



Reaching Out To Families

Our first meeting

On Friday 22nd January 2021 Rebecca from Inclusion North facilitated the first Reaching Out to Families meeting on Zoom.

3 carers came along and together we talked about what we could do as a group and what we would find most useful.

People said:

- *'Its good to see friendly faces'*
- *'It should be a space where people feel safe'*
- *'A place to find out information and to share information – this could be information to help with talking about starting your periods with a young person with a learning disability or autism etc'*
- *'A place to share good news – this doesn't have to be about being a carer'*

The meeting today was an opportunity for people to get to know each other and some shared their journey as a carer – for some people their role of carer is quite different and although their son/daughter no longer lives at home their caring role continues with a different set of stresses:

- Supporting with finances
- Appointments
- Health appointments
- Funding
- Form filling

Some shared that the level of anxiety they and their son/daughter experience as they adapt to the restrictions of Covid and ongoing

changes. They shared how difficult it can be if when out in public other people do not appear to be following the rules. As a carer this can be stressful as they are not sure how their son/daughter will react.

Peer support opportunities

Carers shared recent stories where they had had difficulties in supporting their son/daughter to have their Covid vaccination – someone suggested the use of Social Stories and if used a week or so in advance they can have such a positive impact. Read about Social Stories on the National Autistic Society website <https://bit.ly/2LUg8oN>

Carers talked about how difficult it can be at times as a carer and sometimes you are not believed – being told you are an anxious parent when you know that there is something wrong. Everyone was able to relate to this. One carer shared that because they are autistic this can be another barrier for being believed or understood and often communication is not in a way that is accessible.

Good news stories

A carer shared how their son had not coped very well when he went for his Covid vaccination at the surgery. Due to increased levels of anxiety, changes at the surgery and entering the building by a different entrance they were not able to go ahead with the vaccination that day.

A home visit was then offered and also for themselves as carers – a great reasonable adjustment!

What types of things would we like to look in to in other meetings?

There are concerns relating to the support that people will need after lockdown, for some people the start of lockdown was really difficult, and people have adjusted well. But what happens after lockdown when services etc re-open:

- What support will be available?
- What support will staff have to understand that some people will need to 're-learn' some of the skills that may have been lost?
- What planning is in place for supporting staff?

We would also like to explore what reasonable adjustments are made in hospitals and at the dentist. This is not just in relation to Covid but more about how accessible the environments are, how they can increase peoples level of anxiety.

We also talked about the information that is in place at the moment to support people with a learning disability or autism who may be going into hospital which is Covid related.

The NHS have produced a grab and go form to put with hospital passports.

It is not in easy read but is really useful for sharing clear information to support the person with a learning disability should they have COVID-19 and need to go to hospital.

The guide to how to fill in the form with suggestions of useful information is here <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0381-nhs-covid-19-grab-and-go-lda-guidance-notes.pdf>

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How often shall we meet?

It was decided that we would like to meet every 6 weeks. The next meeting will be on **5th March at 10.30am**

To book your place and for information to join please contact Rachael Rachael.MunroFawcett@inclusionnorth.org or telephone: 07960 388628