



A Mindset Problem

An interview with Linda Jordan (PfA Regional Lead for London and Senior Development Advisor at the National Development Team for Inclusion, NDTi) about some of the challenges of an inclusive education for children and young people with profound and multiple learning disabilities (PMLD).

Tell me about the project that you're working on at the moment?

We've had a contract with the Department for Education (DfE) now for 11 years in total. Every year our contract is slightly different, and DfE give us slightly different things to look at each year. This year we were asked to run three accelerated working groups looking at issues that are continuing to be of interest or continuing to challenge local areas.

We came to a consensus that one of the groups needed to look at young people with profound and multiple learning disability labels (PMLD) because we're never absolutely sure that people are including children with PMLD in their conversations when we work with local areas to talk about children and young people with SEND. We feel they're being left out.

We already work with some people with the PMLD label who have really great lives, but we know that they are in a really small minority. Young people that are living independently with support in their own homes, some of them have employment and have good social lives. So, we do know it is possible.

However, we know that for the vast majority, they attend special schools and have very little social life outside of special school. And as they get older and are moving into adulthood, many still continue to live at home or go into residential care. For those living in the community, some of them will go to Social Care Day services.

So, what we really wanted to look at was: "Is this the only way that those people with those labels can live?" Can we not support them better?

We developed the program looking through the lens of human rights for people with these labels. Obviously one of the things that we then asked was, do we actually measure the Special Educational Needs (SEND) system itself in terms of human rights for anybody?

But we thought it was a really good idea to have a specific look at this group of people and whether or not their human rights are upheld. So that's how it began.

And what kind of number or percentage of children and young people in our schools are we talking about, just to put that into perspective for people?

Yeah, that's a good question. I haven't got a total number. I mean, one of the problems that we identified at the beginning of our work was that the label is quite fluid. These labels that are used within the disability system are not scientific descriptions. There are things that have grown up by custom and practice over many years and are the latest in a long line of labelling that goes back to the 18th century and before. In the 19th century we had the classification in law of 'idiots', 'imbeciles' and 'feeble minded'. Then followed terms such as 'dumb', 'educationally subnormal' or 'maladjusted' if people had behaviour difficulties; and we kept those labels up until 1981 when the term special educational needs came in. It was seen as quite a positive change. However, the law that sits underneath that term, created new (and not so new) categories such as severe learning difficulty, moderate, learning difficulty and Profound and multiple learning difficulties. Hence, the PMLD term comes under the general heading of a special educational need, but of course they're not scientifically determined or described. It's all based on a generalized idea of what it means.

The SEND code of practice defines PMLD as people who have a profound learning disability or very severe learning disability but have additional challenges such as sensory impairments or physical disabilities, and many have very high medical needs. So that is really the definition, but the term has become fluid and is used for a much wider group of young people.

As an example, I work in London. London boroughs have a population of around 300,000 as an average with a school population of approx. 50,000. In any school population there would probably be approx. 30 young people who genuinely had that level of complexity, but a lot more will have the label, because schools complete a census for the DfE. Many schools describe children without PMLD labels as PMLD on the census. So, it has become a bit problematic, and we did discuss that in our working group. Nevertheless, we're talking about young people who have very high support needs, have medical needs, often sensory, physical and significant learning disability so that that's the group. But it is a relatively small group and that is part of the problem. Because it's quite easy for them to be out of sight, out of mind in terms of inclusion in society.

So, you've described some of the challenges already. Are there any others?

The biggest challenge is that this is a mindset problem. One of the aspects that we looked at was inclusive education. We know that very few children and young people with PMLD labels go to mainstream schools. The overwhelming majority do go to special schools, so one of the questions we asked ourselves was, why? Because in law everybody has a right to express a preference for mainstream education.

People make assumptions: *"How can somebody with PMLD fit into a mainstream classroom? How could it possibly work?"* or *"How could they have their health, medical and physical needs met if they're spread around in different mainstream schools?"* or *"It just doesn't make sense to even think about it because they need to be in environments which are specifically for them"*.

So that is a huge barrier, a really big barrier.

Inclusive education is under threat anyway at the moment, for all young people, because there have been so many changes in the education system. The focus on academic attainment has put a lot of pressure on schools, so they've become less flexible in what they can offer.

It also means that secondary school children are streamed by ability, which had reduced as a concept for many years, but it has come back.

Therefore, the opportunities for really great quality inclusion have reduced and we are finding that in many schools that traditionally took children with high needs, they are tending to group them together now.

So, where's the chance for young people?

What thinking has come out of the group's work?

The group consists of 3 teachers. 1 from a mainstream primary, which includes children with these labels, a mainstream secondary and a college.

We were able to hear first-hand about what works? What are the benefits? What, in practical terms happens to make it work. Despite people's assumptions, we've got a lot of rich evidence about positivity and good outcomes and that having children with PMLD labels in mainstream classes doesn't impact negatively on other children. It also doesn't have any negative impact on attainment outcomes.

This as a first step in overcoming the challenges and changing the mindset. Just talking about it is an innovation in a way. There are other people that are involved too and we've given some links to those within our report.

It's important from a human rights perspective that young children have a right to access their community, to be part of their community. It's very rare that young people with PMLD are part of social groups with their own generation, so there is quite a lot we can do about that. I think that's something that we might pursue further after this group if we get that opportunity.

The other thing is about voice, and there's a lot of misunderstanding about what we mean by young people's voice. Or anybody's voice. We have got stuck in this unfortunate groove, that if you don't speak, if you don't use words to speak, you are considered nonverbal. And that brings with it a risk that your human rights can be overridden. It's assumed that you can't be in planning meetings, for example, or it wouldn't work for you to be in a planning meeting or what would be the point of you being in a planning meeting.

Quite a lot of the work we do as a team is helping people to understand that communication is only a relatively small percentage of verbal communication.

Human communication is through body language. Facial expression through using pictures, symbols, electronic communication and so on and so forth. And of course, finally with communication partners - having people that know you really, really well, who then support your communication. So there's a whole range of ways that we can hear from people.

The one thing that I think people find it difficult to do is put themselves in that person's shoes. Knowing somebody well means you know what makes a good day for them. What makes it bad day for them? What causes them to have a bad day?

Our person-centred planning tools that we launched just at the beginning of lockdown, are helpful in supporting that thinking.

We feel really feel strongly about presence too. We feel that people should be in the room when planning is happening about them so that it's with them rather than for them and the starting point for that has got to be presence. So even if people are not confident about using tools or not confident about eliciting People's voice, they must start with presence, because if the person is there, that in itself changes the nature of a meeting.

Then you can go on to thinking about how we go from presence to contribution. So first of all, let's make sure that the facilitator of the meeting addresses themselves to you. Everyone understands, it's your meeting and we're here to help you to plan for your future.

So, there's a whole range of ways we can overcome the challenges and cover most of those in the report which will be published on the NDTi website later this month.

Thinking back to one of NDTi's early and very popular podcasts, which was with Liz talking about Eleanor's life and the richness that was felt by other people within her class, as well as people that were working with her in her community. I'd like to think we've come a bit further since those days, but it sounds like we really haven't.

Eleanor is a one of our gurus. A young woman who has had the label of PMLD. She has got a severe learning disability and physical disability and other challenges. But she come she went through mainstream secondary school and has a great life in her community. She's had job, I think she still has some work, she's got an amazing life, and she's been a big inspiration to our team as well as to others.

We've got other young people too that inspire us. What they all talk about and what the people who are close to them talk about is the importance of their inclusion in communities. If we want to

build a society where people understand difference and we stop hate crime and we stop people being harassed on the basis that they're different, then inclusion is absolutely essential. We heard many similar examples of the benefits, mainly from the schools, but also from other people that joined the group.

The primary teacher was talking to us about a little boy who had been in hospital for several months. On every Friday, he's class sent him a card. That was their own initiative, and it didn't wain through the months - every Friday, they knew they were going to send him a card to wish him well. He knew they were thinking about him. And when he came out of hospital, they did a really wonderful celebration that he was back. These actions have lifelong benefits really, because it means that those children will never be scared of somebody who's got very high needs or who looks different or who doesn't use words to speak. They will never be scared of that for the rest of their life. So that's such a gift.

People go on to have social circles and friendships. There's another young woman called Stere that we work with quite a lot, and she did have a PMLD label initially, but through excellent support and a really gifted communication partner she learnt to sign. Now she doesn't carry that label anymore. She carries the label Severe learning disability because although she has got amazing challenges with her health and she does have multiple disabilities - in terms of her learning, it is clear now that she has got a lot more ability and cognition than was felt before. We do need to make sure that we are giving every young person the best opportunities to communicate to develop their skills.

The really important issue though, is social inclusion and in discussing these issues over the years I have had people say to me.

“What is the point of that person being here? They're not doing the same as everybody else in the classroom.”

And this is quite a common perception and it's growing. It is why so many children now are being put together in groups in mainstream schools. I'm not talking about young people with PMLD labels, because very few of them are in mainstream, but children with high needs attending school.

Every school makes its own decision about how they how they do this, but they are tending to go back to more of a unit provision because this perception has grown that if children are not doing the same activity as everybody else, it's not inclusion.

Whereas in fact the opposite is true. People don't understand that children in classrooms are not only learning the curriculum. What we learn at school is how the world works. We learn about social relationships. We learn about good and bad. We learn about how people are different, etc. That's all going on alongside the taught curriculum. And yet, if children are not exposed to the whole peer group, then they're denied those opportunities.

And so, because somebody in a primary school sitting at the table doing their Pokémon and everybody else is doing literacy or numeracy, that is something to be celebrated. Because behind

that child coming into that room will be a very long period of work (I'm talking particularly about autistic children) to get that child into that group and to be relaxed and comfortable. It is a massive, massive piece of progress and it's a massive achievement for that school and for that child.

And yet, we still have people who don't get it and would go into that classroom and say he shouldn't be there because he's not doing the same as everybody else. I'm just giving you yet another challenge in general about inclusive education and where we've got to. When Eleanor was at secondary school, we were in a different time and there was a big focus on achievement so it was possible then to do that at the same time as being child centred and inclusive. We do know that it's possible to do both, but unfortunately the way things have gone over the last few years, that is kind of under threat really and it's very sad. We still got a lot of inclusive schools across the country.

So when will the report come out?

Hopefully, before the end of March. It is quite brief for this kind of report and I think that's because (as the teacher said) "It's not rocket science". Many other topics in the SEND world have a lot of complexity, and a lot of the aspects that we look at are very complex. But this is quite straight forward in a way with clear findings and recommendations.