

Ambient Jam – how can people with profound and multiple learning disabilities be advocates for their rights?



20 years ago, a group of people with learning disabilities from an organisation called Entelechy Arts came together and said, “We want to advocate for our rights”. They made Lewisham Speaking Up, a charity that champions the rights of people with learning disabilities. Now, we are still here doing the same thing. We advocate for people with learning disabilities, when they need support to speak up for their rights. We hold People’s Parliaments, where people with learning disabilities can say what they think needs to change, and we share what they say with decision makers. We lead our council’s partnership board, where council staff come together to make sure people with learning disabilities are getting what they need. We go to conferences with other self advocates from all over the country, and work together on campaigning for rights for people with learning disabilities. Most of us have a learning disability or autism. Most of us speak verbally, but we make sure we speak up for people that don’t. We’re not even sure exactly who those people were that started our charity 20 years ago, but we work hard to continue what they started.

Last year, Entelechy Arts got in touch. They had one big question for us – how can people with profound and multiple learning disabilities be advocates for their rights? Since then, we have been setting out to answer that question. The answer, it turns out, is actually very simple. In fact, you might already know it!



We met with Entelechy Arts and told them more about what we do. We explained our People’s Parliaments, and the meetings we have with decision makers in Lewisham. We told them we have a lot of influence, lots of big decision

makers in the council come to our events or read our People's Parliament reports or arrange to meet us, and they value what we have to say. But, most of what we do is using verbal ways of communicating, that wouldn't be accessible to a lot of people with PMLD.

We were planning to hold a People's Parliament about the history of the self advocacy movement, and how people can be leaders and represent their community. We invited Entelechy Arts to talk to us about ways of communicating how you feel about something without using words. They held a workshop where we used music, smells, movement and touch to express how we were feeling. They also told us about their Ambient Jam sessions, where people with PMLD, along with other artists and dancers, do improvisation to live music. They told us about some of the members who have been there for 30 years, and helped shape the sessions and make them what they are today.

We were amazed by the idea of communicating what we want and how we feel without using words. We realised that even though we think of ourselves as completely verbal communicators, we in fact communicate without words all the time! Some of us hug each other goodbye. Some of us notice how each other is sitting or what we do with our hands, and we know what that person thinks or what support they might need. So, how could we use that in our work on self advocacy?



We decided that to really answer this, we had to come to Ambient Jams and learn more. Not just us, but also the decision makers who take the time to listen to us. We invited everyone we could think of, and lots of them said yes! One at a time, they came and took part, learning from the regular members how to improvise to music, let go of their usual way of moving and have fun. Some formed friendships with one person in particular, who guided them through the session and showed them things they could do. Others did their own thing, listening to the music, dancing, singing along, and contributing to the atmosphere in the room. Often, there was a moment where the whole group came together to dance or sing or create a shape, and it always happened completely naturally, without force or judgement. Afterwards, we asked them what they learnt and how it will change the way they work going forwards.



They told us that they felt calmer and freer. They said it taught them that people with PMLD have opinions to express, and want opportunities to meet other people and learn from each other. They also said it made them think about how they measure success and outcomes in their work. They said that often everything is measured in numbers, but something like the Ambient Jam couldn't be measured like that. If more things were measured in experiences, we would all benefit from more interesting and creative lives!

We learnt how to go into something with fewer expectations, and to let things take their time. We spend lots of time pushing for meetings with certain people, or asking for certain things to be changed, but when you go to an Ambient Jam, everything slows down to a natural speed. Then, we get to create relationships with people that nourish both us and them. We learn what is most important to them, and over time, we can both introduce new ideas and ways of working to each other that give us both more power and joy! We can do this with anyone, and the relationships we form with decision makers, other self advocates or anyone who cares about what we do is one of the most important parts of our work.

So, how can people with profound and multiple learning disabilities advocate for their rights? The answer is, they do it naturally. Just like all of us, it is at the centre of every time we communicate, every relationship we have. It was the same 20 years ago, people with learning disabilities were expressing what they need and didn't think people were listening enough, so they invited decision makers to come and listen. And now we can do the same thing for people with PMLD, and we will all be better off for it.



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