

Putting Empathy at the Heart of Support Work

AJP Dreams and EDG

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The story behind this work:

We are Alexander Warren of AJP Dreams and Gillian Allan of Edinburgh Development Group (EDG). Alexander is a man with a learning disability who runs his own training and consultancy business, inspiring people all over Scotland to live their Dreams. Gillian works with EDG to create projects that facilitate the inclusion of people with learning disabilities in the community. She has a PhD in Social Policy and she has worked as a support worker in a l'Arche community and been employed directly as a PA.

We first met six years ago when we made a video of people with learning disabilities talking about their experiences of good and bad support. While we were making this video we became very interested in why some support workers seemed to have more empathy with the people they support than other workers did.

Alexander was coming to the topic with fresh eyes as he has not yet had one to one support. He was particularly shocked by some of the stories, for

example a person who had been told by his support workers he was ‘too stupid’ to pursue his hobbies and another man whose support worker expected him to go a whole day without a drink because the worker had forgotten to bring the thickener he needed in order to drink it. We both felt very sad when we reflected on this.

We decided it would be a good idea to do some research looking at what helps support workers to have empathy, what gets in the way and how we can help support workers to work in a way which puts empathy at the heart of their work. We thought it is important to concentrate on support workers who work with people with learning disabilities because this is the area we both know best.

Alexander was feeling motivated to make this happen as soon as possible so he applied to the Paul Hamlyn Foundation to get funding to carry out the research and develop a training programme around empathy for support workers with support from EDG. He was successful! This report describes what he did with EDG and what we found out.

We hope you will find it useful. We have tried to write it in as straightforward language as possible because neither of us like jargon or complex language when straightforward language can be used instead. We welcome your feedback about this – especially if we have accidentally slipped into explaining things in a way which is too complicated.

In the report we explain what we did to research the issue of empathy in support work with people with learning disabilities and what we found out about what helps empathy happen and what gets in the way. It also describes what we discovered about what to do next and the training we offer. Maybe you are not interested in every part of this, you might just want to skip to the bits that you want to know about.

What we did:

Because empathy is an experience which takes place between (at least) two people, we thought the natural starting point to find out more about it was to talk to people and hear their stories and experiences. Research which involves asking a small number of people questions and listening deeply to their detailed answers and recording is a kind of research which is known as 'qualitative research'. Qualitative research is a method which is useful for finding out more about issues which arise in human relationships, especially when we don't already know very much about those problems.

By taking a lot of time to speak to people, and mostly listen to what they had to say, we were able to build up a detailed and complex picture of what was going on for them.

People often refer to the phrase 'seeing a world in a grain of sand' which comes from a William Blake poem. This idea explains why the kind of research we did is useful.

The saying that by looking at a grain of sand closely, we can learn things about how the entire world is made up. This is because grains of sand are made up of smaller elements that can't be seen with the human eye and these smaller elements can also be found in all other things that exist in the world. The grain of sand is not the full story but it can give us a big clue as to how things work.

So when we ask a small number of people questions about the experiences in their daily lives and they all say similar things, it is likely that these things are happening for other people in other places. It may not be the whole story. If we spoke to 100 people, we would know more but it sheds light on important parts of the story. We'd love to speak to 100 people but it would take us a few years!

The Questions:

Our research questions were:

- What is empathy?
- Is it important in support work and if so, why?
- What gets in the way of empathy happening?
- How do we overcome the barriers to empathy?
- What is a 'day in the life of a support worker' like?
- What would an 'ideal support worker' be like?

How we asked them:

We used a few different methods for asking our research questions because we wanted to find out as much as we could by looking at the issue through different lenses.

- One to one interviews: We interviewed 8 support workers, 7 people with learning disabilities. Each interview took about an hour. We developed a questionnaire before the interviews to guide us through the conversations to make sure we were on topic. But the questions were open-ended so that the person answering them would feel able to answer them freely and openly and think things through as they spoke. We wanted people to have space to talk and we had the intention to listen empathically in our best efforts to fully understand what they were saying. This sometimes meant checking we had understood properly and asking follow up questions to find out more. If you want to know more about our questionnaires, you can get in touch with us. We thought it is very important to get both sides of the story: from the person who is receiving the support and the support worker as both people will see things that the other may not be able to see.
- Forum theatre group: after we completed the interviews, we ran a forum theatre workshop with Mark Traynor, a forum theatre facilitator. Forum theatre is a type of theatre where people create their own scenes as a way of thinking about how to solve problems. We made the workshop open to both support workers and also people who receive support but only support workers came along. We are not sure why. The reason for doing this was to find out if the same themes would come up as those we had found in the interviews. This would give us more certainty that these themes are important. We also wondered if other themes would arise.
- Focus Group: finally we did one focus group with managers of a support workers who all work for the same organisation. A 'focus group' is a type of group discussion about particular questions. This gave us some insight into another part of the picture. We chose to do a focus group because it was easier to arrange for everyone to come at the same time,

rather than interview busy people individually. The focus group has the advantage that people will expand on and build on each other's ideas or disagree with them but it has the disadvantage that there may be some things people didn't feel able to talk about in front of others. We used a semi-structured questionnaire for this group too. If you would like to know more about that, please get in touch.

We recorded all of the interviews, listened back to them and made notes about the main themes that came up. We then compared the themes that came up in each recording and looked for similarities and differences in what the different people were saying. We created maps of the main themes that came up to help us organise the information.

What we found out

As we explained above, we had six main research questions

- What is empathy?
- Is it important in support work and if so why?
- What gets in the way of empathy happening?
- How do we overcome the barriers to empathy?
- What is a 'day in the life of a support worker' like?
- What would an 'ideal support worker' be like?

In this section of the report we will tell you what we found out from people who took part in the research.

What is empathy?

'it's just about being a human being'

- Support worker

We asked support workers, people with learning disabilities and managers of support workers what they think empathy is. We thought it was important to understand what they mean by empathy, before finding out about how important they think it is and what helps/gets in the way of it happening.

When we looked at what everyone was saying we saw they described empathy as having three parts

- (1) Thinking: imagining what it is like to be the other person
- (2) Feeling: feeling how the other person might feel
- (3) Acting: being moved to take action to support the person they're empathising with

Support workers, managers and people with learning disabilities saw empathy as being an active process: 'I try to put myself in someone else's shoes' or 'I step outside of myself and get a new perspective'. This involves both thinking and feeling:

Thinking:

- How would I feel in this situation?
- Imagining what it is like to be them
- Staying open-minded
- Understanding

Feeling:

People described empathy to mean feeling something similar to what the other person might feel: Lots of people used phrases like

- being ‘in tune’, ‘tuning in to what people need’, ‘being intuitive’
- ‘feeling into’ and ‘using my senses’
- connecting
- ‘touchy feely’
- ‘listening to tone of voice and body language’

Taking action:

Most people talked about feeling moved to respond in a way which helps the person they are empathising with, for example

- to offer ‘practical help’
- ‘to hug people when they are upset’
- ‘to care for someone with complex needs’

We think it is important to point out here that taking action doesn’t have to mean doing something, it can mean simply being there and listening.

The people with learning disabilities who we spoke to emphasised this part of empathy more than the support workers or managers did.

As part of our research we read up on different definitions of empathy. The way the people who took part in our research defined empathy is similar to the definition by Roman Krznaric:

‘empathy is the art of stepping imaginatively into the shoes of another person, understanding their feelings and perspectives and using that understanding to guide your actions’ (Krznaric 2014 p.x.)

There is a lot of debate about different definitions of empathy. We won’t go into this debate here but for the purpose of this report and our training, we take on the definition given by the people who took part in the research which we described above.

What empathy is not:

In the discussions about empathy, some people also talked about ‘the opposite of empathy’:

- imposing my experience on you i.e. thinking because I’ve faced something similar you feel the same as me
- judgement
- not valuing person’s feelings/seeing the importance of them

How we empathise:

People also reflected on how we do the thinking, feeling and acting that is part of empathy.

People thought that to empathise well you need some tools. These are:

- know yourself well: ‘if I don’t know what’s going on with myself, how can I know what’s going on with anyone else?’
- to understand that we are all different: ‘we can try but we’ll never really know’ what it is like to be someone else
- ‘listening with all my senses’
- know we are all equal: ‘realising everyone is human, everyone has issues’,
- ‘suspending my judgement and understanding why’

As well as speaking to the people who took part in our research, we also held a panel discussion with four researchers on empathy from Edinburgh and Napier Universities. What the people who took part in our research told us about empathy is also quite similar to what the researchers said. The researchers spoke about some extra tools to help us to empathise:

- bravery (you might hear or feel someone else’s suffering)
- trust ‘empathy is the ultimate act of trust’
- spending time with people, not screens

Discussion point: Can empathy be learned?

In the interviews and group work with support workers and managers, some started to wonder out loud whether empathy can be learned. Some people thought that it can't be learned: that we are born with a certain ability to empathise and it is fixed. Others thought that people can learn empathy and improve their skills.

Researchers in the panel discussion told us that both are true: we are born with empathy and we can learn to get better at it 'we are hard-wired for empathy but we need to grow it'.

How we learn empathy:

- Through relationships
- Through conversations
- Curiosity
- Creativity
- Experiential learning e.g. imagining, role play
- We need to receive it, in order to learn more about it

There is a lot of research on this if you want to know more about it you can read the books listed in our reference list at the end of this report by: Cozolino, (2014) Krznaric (2014) Stern, (2004) Perry and Szalavitz, (2010).

Is empathy important in support work?

'If you don't know what empathy is, you're kind of in the wrong job'

- person with a learning disability

Everyone we spoke to thought empathy is key to support work. Because we think empathy is so important we were not surprised by this.

Support workers and managers said things like:

- 'support work is all about people, empathy is a big part of it: training is needed to help people appreciate this'
- 'the people who stay in the care sector are the empathic ones'
- 'I'm in the job for the people, not the pay'
- 'I'm in the job because I know what it's like to need support'

The main reasons people thought empathy was important are because empathy:

- is key to person centred working
- helps people to know what the person they are supporting wants and needs
- it helps overcome the difficulties that arise in relationships: it helps workers 'see the bigger picture' and overcome emotional challenges or initial personal reactions and to understand the person or family and why they are responding the way they are
- means it is easier to build relationships
- it helps overcome the difficulties that arise in relationships

We were really interested to hear from support workers and managers that they felt empathy actually makes the job easier. This is because it means it is easier to find out what the person they are supporting wants and needs. Empathy also makes the relationship with the people they are working with better and means they can overcome challenging times in the relationship.

But support workers also talked to us about how it can be emotionally difficult to get alongside someone if they are having a really hard time therefore self-care is important.

The people with learning difficulties said things like:

- 'Empathy is a really big thing, it should be carried across the board with every supported people's organisation'
- 'When people listen and understand I feel equal'

The last point emphasises how empathy is not only important for finding out what people want and need and creating a good relationship between the support worker and the person who is receiving support, but it also has another, very profound function: it lets people know they are important, that we are all human and all equal.

Barriers to empathy in support work:

Support workers identified 'feeling under pressure' as the main barrier to empathy. One support worker told us: 'It's difficult to step into someone else's

shoes when your own are full of worry and pressure'. There were lots of different ways that they felt under pressure.

Not enough time:

Different things made the support workers we spoke to feel that they did not have enough time for empathy.

- strict time limits on working with people. For example, one support worker told us: '2 hours a week is not enough time to get to know someone'.
- working in environments where a lot is going on and they are rushing from one thing to the next.
- feeling there is no time to get support from management if they are having a difficulty.

Support workers explained that not having enough time meant it is difficult to empathise for different reasons:

- they had no time to take in the body language of the person they work with and be open to non-verbal cues, or to slow down, relax and have the patience they need when trying to understand someone.
- one support worker explained this meant she had 'no time to think about me or how I feel' and so it is difficult to feel into the world of the person she is working with.
- being tired from rushing around means it is harder to empathise
- another support worker explained time pressures made her feel stressed and over longer periods of time she would get depressed.

Some people with learning disabilities who get support also saw this as a problem: for example, one person told us:

- 'my support workers help me to go shopping, they do mostly practical things, they don't sit down and listen to me. I'd like them to have time. I feel upset and uptight sometimes'

On the other side of this, spending too much time working with just one person can also create pressures for some:

- '8 hour shifts with just one person put pressure on the relationship'
- 'always working with the same person and facing the same difficult situation over and over again is draining'.

Rota Pressures:

Most of the support workers we spoke to felt that their work rotas created pressure because:

- they are regularly asked to do too many extra shifts
- 24 hour shifts put 'pressure on lifestyle': being with families, interrupting sleep
- sometimes they do not get 'annual leave entitlement' (the number of holidays they are supposed to have)
- being texted about extra work shifts on day off gives a sense of pressure when they should be re-charging

Rota pressures affected support workers' ability to empathise with the people they work with in different ways:

- one support worker explained over long periods of time this leads her to feel stressed and then depressed
- others commented this makes them feel tired and they can't be as present as they need to be to empathise.

Pressure outside of Work:

The pressures outside of work included:

- pressures from other jobs, extra sleep over shifts for other organisations at weekend
- study pressures
- poor work-life balance: not having enough time for family or children
- 'support work doesn't have status and my family don't support my choice and pressure me to do something else'
- my friends don't understand what support work is, it's abstract to them.

Support workers explained very clearly how these pressures get in the way of empathy:

- 'stress and thinking about other things mean I'm not fully there for the person'
- 'if I feel stressed, I can't relax, be open or think about what I'm doing and the person I'm working with.'
- 'it's hard to give myself permission to look after myself'.

Pressure in the relationship:

Because a big part of support work is about the relationship between the support worker and the person who is receiving the support, support workers thought different things cause pressure in the relationship between support worker and the person they support.

- differences of opinion/values
- it's 'emotionally draining if [the person who gets support] constantly complains'
- 'the client may ask you to do more than you're supposed to'
- not getting on with each other
- not understanding the behaviour of the person they work with or what triggers are distressing for them and so not feeling they know how to support that person
- always working with the same person and facing the same difficult situation over and over again
- feeling 'pushed in a direction you don't want to go': some described feeling stressed and under pressure to pressure the person they work with to do activities they don't want to do. This is especially hard when they know the person they work with really enjoys other meaningful activities but they feel their hands are tied because the decision has been made by family/management
- having to think about how they feel about how you are communicating with them even if they can't tell you, always have to be one step ahead.

Many of these are the kinds of things that come up in any close relationships over time.

Money pressures:

Before we started the research we thought that money pressures would be a big problem for support workers, however there were mixed ideas around this.

Some support workers said thing like:

- 'Money is not a barrier for me, I try not to worry about it, I've never had much'

- 'I'm not in it for the money'
- 'I'm in it for the people, not the pay'

While some others thought it is a problem:

- low or Minimum wage pay means 'I can't do this forever'
- 'you can't get a mortgage or financial stability' (This means the bank won't let them borrow money because they don't earn enough money)
- some workers have to take other jobs to make ends meet leaving them tired.
- being paid more helps us feel recognised

These worries added to a sense of pressure for most.

Not enough support:

Some support workers spoke about feeling like they didn't get enough support with emotional or practical difficulties. In particular people spoke about not knowing whether they were doing the right thing and not feeling they could go anywhere to get useful advice/feedback.

- One worker said 'if you don't get any feedback you feel insecure that you are not doing a good job'. Another said 'not enough support when I need it means I get lost in my problems and can't empathise'

Overcoming the barriers to empathy

Support workers had clear ideas about how to overcome the barriers to empathy. Some of these solutions are already happening within organisations, and some are not happening yet. First we will describe the solutions that are happening, then we will look at the ones which could be happening.

Where support workers get support now:

Some support workers felt more supported than others. These are some of the ways some support workers get help with their role so they can empathise more.

Some support workers felt they have the following resources at work:

- support/advice from family of person they support
- feedback from management about how they work
- emotional support from management
 - ‘I know I can talk to them anytime’
 - ‘they say things like ‘if you’re having a hard time you can always talk to me’’
- team meetings
 - sharing information and ‘figuring it out together’
 - team leaders who look out for staff and person who gets support
- one to one supervision with manager:
 - ‘one to one it’s easier to say everything I need to’
 - emotional support ‘just letting you cry if you need to’ ‘offloading’ ‘reassurance/feedback about whether what you are doing is useful, ‘just letting you talk’
 - practical advice
- empathy from co-workers
- time off when I need it

Those support workers who had access to these resources found them useful for sustaining empathy and dealing with the different types of pressures described in the last section.

Some support workers also did things to support themselves and their ability to have empathy outside of their work-time. For example:

- making sure I have ‘me time’: for example, drinking coffee, skateboarding, eating, time to reflect over a cup of tea
- time with my family/friends/partner where
 - they listen to me
 - I share thoughts/feelings
 - they let me vent
 - they let me feel whatever it is I’m feeling

Support workers had some important suggestions for further ways to support empathy in their work. These were:

Peer support time:

One of the most popular suggestions made by support workers was to have regular peer support time which they are paid to attend. Support workers felt this should be facilitated by someone outside the organisation so that they would feel free to explore ideas without judgement. They really described the need for an empathic environment in which to explore their work and deal with the pressures of working environments and difficulties in relationships with the people they work with. Receiving empathy in order to be able to empathise would be an important aspect of this.

The purpose of this peer support time is to have:

- time to reflect on practice and share knowledge about what works
- knock ideas around and get to know each other
- be part of a supportive community

Everyone who suggested this felt that peer support should be facilitated by someone outside the organisation so that they could feel safe to explore.

On top of this, some suggested that having more opportunities to get together and reflect on practice as professionals, e.g. conferences for support workers, would be beneficial.

More Time:

Many felt that having more time built in to rotas to

- rest/recharge/'reset'
- reflect
- get to know the people you work with

This would also include enough staffing to prevent rota problems. We recognise this is an issue across the board, especially in Edinburgh without an easy solution.

Enough support when I need it:

Connected to the idea of time is the idea of having 'enough support when I need it'. Not everyone was getting the kinds of support describe above.

Suggestions for support took different forms:

- empathy: ‘when someone empathises with me, I can empathise with someone else’
- emotional support
- transparency and communication from organisation
- practical advice from management and other relevant professionals (Occupational Therapists, Social Workers etc)

Empathy Training:

Support workers also suggested that empathy training would be useful. Such training should include

- learning what empathy is
- finding out how to improve empathy skills
- considering how to overcome obstacle to empathy
- experiential learning: practising empathy skills

We also asked people with learning disabilities what they thought would help support workers empathise more. Their answers were quite similar but also a little different to what support workers said. They said:

- ‘more help’
- to ‘ask each other for more help’ (this links in with peer support)
- ‘more time’
- listen more
- quiet atmosphere
- speak quietly, that will help me talk about my feelings

A day in the life of a support worker

We wanted to step into the shoes of the support workers we interviewed, so the first question we asked them was, can you tell us what a ‘day in the life of a support worker’ is like?

All the support workers we spoke to talked about wanting to do a good job. They need many different skills to do this.

Support workers told us that each day they may be working with different people: the person they support, their family, managers from their organisations and other support workers and that they will be trying to empathise with all of them.

Each one will have a different set of needs:

- doing activities
- creative
- challenging
- learning from the people you work with
- I have become more creative through doing this work
- treating the person you work with like a friend
- bringing people out of their shell

Support workers also described the kinds of skills that they need which go beyond the practical skills needed for day to day tasks:

- patience
- good self-care
- being able to 'constantly put someone else first'
- good time management: don't rush, plan ahead
- 'having to re-set and go back into a difficult situation every day'
- open and flexible, what works one day, won't work the next
- doing things you don't want to and thinking about the impact of everything on [the person I work with]
- awareness of use of power: 'making a judgement call on someone else's life', 'balancing need against want', 'can against should'

Everyone described their day as involving 'wanting to do a good job' or 'trying to do my best with everything' which has its challenges:

- 'not knowing if I'm doing the right thing'
- 'not understanding the person's difficulty' – need for professional advice
- feeling everything I'm trying isn't working

Support workers described having lots of different feelings while doing their work:

- ‘having fun and growing together’
- engaging and having fun
- ‘fun, laughing’, doing activities
- excited
- depressed
- stressed:
 - you can get into a cycle of stress: ‘pushing, arguing, getting stuck’
 - covering rotas, working too many hours
 - not enough time
 - pressuring yourself, hard to work out if you’re getting it right

An ideal support worker

We asked people with learning disabilities to describe their ideal support worker to find out if being empathic is an important part of the job description.

People said things like:

- ‘very caring, good natured, looks after my every need, and knows if I’m upset’

They thought ideal support workers would offer the following

- listening,
- understanding,
- emotional support and practical help are key

We think this is very interesting because these are all elements of empathy.

Of these, the most important quality in a support worker was listening:

‘you have to have someone who listens and doesn’t walk away ...I just think what’s the point in being a worker if you’re not going to listen? Others said things like ‘when someone listens I feel great’.

Other skills that people thought ideal support workers should have would be:

- being there
- giving advice
- being supportive and caring
- giving practical help :

- help me with whatever I need
- take me where I want to go
- help if I'm upset
- turn up on time
- good sense of humour

Some had real life experiences of these qualities in their support workers

- 'he just looks after me well, if I'm feeling down, I go to him ...he goes out of his way. I'm glad I've got him to be honest'
- 'they are my back up, my security'
- she has a calming influence on me because she listens, it makes me feel safe'
- 'if things are not going well, once I've spoken to them, I feel fine'
- 'there have been times when I have been close to losing it and my support have been at the other side of the phone', they make me feel 'at ease'.

From these experiences we can see that many support workers are doing a good job of empathising.

But, there were other, negative experiences too:

- 'my support workers help me to go shopping, they do mostly practical things, they don't sit down and listen to me. I'd like them to have time. I feel upset and uptight sometimes'
- 'this staff turned round and swore at me. She called me a b-a-s-t-a-r-d'
- 'she didn't listen when I said I don't want to watch TV because I am blind'

What we decided to do next

Now that we understand more about empathy in support work, why it is important, what stops it happening and what helps empathy to flourish, we have developed a peer support programme and a training course for support workers about empathy.

We realised there would be some barriers that we won't be able to help with, like rota pressures or time pressures but that we could support people to feel more resourced to deal with the different pressures they face.

Peer Support:

One of our main findings was that support workers would really value regular opportunities to get together, talk openly and to support each other with best practice, especially in relation to empathy. Everyone who suggested this felt it was a good idea to have this facilitated by people outside of their organisation. AJP Dreams and EDG have many years of experience in facilitating workshops around connection and peer support. We have combined our knowledge and experience of what works best with the insights from the people who contributed to our research to create this package. It includes the following key elements:

- Creating an empathic environment for workers to empathise with each other and create a supportive community
- Time to get to know each other
- Time to relax, learn about and develop self-care strategies
- Space to reflect on practice and share knowledge about what work in difficult situations

Empathy Training:

We have also created an empathy training based on what we learned. We create an empathic and non-judgemental atmosphere in our training which involves:

- role play
- art
- personal reflection
- interactive exercises

With the aim of increasing understanding of:

- empathy and what it is
- overcoming barriers to empathy
- how to engage in self-care
- the importance of listening
- the link between empathy and supporting service users to live their dreams

We offer this as two half days, or as a condensed version in one half day.

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