



Service users' experiences of Understanding Autism North West



Introduction

This report summarises the views of service users that received counselling from Understanding Autism North West, to show their experiences of its accessibility and impact.

General Information

What is Understanding Autism North West?

Understanding Autism North West is a specialised counselling service provided by The British Association for Counselling and Psychotherapy (BACP) registered counsellors for individuals who are affected by Asperger's Syndrome and High Functioning Autism.

Understanding Autism North West offered six free sessions of counselling to anyone with autism or with autism in their family, whether diagnosed or seeking a diagnosis. This was enabled due to a social prescribing grant from East Lancashire Clinical Commissioning Group. The social prescribing grant was a new funding stream for Understanding Autism North West and was time limited to February 2016. This funding has now been used and there is a waiting list of 34 people to date.

Understanding Autism North West also provide counselling to adults that have recently received a diagnosis of autism; this is funded by Action for ASD which is also funded by East Lancashire Clinical Commissioning Group. This funding stream is continuing.

Individuals can self-refer or can be referred by their GP or any other agency. Individuals may also pay for their counselling which currently costs £50 per session for individuals and £55 per session for couples.



Methodology

Why did Healthwatch Lancashire undertake this project?

East Lancashire Clinical Commissioning Group provided a grant to Understanding Autism North West to provide six free sessions of counselling to people with autism or with autism in their family. In turn, Understanding Autism North West were required to provide evidence on the impact of these sessions to East Lancashire Clinical Commissioning Group; in particular, in respect of the health and wellbeing of those who undertook the above programme.

Healthwatch Lancashire were asked, in its capacity as the public voice for health and social care, to gather the views of the service users.

For Healthwatch Lancashire, this project enabled the organisation to speak with parents about their general experiences of health and social care services in Lancashire whilst also asking their experiences of receiving counselling from Understanding Autism North West.

What did Healthwatch Lancashire do?

Amanda Higgins, Project Officer for Healthwatch Lancashire, carried out this project and undertook the following activities:

- Produced a consent form
- Designed a questionnaire
- Scheduled meetings or phone calls with service users
- Undertook service user interviews
- Produced a report with the findings
- Presented the report to East Lancashire Clinical Commissioning Group and Understanding Autism North West

Under the social prescribing grant, approximately 48 service users received counselling with Understanding Autism North West. In total 13 people responded to the consent form and were interviewed by Healthwatch Lancashire.

Healthwatch Lancashire asked service users questions either individually or with a family member. Some service users were interviewed over the phone but most were interviewed in person. The questions were split into two themes:

- Identifying how accessible the counselling sessions were
- The impact that attending the sessions had on the services users' health and wellbeing



Findings

Accessibility - Themes Identified:

- Some service users had been referred by their GP, others had found out about the sessions through word of mouth, friends and the internet. Most service users had heard through Action for ASD or other specialised centres.
- Some service users found their family to be important in terms of supporting them emotionally to travel to the sessions and to support them during the sessions.
- Some service users travelled to the sessions by bus or received lifts from friends and family. Most travelled to the sessions by car.
- Some service users found the travel to the sessions difficult. Most found the travel easy.
- Service users found the session times very flexible. This was seen as important for their condition and for maximum benefit of the counselling.
- All service users felt comfortable during the sessions, in terms of the environment and with the counsellors.
- Some service users attended other support groups but most did not.
- Some service users were unaware of how to find out about support groups.

At the end of the accessibility questions, service users were asked to score overall how they would rate the accessibility of the counselling sessions at Understanding Autism North West. Out of the 13 service users interviewed, 12 felt that the accessibility of the counselling sessions was excellent, and one person felt it was satisfactory. None of the service users felt that the accessibility was poor.

Accessibility - Quotes from Service Users

We asked “Was it easy for you to find out about the sessions?”

“My son had problems relating to life and making friends. He was made redundant from work and has struggled to get more work. The GP referred him to Action for ASD and they gave him a diagnosis. He was then referred to a clinical psychologist. He was formally diagnosed and then referred to see them at Understanding Autism. Because of his level of need, they have enquired to get more sessions. I think a great credit goes to our GP. He looked into it and found the right people to speak to. My son is lucky.”

“It was great, my mum found it, probably on the internet.”

“We didn’t know anything until we went to Queens Street Mill Asperger’s Centre. They put us in touch with them. They said I can have sessions separately to my husband because I am a carer for someone with Asperger’s.”

“It was fine finding out about the sessions. I knew what I was looking for. It was very clear and helpful.”

“Action for ASD told me about the counselling. It’s an essential service for people like me. Prior to going there, I was sent to general mental health teams which did not help.”

“My sister has behavioural needs so I recognised the symptoms. I was prescribed anti-depressants but they didn’t work. I felt I needed to talk to someone. Getting the diagnosis of Asperger’s took me out of depression immediately. I heard about the counselling from someone else and then mentioned it to my GP. He hadn’t heard of it but looked into it afterwards and got back to me.”

“It was easy because it was Action for ASD that gave me the details of them. They helped me to get a diagnosis for my son and the support I got from them was superb.”

“Action for ASD told me about it and referred me to them.”

“My daughter found it through Action for ASD. My husband was diagnosed with Asperger’s and agreed to go but then he changed his mind.”

“Very easy. I found out through a friend recommendation.”

“I found out about them after being diagnosed with Asperger’s at Action for ASD.”

“I was contacted by Action for ASD to see if I wanted the sessions.”

“It was through Action for ASD and they referred me onto them. It took a couple of months to see them because they were fully booked.”

We asked “Did you find it easy to travel to the sessions?”

“To get him there initially my wife went with him for 10-15 minutes. He can drive himself if we go through the route together first.”

“I get a mini shuttle to the sessions. I had to pay £10 in total but it was easy and I’m happy with it. I didn’t need to be eligible.”

“I found it hard to get there because I don’t drive. My wife is learning so it will be better then.”

“It’s expensive getting the bus. My dad brings me but it was hard work.”

“It’s quite close to where I live so it was easy.”

“If my mum didn’t take me I wouldn’t have been able to get there because it would have taken two and a half hours. I would have the same transport issues accessing Action for ASD.”

“I drive so it was convenient to get to the sessions.”

“I drive so it was easy.”

“I drove there and it was fine.”

“Friends dropped me off and my sister, so it wasn’t a problem.”

“I used to drive to the sessions - it was easy and easy to find.”

“I drive - it’s easy. Even if I couldn’t drive, I’d make sure I could get there. It’s worth it.”

“My husband took me and it was fine.”

“My partner took me by car and once I got the bus.”

We asked “Were the days and times of the sessions convenient for you?”

“My son has an awful sleep pattern but they have fit around this. They rearrange when we need to and is flexible. He doesn’t feel that he is rushed.”

“The sessions have been very much flexible.”

“We went every other week so it was easier for my dad to take us.”

“We arranged appointments together - it’s very flexible.”

“It was very flexible. It was ok if I arrived late or if I needed to change appointments.”

“The sessions were flexible - so issues could be stored and saved until the appointment or I would have solved them myself over a few days. They were very accommodating.”

“They were very flexible.”

“Yes, they were flexible and could be changed”

“Yes, they did suit me. They did 12 sessions rather than six.”

“Yes - in the early days they kept the appointments at the same time because it was better for me. It was good because then I remembered them.”

“They were very flexible. The counsellor would get her diary out and see when we were available.”

“Yes.”

“Yes, we had morning and afternoon options.”

We asked “Did you feel comfortable during the sessions?”

“He went a lot to the sessions and my son generally does not go anywhere, so this speaks for itself. He felt safe and respected.”

“I felt comfortable in the room where we had the sessions.”

“It was like home from home. They made us feel welcome. I went with my wife but I went a couple of times on my own. This made me come out of my shell a bit because I wasn’t worried about upsetting my wife.”

“It’s a nice little counselling room with comfy chairs. There are no barriers to accessing it.”

“It’s a very good counselling room. I think this is important because I wouldn’t have opened up otherwise.”

“The room was extremely comfortable. Well away from everything with no distractions.”

“Yes.”

“Yes, it was lovely. There was a toilet available, very comfortable and relaxing, drinks available too.”

“Yes, always. They have it very nice. It’s nice that it’s separate from the house with no bright lights and things.”

“Very comfortable.”

“Very comfortable. The place where you go is separate to the house. It’s beautiful with nice surroundings.”

We asked “Do you attend any other support groups?”

“At this point in time no but we are trying to find more. My son has high functioning ASD and some clubs have people that he struggles to relate to.”

“We don’t know any other groups but we’d want to go to them. The counselling was really beneficial and we would want to keep going.”

“Open doors- but it took seven months to get an appointment outside of working hours. Other appointments are not flexible so I can’t get to them.”

“No.”

“Action for ASD, they answer calls or texts from me.”

“I go to the hospice for my own illness and I’ve met lots of friends there.”

“I attend the women’s group.”

“Action for ASD a couple of times but I found it difficult because it was in a group.”

“Wellbeing centre, Action for ASD Resource centre, Minds matter.”

Impact on Health and Wellbeing - Themes Identified:

- All service users enjoyed the counselling sessions.
- Most service users felt that the counselling had improved their mental health.
- In particular, service users talked about feeling understood and listened to, feeling calmer, being given practical tips and helpful advice, understanding themselves more and therefore increased confidence and acceptance of themselves and a reduction in anxiety.
- Some service users also felt that they had noticed improvements in their physical health.
- Some service users were able to stop taking anti-depressants which improved their physical health.
- Most service users felt more positive and confident about life.
- In particular, service users talked about being better equipped to deal with challenging situations, at work, with friends and family.
- Some service users felt that family relations had improved, with service users better able to manage how they feel and deal with issues more patiently. Some service users had not noticed any improvement in family relations.
- For service users that had couples counselling, the sessions enabled them to better communicate and understand one another more.
- Most service users felt that the counselling had a long term impact on their health and wellbeing. One felt that the effects were short term.
- Some service users would have liked more free sessions, or being able to call one of the counsellors for a quick conversation. Some felt that the sessions provided everything that they needed.
- Some service users would have liked more signposting to other support groups and services.

At the end of the impact questions, service users were asked to score overall how they would rate the impact of the counselling sessions on their health and wellbeing. Out of the 13 service users interviewed, 12 felt that the impact of the counselling sessions on their health and wellbeing was excellent, and one person felt it was satisfactory. No service users felt that the impact of the counselling sessions was poor.

Impact on Health and Wellbeing - Quotes from Service Users

We asked “Did you enjoy the sessions?”

“It probably is difficult for him to go to the sessions because it is counselling. At the moment he looks forward to it. He willingly goes along. He appears calmer afterwards. He hesitates over most things in life so for him to attend regularly and willingly is incredible. They have been a beacon of light in a dark landscape.”

“I enjoyed going very much. I felt better afterwards.”

“I enjoyed the sessions. They explained to us how to cope. It was good to talk to someone who understood. I looked forward to it. It gave my wife two hours break.”

“I’ve found it helpful and so in that way I have found it enjoyable.”

“I actually looked forward to going. They make you feel you can completely trust them. They are genuine and have a knack of remembering things. They speak to you like a person and not just a next client.”

“Very much so. More than I have with any other counselling sessions I have had. I always felt no one ever got me. They have made me understand how I feel and why I do what I do.”

“Having someone in front of me telling me. I’ve never met anyone that gets me as much and helps. I don’t feel they are judgmental at all. I totally trust them.”

“I did. I’ve had really quite a difficult year and it was great to be able to talk about it with them, and not be judged. They told me it was ok to feel angry and I looked forward to going. I’d go with my list of things I needed to talk about.”

“Yes, it was very helpful. We went to a lot of places with my daughter when she was younger. The great thing about the counselling was that we could talk broadly - how it affects all aspects of our lives which are loosely related.”

“Yes, I did. I looked forward to it. I was nervous the first time. I got help, I feel better about myself, and my self-esteem has never been higher.”

“Yes, absolutely. Reassurances that I’m perfectly normal. Affirmation that I was ok. I was afraid about misreading people but I understand it more now.”

“Yes, I loved seeing them. They know what they are talking about. You get things off your chest. They give me practical advice.”

“I felt comfortable. They were very approachable. I got on really well with them. They explained everything.”

“Yes, they spoke to me - they were down to earth. They didn’t sugar coat it and they made me feel welcome, I could be myself and they totally understood me. I was in denial at first and confused. I’m less so now. They put things across easy in a way I understood.”

We asked “Have you noticed an improvement in your mental or physical health and wellbeing as a result of attending the sessions?”

“He says that someone now gets it. He’s making great responses to each session. Physically because he has another major health condition it is difficult. He is trying to come to terms with his condition and look at the positive things he can do and work through the things he can’t.”

“Mentally and physically, I have improved. I feel better.”

“I haven’t noticed any mental or physical improvement because we need more help. We need something to calm him down.”

“Yes, definitely. It’s helped me understand why I do things and this reduces anxiety.”

“I feel a lot happier in myself since going.”

“Absolutely without a doubt. I don’t know how they did it. Their job is to give me a platform to solve my own problems. They helped me to put things into perspective. I care less about other people and think more about myself. I think it has had a long term impact. If I was to go back, I don’t think it would be to talk about the same things. They screwed my head on. The ingredients were there but they were the catalyst to put things together.”

“Yes, more understanding of myself has led to me feeling better. This means I am less fearful - there were many times I worried I’d end up in a psychiatric unit, and now I don’t physically I’ve not had to take anti-depression pills which helps with my physical health. I had a permanent headache when I was on them. They made me feel disabled and they made me shake. I decided to change my doctor whilst I was receiving the counselling and they agreed to take me off them.”

“I have. They have made me less impulsive. I now step back and can go through a checklist.”

“Yes, more self-acceptance. Feeling ok that if I don’t want to do something I don’t have to. They reinforced what I think I already knew.”

“Yes, a lot. I have a reason to get up in the morning. I’m now the chief baby sitter. I wish I’d have gone years ago because we didn’t have the same interaction with our children because my husband didn’t like doing activities with the kids.”

“Absolutely. I got myself into a bit of a flap and started thinking about leaving the voluntary work I do. They understand my anxiety. This has improved my life. I know what’s causing me to think and behave like I do now. It’s helped me with my voluntary work because I’ve been able to talk to my manager and explain how I struggle with sensory issues and anxiety on a day to day basis.”

“They helped me to understand.”

“I was very confused, they explained why I was confused. I understand now why I did things as a child. I felt stupid as a child and now I see myself more positively.”

We asked “Have you noticed a difference in your family’s mental or physical health and wellbeing, since you have attended the sessions?”

“We are extremely relieved that he can talk to somebody. That he can have the sessions and talk to someone outside of the family. It’s more about a sense of relief than anything. That he can relate to and move on in himself. We are pleased he is receiving the sessions and is making progress.”

“I feel like I’ve been arguing less with my mum. Mum seems a bit happier. I’ve been a bit calmer.”

“We haven’t noticed any family improvements. It’s good to go to these sessions but it might only last a couple of days or sometimes a couple of hours.”

“I wouldn’t say it has changed anything relationship wise. But things that I hadn’t thought of before; such as I hate the sound of the washing machine, so we put it on when we go out now.”

“My family are happy to see me happy. They were worried before.”

“Mum is happier and dad. There’s no panic or worry anymore. It’s a direct impact from Action for ASD and the counselling. Its changed my life, as a partnership, Action for ASD and the counselling work very well together.”

“Perhaps they have because I have been able to support my mum and dad who are very unwell. I think my partner has improved because I have been able to explain to him how I feel in a calm way rather than an outburst.”

“It might have but it’s hard to explain. A lot of my family have learning disabilities and autism. It’s only now talking about it that I think it has made me more patient with them. I do not live in a quiet house.”

“Yes, it has improved. It has reinforced my confidence in the family decisions. I am more accepting of my son.”

“I wanted a connection with my husband and I know that’s not going to happen now. The physical violence has stopped but emotionally it’s still there. I understand him a bit more now but I still don’t know what he’s thinking. He is on the defensive because I left him for a few months.”

“The way they behave with me has improved. I am less stressed. It’s good to have the knowledge so that you can adapt.”

“Yes, my wife gets the chance to say how things are affecting me. She is in this with me and the family so she understands me more. It means she doesn’t need to sit back as a victim. She can get on with it with me. The counsellors helped me with my daughter’s diagnosis as well.”

“I found relief because he was drinking due to the confusion. It helped our relationship. It helped me to understand and communicate with my husband. This has helped my mental health partly because we can help one another more now. [service user] My daughter understands more now and I get on better with her. She’s been treating me better. My daughter’s children have autism and I feel I can relate to them and help them more now.” - From service users wife.

We asked “Would you have liked the sessions to provide anything additional?”

“The only thing I would like them to have provided is more sessions. I think he is fearful that they will come to an end.”

“I would like more appointments - continuing appointments for as long as I need them.”

“It would have been good to be given information of other support we could get.”

“It would have been good to get the diagnosis from Understanding Autism so I didn't need to go to more than one place.”

“Having the ability to call them whenever I need to. It would mean 5 minutes rather than 30 minutes with Action for ASD, because I don't see them as often.”

“They gave me everything I expected and more. They agreed with me that it would be different because I had only just started to learn about this after a long time not knowing I had it. I think there should be sessions particularly for people with a late diagnosis. It's also contained at work because I know there's someone I can call who is familiar and is dedicated to just speaking to people who need to have a quick chat when life happens.”

“No the counsellors were fine. It was just a shame that I had the sessions quite close together but I wanted and preferred to have them close together.”

“No.”

“I don't think so. They could have counselled my husband if he would have gone but he wouldn't. They said if I started feeling low I can call them again.”

“More free sessions.”

“Continued sessions. It's so good to have someone to touch base with. My GP doesn't understand and they can't do much in a ten-minute appointment.”

“No, they explained everything.”

“I think they provided everything I needed. They extended the sessions from three to six. I would like more sessions if possible.”

We asked “Do you think that attending the sessions have had a long term impact on your health and wellbeing?”

“I think he is beginning to have an awareness of the implications of why he is struggling to socialise and it’s helping him to understand why he feels this way.”

“Long term I think it has helped a lot.”

“The effects are short term. It’s been good to talk to them though.”

“I think it has had a long term impact. It’s been very positive. The tips have been very useful and practical.”

“It’s all the senses- smell, light, noise, vibration. I’m working freelance now which was not a direct impact from the sessions but it gave me the confidence to make the decision. It’s made me think harder about what I should do in my career; only to do things that I’m passionate about to maintain positivity.”

“Yes, making me not as impulsive and taking a step back. I have trouble with social workers and without their help I don’t know what I would have done. It fit together when I got the diagnosis. And they cemented this together. They made it ok for me to be who I am.”

“Yes, a more positive view of things. It’s helped with my daughter in terms of communicating.”

“I don’t know where I’d be without them. They helped me immensely. It meant not taking medication. Previous counselling did not work. I felt better during the appointment but after, it went back to normal. The counsellors’ understanding of autism was more beneficial - they understood me, and my husband, and the things he did. I wasn’t sleeping or eating. I was on the verge of a nervous breakdown. I’m 90% better than I was. I have a life now - I exercise, have family relations, friends. I can see a way forward now.”

“I would say so. They are always there even if I just need to email them. It’s good to share information. It’s good to touch base.”

“It’s had a big impact definitely. I’m a natural born pessimist but now I see things more positive. I still have a rant occasionally.”

“Yes, I understand more, I feel happier. I used to struggle with people before and now I don’t struggle as much.”

“I understand myself more. So its improved my outlook on life.”

We asked “Is there anything additional that you would like to add that I have not already covered?”

“I hope I get better soon.”

“They were fantastic. They really knew their stuff. It’s just a shame it had to end. At first it was difficult but the more we went it was great to talk about things.”

“Overall the counselling has been great and it has been great. I haven’t once come away wishing that I wanted more, it’s been completely positive and a nice experience. I would definitely recommend to anyone. Extra excellent.”

“I don’t like going to different people because then I have to explain everything again. Providing funding to keep the counselling going for people would be good. I’d be in a right mess without them.”

“I understand myself now and this has given me confidence. They have given me the words to express myself to other people. People have said it’s enlightening talking to me now. When people see me upset they get upset because they can’t help me. It enabled me to see my sister in hospital. It’s like a big bell; when the bell chimes it takes a while for the vibrations and reverberations to end.”

“I just wish I could go to see them again. Some people with Asperger’s have become dependent and needy but I wouldn’t. It would just be nice to know I have a safety net. When I have a problem I can’t let it go and this affects and wears my partner down, whereas they would take this from me and I’d move on.”

“I found Child and Adolescent Mental Health Services to be very bitty. There were new referrals made with large chunks of time waiting and that’s her GCSE years gone.”

“I think people need more than 6 sessions. I think maybe they could train other people to provide sessions more widely.”

“I’d like to get more sessions if I need them. It’s been an eye opener for me.”

“The counsellors are excellent workers. I’d recommend them to anybody. There’s not enough of them to go around. She’s a one off.”

Response from Understanding Autism North West

This report was shared with Jan Livesey, BACP Senior Accredited Counsellor for Understanding Autism North West. She provided the following response:

Understanding Autism North West are delighted to have been given the opportunity to have an independent evaluation of our counselling service and are grateful to Healthwatch Lancashire for interviewing over 25% of the clients who attended this project. It is interesting to note that our comprehensive understanding of the autistic condition is acknowledged by our client group, particularly in their comments about our flexible approach to appointments and the care and attention that has been given to the counselling environment. This is useful information for the development and expansion of the service. It is also pleasing that many of the comments and findings indicate a significant social return on investment to a minority group in the community, who have previously struggled to access appropriate services.

The report has provided reassurance for us that we are developing a service which best fits the needs of our client group and we will be working very hard with partners in order to secure funding to continue and develop this work.

healthwatch Lancashire

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