve the same authority to make decisions as the rest of us.

Solution:
People who have disabilities must be in the room where bills are being discussed. We might need to figure out the legal terminology of bills but this should not keep our ideas from being translated into legal language. Advocates must generate ideas for government policies. By taking part in the writing of legal language, advocates will know what is in a bill.

Ask:
As advocates, we should know how legislation would affect our autonomy. Having at least one person with a disability on any task force or work group will give other policy makers the perspective of those with disabilities. Without this perspective, lawmakers will make decisions about us without knowing what would be the best for us. SAIL has worked for several years on the Nothing About Us Without Us bill that will help us accomplish this and ensure our voices are heard.

While experts say they understand, they do not share the same perspective as a person with a disability. We need to speak to people on these task forces in order to be heard by those who are writing the legislation.

Please Pass Nothing About Us Without Us!

For more information:
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