



National
Autistic
Society
Cymru

Peer support experiences:

Autistic adults in Wales



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Peer support experiences:

Autistic adults in Wales



Foreword

We often hear about social isolation and how it can affect people throughout their lives; how it might impact someone's mental health; their ability to meet people; and how it could limit their access to vital help and support.

But, until now, we haven't had a clear understanding about what social isolation means for autistic people in Wales and the specific challenges that they face as a result of being isolated. This understanding is crucial if we are to develop opportunities aimed at reducing the impact that social isolation can have on autistic people.

We now know that autistic people are eight times more likely to be chronically lonely than the general population of Wales, and that one in four autistic adults have a severe mental health condition. But we also know that 82% of people surveyed would want to take part in peer support opportunities and one in six people surveyed would like to lead their own peer-led activities.

There is nothing inevitable about autistic people being isolated. It's a result of a lack of the right opportunities; groups that understand their needs and take them into account. This research highlights encouraging solutions to these issues, and that autistic people are at the centre of providing them. Our report shows the steps that we can begin to take to develop peer-led support networks that tackle social isolation and improve the lives of autistic people in Wales.

A handwritten signature in black ink, appearing to read 'C Stevens'.

Caroline Stevens
Chief Executive, National Autistic Society

Introduction

Autistic adults are eight times more likely to report feeling chronically lonely than the general population of Wales.

Without support, this isolation has an extremely detrimental effect, not least on their mental health. One in four autistic adults report that they have a severe mental health problem.

Reasons behind this are complex but we know from surveys that peer support and social groups have a positive impact on this isolation, as well as on confidence, on reducing anxiety and on improving family life.

Through the implementation of a three-year peer support development project, funded by the Welsh Government, the National Autistic Society Cymru aims to increase the number of our peer support and social groups available to autistic adults across Wales, and to reduce feelings of isolation among those who attend.

The goal of the peer support survey and consequently this report is to:

- 1** understand and share peer support experiences of autistic adults in Wales to inform the National Autistic Society Cymru's Welsh Government funded peer support project
- 2** understand preferences for and barriers to participation in peer support in Wales by autistic adults.

Methodology

Between October and December 2020, the National Autistic Society ran a survey for autistic adults or their carers (answering on behalf of autistic adults) to tell us about their experiences of peer support. English and Welsh language versions of the survey were available, with one person completing this in Welsh. The English language survey was completed by 201 respondents: 149 autistic adults and 52 parents or carers of autistic adults, answering on their behalf. Survey responses were received from people in all 22 local authorities in Wales.

What is autism?

Autism is a lifelong disability which affects how people communicate and interact with the world. There are approximately 700,000 autistic adults and children in the UK. All autistic people have difficulties with communication and social interaction. These can include not being able to speak, delays in processing information or difficulty holding conversations and making friends. Autistic people also engage in repetitive behaviours, such as hand flapping, rocking or repeating sounds. They can experience intense anxiety and extreme unease around unexpected change. Many autistic people have sensory issues with noise, smells and bright lights, which can be very painful and distressing. Without the right support or understanding, autistic people can miss out on an education, struggle to find work and become extremely isolated.

Desktop review of existing peer support in Wales

Access to peer support for the general population in Wales, whether free or fee based, is difficult to navigate. Our experiences of navigating multiple websites gave broken links, and activities that have paused indefinitely due to coronavirus. Some areas provide multiple opportunities to many communities each day of the week, while other areas offer no peer support opportunities at all.

Narrowing the peer support search for autistic people narrows opportunities for support. Further specifying of autistic adults can take these narrowed results to as little as 2% of these already limited search results.

Five National Autistic Society branches in Wales support activities exclusively for autistic adults, but we need to do more to increase the opportunities available.

There is a clear gap in social connection opportunities for autistic adults in Wales, further exacerbated by coronavirus.

“100% dependent on younger sister to provide company when wanting to discuss games/thoughts on games. It’s virtually impossible to access ASD specific support.”

Survey respondent

Closer inspection of the make-up of some longstanding social groups shows that although they offer many invaluable opportunities for peer support and social connection, they are supported by employed staff. This needs to be considered when analysing best practice in the context of this peer support programme.

The project that the peer support survey was designed to inform is focused on sustainable peer support and will be volunteer driven.

Many recent peer support initiatives in Wales have been sporadic, active during the time they had funding and stopping after this. To avoid historic patterns of inconsistent peer support in Wales, the National Autistic Society Cymru’s peer support project will focus on volunteer-led peer support. We hope this will foster sustainable programmes as well as training and volunteering opportunities for autistic adults in Wales.

For groups in Wales that are active; finding the leader of a peer support initiative can lead to a recommendation of another physical or social media group organiser, but details aren’t always readily available. There are online social media groups organised for particular areas in Wales that welcome new members, whether from their catchment or not, or with diagnosis or not. Others are still viewable online but defunct, adding dead end enquiries to the search for support. For someone who is experiencing low confidence and anxiety, difficulty accessing information for support could cause them to give up their search altogether, leading to further isolation.

The British Red Cross’ recent research¹ highlights a difficulty in finding support for the general population of Wales: “as the pandemic continues into the challenging winter months, half (52%) of those who anticipate needing support said they wouldn’t know where to turn.”

This in itself is concerning but when we consider the increased risk of loneliness and isolation for autistic people, it’s clear that making it easier to search and access support is vital to reducing social isolation for autistic adults in Wales.

1 Online survey of 192 adults in Wales, carried out by Opinium for the British Red Cross between 27 November – 1 December 2020.

What is social isolation?

Social isolation describes the absence of social contact that can lead to loneliness. For some, it might mean being cut off from 'normal' social, societal and community networks. This can be triggered by factors such as disability, unemployment, poor transport links, domestic abuse or health issues.

Social isolation is the objective physical separation from other people (living alone for example), while loneliness is the subjective distressed feeling of being alone or separated. You can be lonely in a crowd, but you will not be socially isolated. There are instances of people who could be described as socially isolated not describing themselves as lonely. 4% of respondents cited minimising social contact as the best way to protect their mental health, so they could be described this way.

There is evidence linking social isolation with adverse health consequences including depression, poor sleep quality, impaired executive function, accelerated cognitive decline, poor cardiovascular function and impaired immunity at every stage of life.²

Social isolation can be an indicator and instigator of many physical and mental health problems and is self-reinforcing.

Social isolation can be described as a chronic stress. It has the same effect on the body as stress does, including increasing stress hormones which can affect metabolism and interrupt regulation of sugar and fat. Social isolation can have the same biological effect as poverty, bereavement, discrimination and other social stressors in terms of stress response of the body.³

“Social isolation lowers self-esteem and enjoyment of life in general. It can leave you feeling flawed, rejected and irreparably broken - an outcast and victim.”

Survey respondent

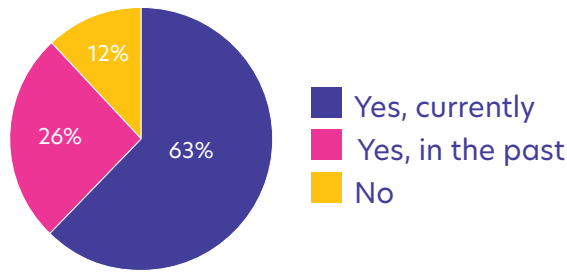
- 2 Mann, F., et al. (2017). A life less lonely: the state of the art in interventions to reduce loneliness in people with mental health problems. *Social psychiatry and psychiatric epidemiology*, 52(6), 627–638. <https://doi.org/10.1007/s00127-017-1392-y>
- 3 Science Weekly Guardian interview of Carmine Pariante, Professor of Biological Psychiatry at King's College London, with Ian Sample. <https://www.theguardian.com/science/audio/2020/apr/15/covid-19-how-can-social-isolation-affect-us-podcast>



Experiences of social isolation and loneliness

Almost nine in ten survey respondents have experienced social isolation, currently or in the past.

Have you/your family member experienced social isolation?



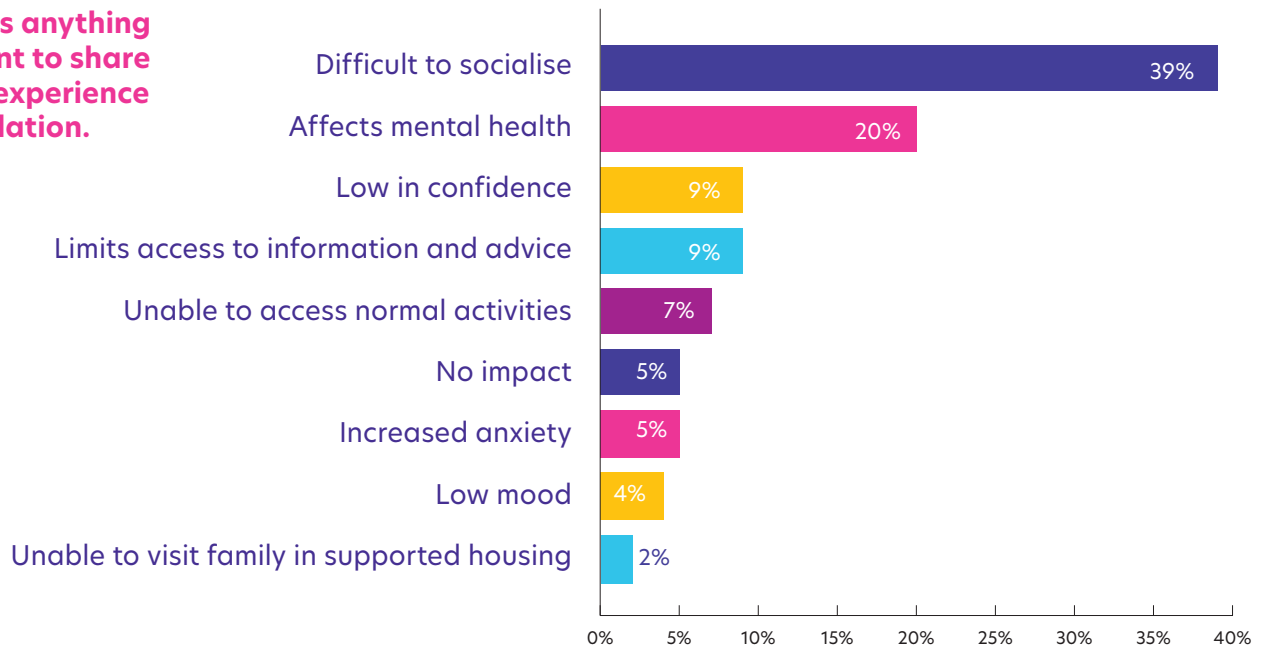
Making it difficult to meet friends and low confidence are the most frequent effects of social isolation felt by autistic adults in Wales.

How does (or has) social isolation affected you or the family member you care for?

	Always/Often	Sometimes	Occasionally	Hardly ever	Never	It doesn't impact me at all	Not sure
Difficult to meet friends	63%	18%	11%	3%	0%	3%	2%
Low in confidence	53%	28%	10%	2%	3%	1%	1%
Affects my mental health	45%	28%	19%	5%	1%	1%	2%
Low mood	42%	36%	17%	3%	1%	1%	1%
Limits my access to information and advice	36%	27%	13%	7%	7%	7%	3%

By far the most mentioned shared experience about social isolation was that it made it difficult to socialise.

Please tell us anything else you want to share about your experience of social isolation.



Experiences of social isolation and loneliness

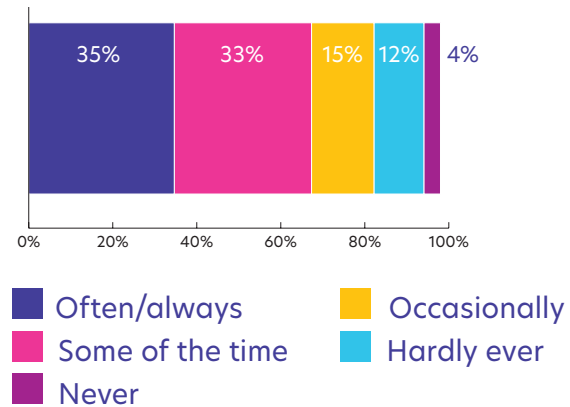
With the support models currently in place for autistic adults in Wales; 90% will experience social isolation and the risk of loneliness and other detrimental physical and mental effects resulting from this proven social stressor. Autistic adults in Wales are eight times more likely to report being chronically lonely than the general population of Wales.⁴ This is worse than the same comparison for the UK as a whole: autistic people were seven times more likely to be chronically lonely than the general population; and six times more likely to have low life satisfaction than the general UK population.⁵ Six times fewer autistic adults in Wales rated their life satisfaction as very high as compared to the benchmark figure for the general population.

This problem will not go away without intervention. Social isolation is shown here to be cyclical, detrimental to confidence and to exacerbate anxiety; a culmination that can lead to increased isolation.

Anticipating and breaking down barriers to participation and an understanding of reduced social interactions due to coronavirus will be vital in assisting autistic adults to feel confident enough to participate in peer activities.

Eight times as many autistic adults in Wales report being chronically (often or always) lonely compared to the general Welsh population.

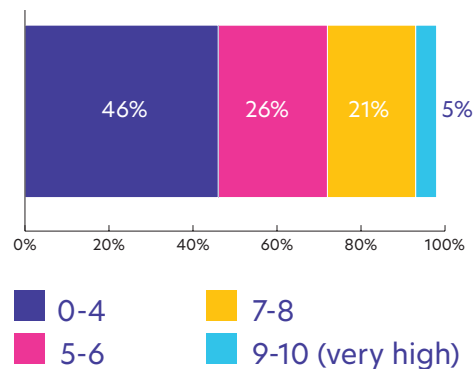
How often do you feel lonely?



In comparison, 4% of people in the general population of Wales reported that they felt lonely “often” or “always” between 3 April and 3 May 2020, about the same proportion as pre-lockdown.⁴

Six times as many in the general Welsh adult population rate their life satisfaction as very high as compared to autistic adults.

How satisfied are you with your life nowadays? 0= not satisfied, 10= satisfied



In comparison, 31% of adults in the general population of Wales rated their life satisfaction as 9-10 (very high).⁷

4 All comparison data about the general adult population in Wales is from Office for National Statistics (2020). *Coronavirus and loneliness analysis, ONS Opinion and Lifestyle Survey.*
 5 National Autistic Society (2020). *Left stranded* report.
 6 National Autistic Society (2020). *Left stranded* report.
 7 Office for National Statistics (June 2020). *Personal and economic well-being in Great Britain.*

“Working from home full time means I don’t practise social interactions in a formal setting, meaning I’m then petrified of informal settings. Regular interactions normally keep up my practice if that makes sense.”
 Survey respondent

“Harder to practise social skills without any social circles.”
 Survey respondent

“I am just very isolated. The only person I see regularly is the postman.”
 Anonymous, autistic person in Wales⁶

COVID-19 and social isolation in autistic adults

COVID-19 lockdowns and resulting restrictions in Wales are exacerbating feelings of loss of control and confidence in autistic adults.

For some, it has meant giving up on their regular activities entirely as the 'stop start' nature of restrictions has proven too unpredictable for those who rely on routine. This is putting additional pressure on the cycle of social isolation in an already isolated group. Some autistic adults might need regular practice to develop social skills and the disruption caused by the pandemic is increasing anxiety and resulting in the loss of learnt skills. For those that have managed to move activities online, there are some reports of positive impacts on wellbeing and reduced need for masking.

"I dread going back to society."

Survey respondent

"I feel like I was starting to get somewhere then COVID-19 started and as I live alone I don't have social contact anymore. No groups to go to etc."

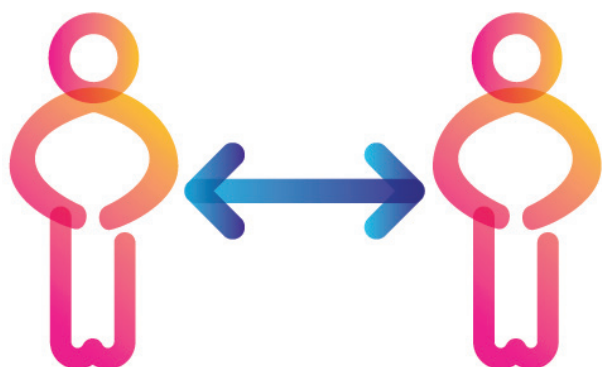
Survey respondent

"I do some voluntary work (online due to Covid) which gives me a level of validation."

Survey respondent

"Now things are changing rapidly - it's closed twice and reopened and it doesn't feel safe to me anymore. I could go back and get used to it again and enjoy it and the next day it could be forced to close again. I can't keep dealing with that unpredictability so I've not gone even when it has been open, and I feel the impact it's having on my wellbeing not creating and not seeing people I know there."

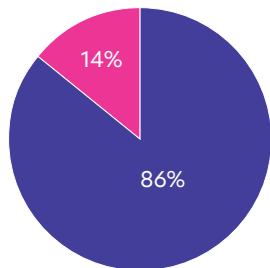
Survey respondent



Benefits of peer support

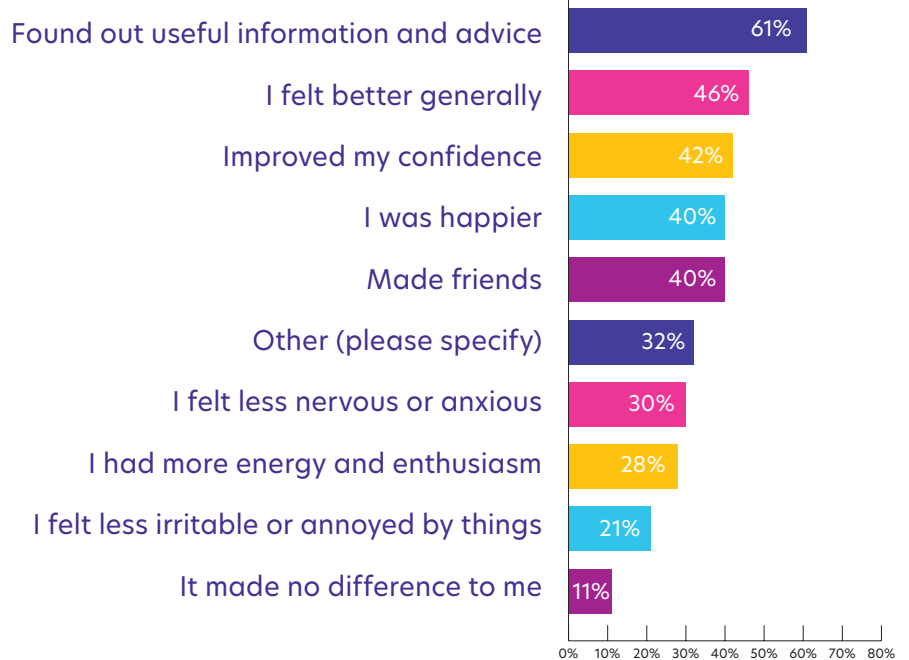
The vast majority trying other peer support services had found these helpful. The top three reasons were finding out useful information and advice, feeling better generally and improved confidence.

Was it helpful?



■ Yes (86%)
■ No (14%)

How was the service you used helpful?



NB This question is specific to non-National Autistic Society groups.

86% of people surveyed described peer support previously attended as having a positive effect on their lives. The top responses were that people found out useful information and advice, felt better generally and experienced improved confidence. A third of people had more energy and enthusiasm and 40% were happier. Peer support and social connection has had a variety of positive effects on people's wellbeing, which may in turn positively impact their health.

Peer support and a need for understanding in social settings emerged as a theme on what can positively impact mental health. Opportunities for social contact with peers are essential for autistic adults who feel the pressure to mask or adapt their behaviours for a neurotypical environment.

"Research online to learn strategies and treatments plus talking to my peers in my closed peer mentoring online group."

Survey respondent

"I could literally write an essay in response to this question but because of autistic burnout, from being battered by NT world, systems and barriers, I'm very quickly losing my voice, becoming made to be mute. Exhausted by life."

Survey respondent

"It validated me and made me part of the human race."

Survey respondent

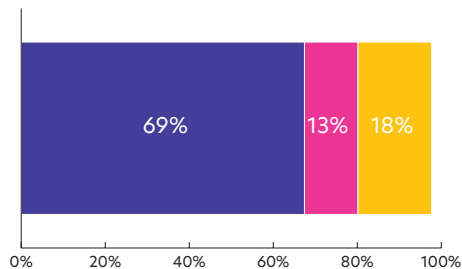
"Working from home has helped a bit as it removes the need to mask for ten hours a day."

Survey respondent

Benefits of peer support

Although the majority would prefer just to participate, one in six respondents would like to volunteer to set up a peer support group. This equates to 25 volunteers.

Would you be interested in taking part in National Autistic Society peer support activities in the future?



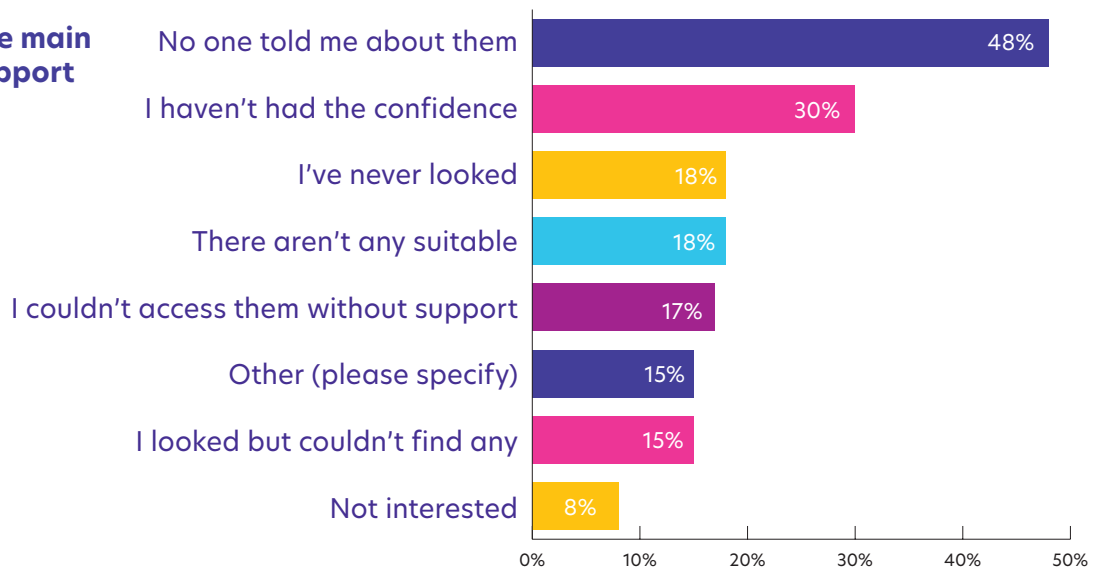
82% of people surveyed would like to participate in any future peer support activities started by the National Autistic Society Cymru. Encouragingly, one in six of these would like to volunteer to start groups themselves. These represent 16 local authority areas and is an early indicator that sustainable, peer-led opportunities are viable.

- Yes, as a participant
- No
- Yes, I'd like to volunteer to set up a peer support group, with support from the National Autistic Society

Barriers to accessing peer support

Lack of awareness is the main barrier to using peer support services, mentioned by nearly one in two.

If you haven't used peer support services, why not?



Lack of awareness, low confidence, unsuitability of existing services, support needs and lack of services are all barriers to participation. When asked how people found out about peer support services, sadly, the most common answer (one in three) was that they didn't find out about them. For those who did, the National Autistic Society's website was used the most.

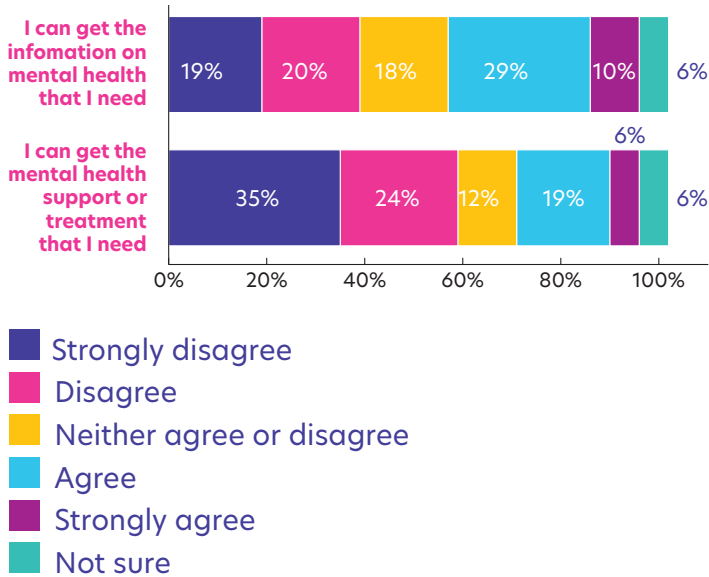
As many activities in Wales are aimed at children, parents and carers, not having a specific group for adults in their area stops some from seeking support.

A 'lack of support in their area' received the highest number of mentions relating to the experience of trying to find or take part in peer support activities, cited by a third of people.

"Adult groups seem to be mixed with parents/carers of young people which isn't helpful to myself."
Survey respondent

Barriers to accessing peer support

Two in five autistic adults in Wales agree that they can get all the information they need on mental health but only one in four that they can get the support or treatment they need.

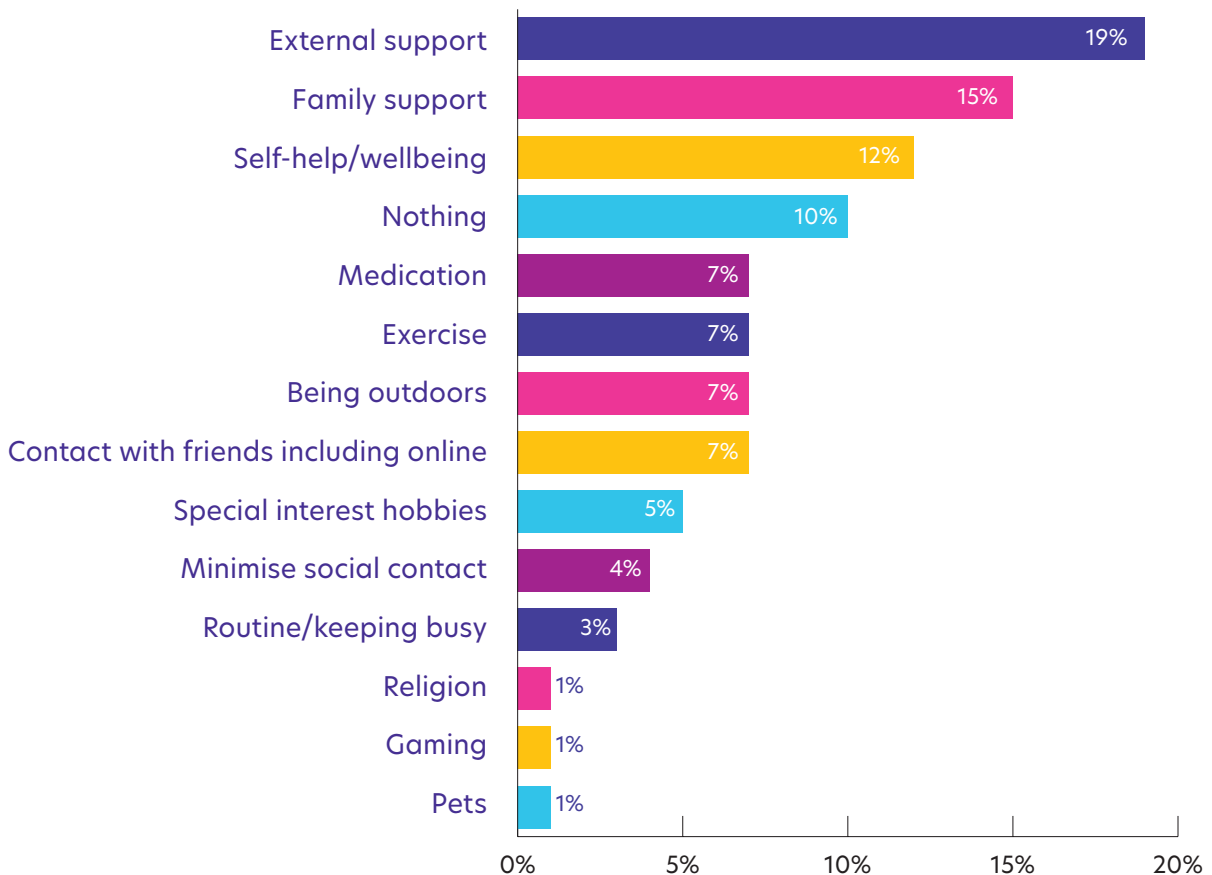


Mental health issues and struggles to access support and treatment can both perpetuate difficulty in attending peer support groups and be alleviated by attending peer support groups (as seen in the top answer for services attended providing useful information and advice). Where appropriate, gathering information on mental health support in the catchment areas of groups would be a helpful pre-launch preparation.

External support, a category that peer groups fall under, is cited as most helpful for 19% of respondents in managing their mental health and shows the value of the services that are provided for people in Wales.

External and family support help most to manage mental health followed by self-help/wellbeing.

What helps you most to manage your mental health?



Barriers to accessing peer support

Advertising and providing up-to-date information about activities in Wales need to be addressed for people to access support. Further understanding of where people look for information about these kinds of services needs to be developed as part of this project through interviews with autistic adults.

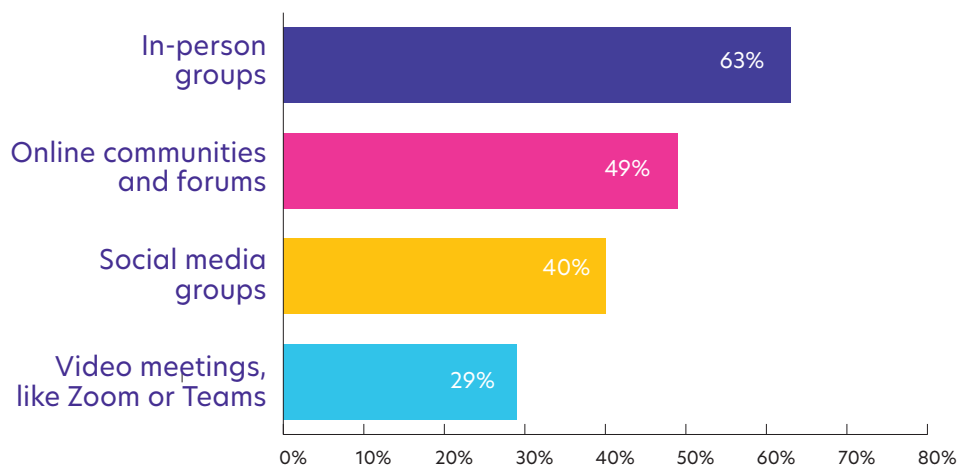
We know that social isolation itself is a factor in preventing people from accessing support, with 81% of people surveyed saying that social isolation 'made it difficult to meet friends'.

Further understanding about what we can do to positively influence confidence when people search for and join groups is essential for ensuring people who want this type of support can participate. One person said they made it to a venue for a peer group but were unsure which door to use so went home without attending. Contact ahead of joining, or providing videos or pictures of venues ahead of time could be enough to make the difference between someone getting the support they need or not.

Preferred peer support opportunities

A clear preference for in-person groups, although one in two said they would like to access online communities and forums.

What types of peer support would you like to access?



It's important that in-person peer support opportunities in Wales are begun/resumed as soon as it is safe to do so as there is a clear preference for this.

However, the fact that half of the respondents would like to access online communities and forums shows us two things:

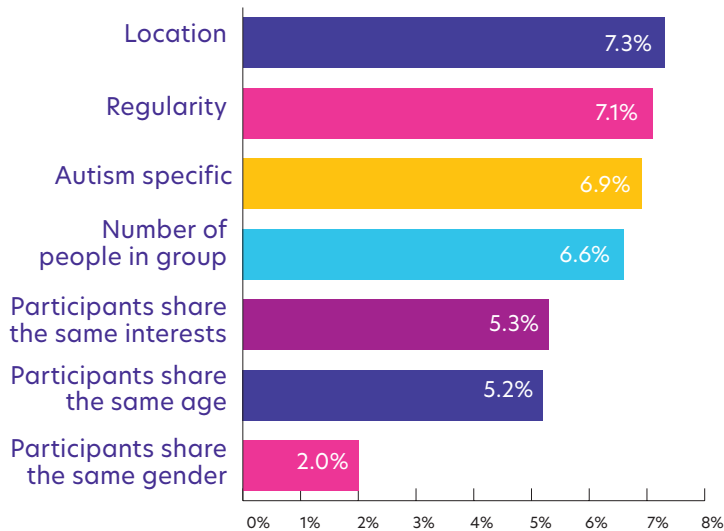
- 1 It's important to continue to offer online peer support opportunities if restrictions to in-person opportunities are in force.
- 2 It's important to maintain these when restrictions are lifted as many would like this option anyway.

Online groups can eliminate geographical barriers to participation which can be a problem due to transport links in Wales and for people with mobility issues. Virtual communities can be more accessible for people with acute sensory sensitivities. Although nine in ten people surveyed have good internet connection, online groups cannot be accessed by those without digital connectivity so it's important that these form part of the peer support offer in Wales rather than being the only offer.

Preferred peer support opportunities

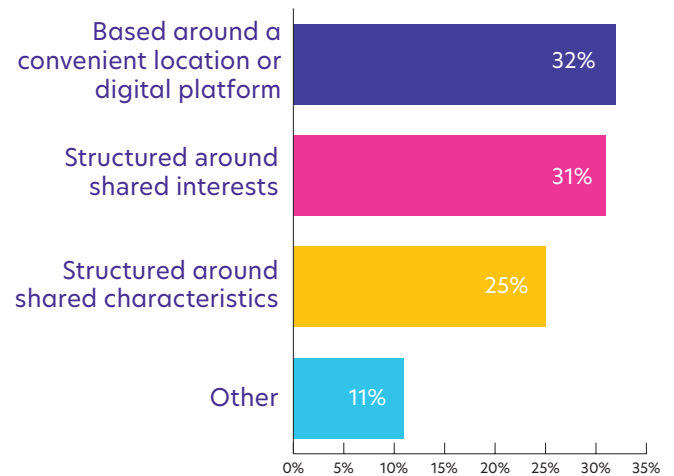
Location, regularity and groups being autism specific are the highest priorities.

What types of peer support would you like to access?

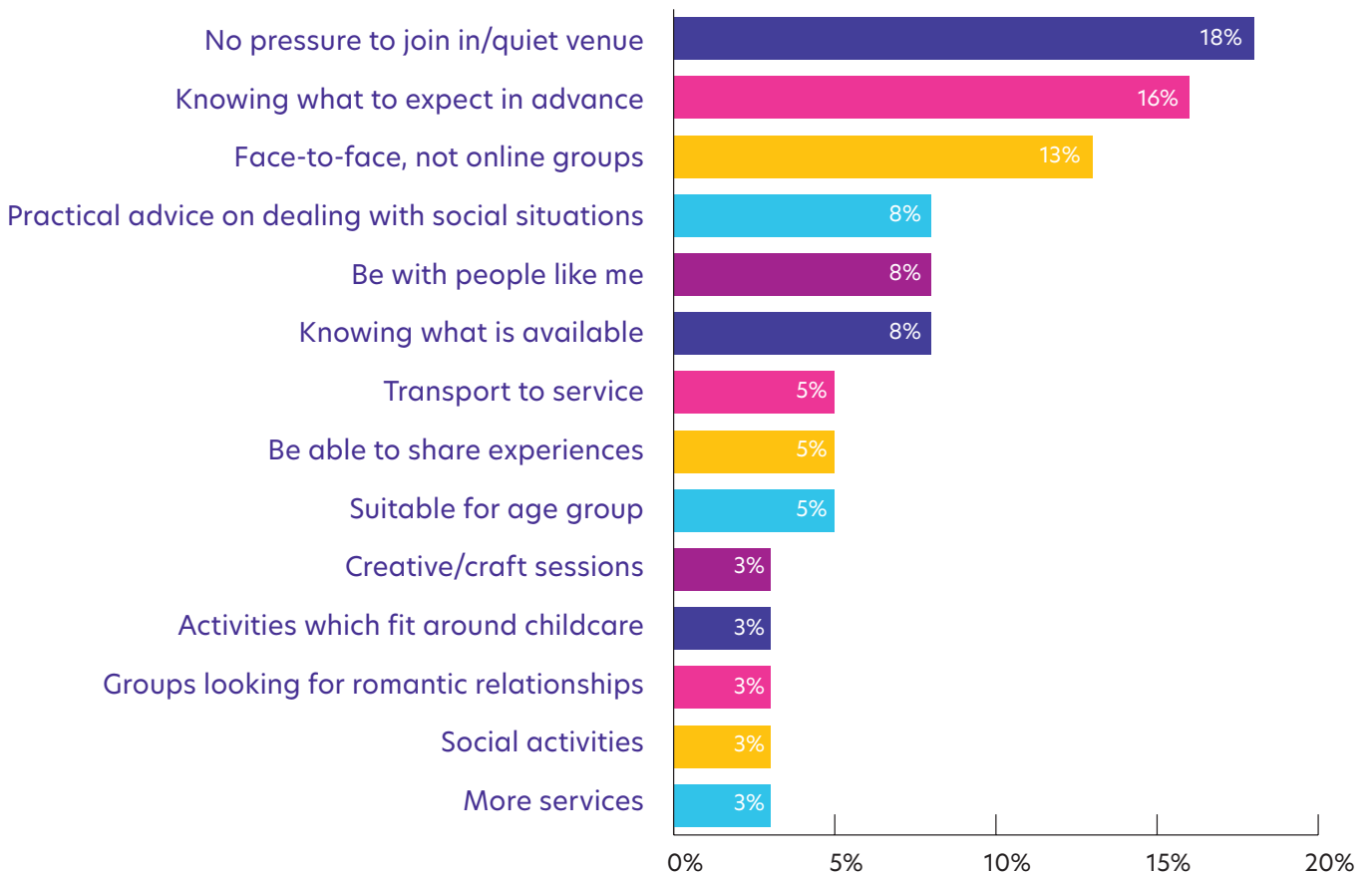


Being based around a convenient location or digital platform and structured around shared interests are selected by a very similar number.

Which of these would be most important for you in terms of how peer support should be organised?



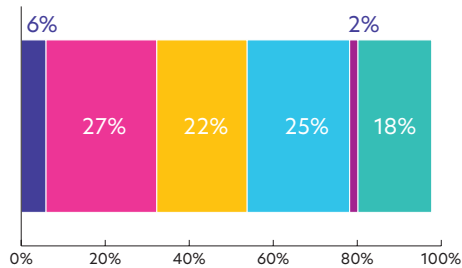
No pressure to join in/quiet venue, knowing what to expect in advance and face-to-face rather than online groups mentioned most in terms of what would make it easy to participate in peer activities.



Preferred peer support opportunities

Predictability of what to expect without pressure to join in with activities is important for reducing anxiety of attendees.

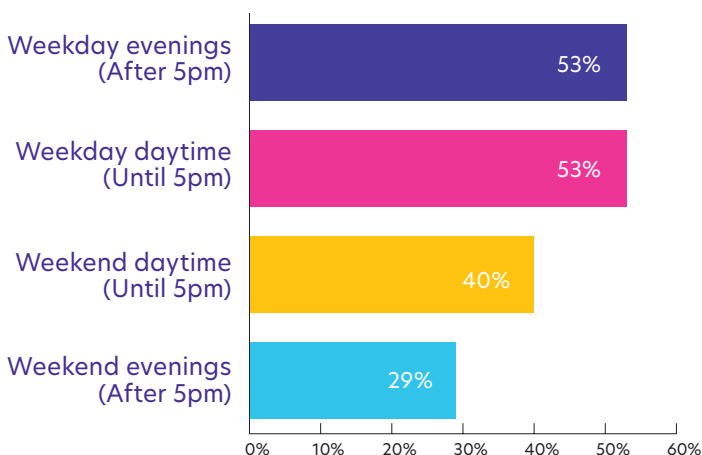
Quite a spread of responses on how frequently meetings should take place, with somewhere from weekly to monthly the response given by the majority.



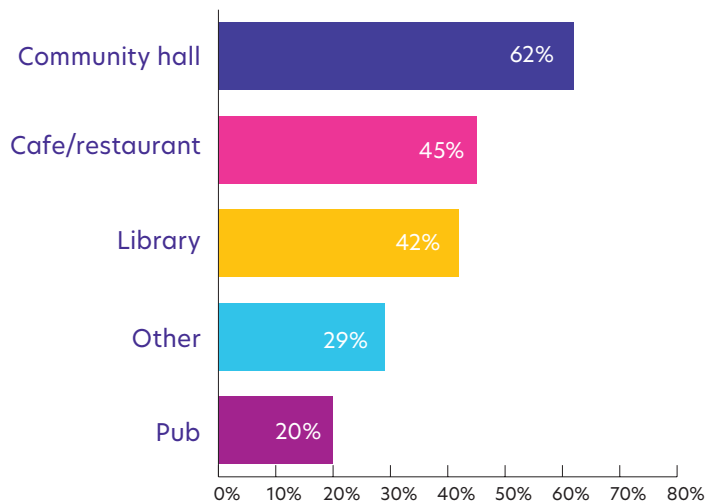
- More than once a week
- Once a week
- Once every two weeks
- Once a month
- Once every two months
- When I need to

The wide range of answers for preferred frequency of peer group opportunities reinforces the earlier result that regularity of activity is more important than how often activities take place. For National Autistic Society Scotland social group members who attend activities online due to coronavirus, being able to dip in and out of groups without pressure is important, and echoed by 18% of those surveyed here.

Weekdays would be preferred by more than one in two, with evenings and daytimes equally popular.

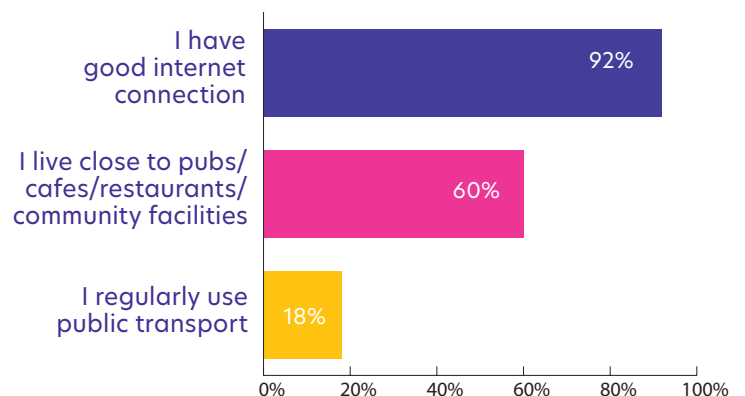


Community hall receives the highest number of mentions on where in-person peer support activities should take place.



It's possible that community halls are favoured because these are quieter venues than public spaces. This correlates with 'quiet venue' being the joint top response for factors that would make it easier for people to attend.

More than nine in ten have a good internet connection and six in ten live close to pubs/cafes/restaurants/community facilities.

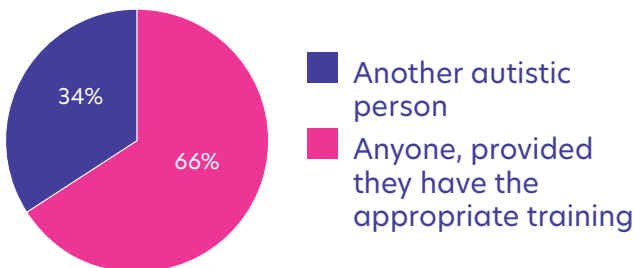


Preferred peer support opportunities

Facebook tops the table in terms of ease of use, closely followed by Zoom.

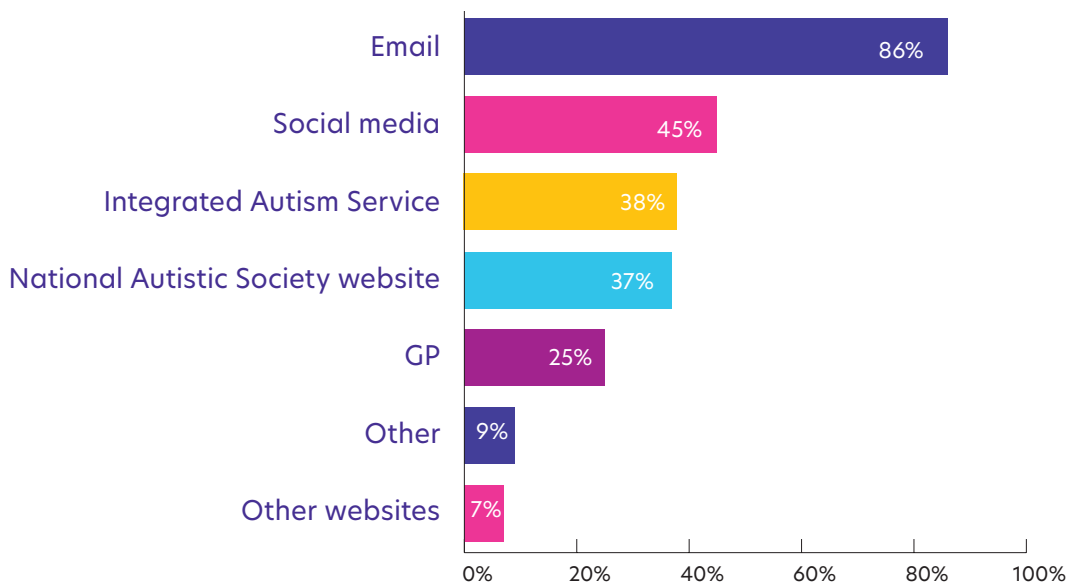
	Yes, it was easy to use	Yes, but it was difficult to use	Yes, but I needed help	No, but I'd be happy to	No and I don't want to
Facebook	55%	4%	3%	14%	32%
Zoom	52%	5%	7%	13%	29%
Skype	41%	9%	7%	13%	33%
Google	37%	5%	5%	32%	24%
Teams	34%	8%	5%	22%	30%

Two in three say anyone can lead peer support activities, provided they have had the appropriate training.



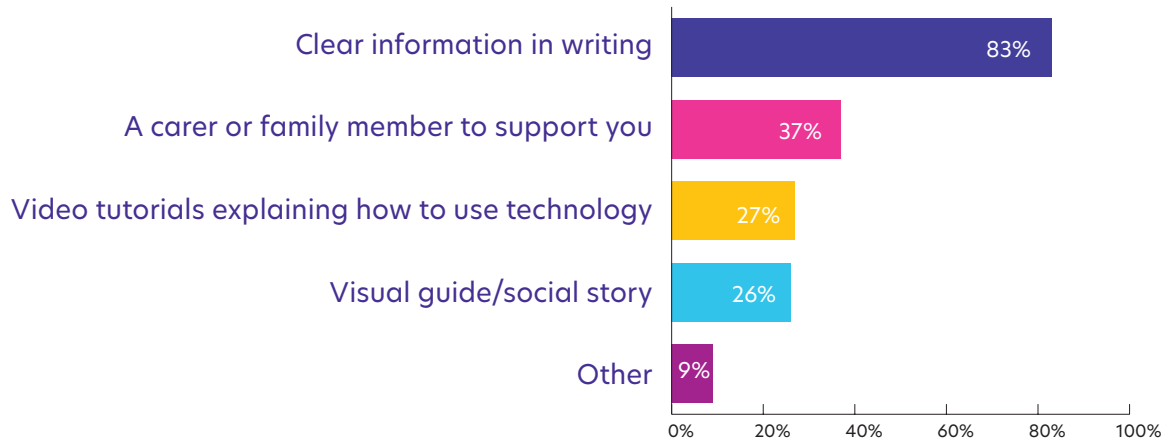
Quality training and understanding of autism for group facilitators is more important to two-thirds of respondents than volunteers being autistic themselves. While offering training and volunteering opportunities for autistic volunteers is a project priority; this widens the potential pool of volunteers we can recruit from, increasing the likelihood and speed of starting peer groups.

Email is by far the most popular response to how people would like to be kept informed about peer support activities.



Preferred peer support opportunities

More than eight in ten say that clear information in writing would help them take part in peer support activities.



Recommendations

Our recommendations are compiled from the majority of responses - these will not be appropriate for everyone. Organisers should get to know the needs of individual attendees when organising peer groups.

Reducing anxiety and building individual confidence is key to empowering someone to attend a group and break the cycle of social isolation. Responses to this survey show that there are key moments that may cause someone to lose confidence in seeking support before they even get to a group; from searching for a group, joining instructions, getting to a venue, arriving at a venue, the venue itself and the group itself. While increasing understanding of autism and helpful adjustments in the general public would be key in building confidence and reducing anxiety overall, there are practical steps that can be taken to positively impact this when organising peer support.

Joining

Clear, written communication is needed. This could be email or closed social media groups.

- A clear explanation of what to expect from the activity/group should be outlined before people attend.
- Visual stories and photographs of the venue and transport links may help people access support.
- For online groups, video tutorials explaining how to use the technology would be helpful to 27% of people.

Follow up

A check in email may be helpful to motivate first time attendees to attend a second time. For some who found it difficult to join what they perceived to be existing groups within an established peer support activity; being able to share their experience with the facilitator could help to alleviate this.

Where appropriate and achievable for recruited volunteers, an ability to signpost to further information on national and local mental health support in Wales may be beneficial.

Recommendations

Environment

Conveniently placed quiet venues or online platforms were preferred by the majority of people surveyed.

Face-to-face support was preferred by 63% of people but half surveyed would like access to online peer support opportunities as well. A mixture of both offerings is needed to reach the most people possible in Wales.

Regularity and predictability of meetings is as important as groups being based on shared interests.

Allow carers and support workers to attend groups and specify this.

Finding peer support activities

Further understanding of where people get information about this type of support is needed to counteract a lack of awareness cited as an access barrier throughout the survey.

It would be helpful if autism groups/volunteers/organisations could check their current listings to make sure information about groups, locations and access is up to date. Removal of any that have disbanded and correcting incorrect information to combat 'search fatigue' in people who have repeatedly been given incorrect information would be helpful. Keeping stakeholders and website updaters informed of changes needs to be part of training for volunteers setting up groups.

Volunteer training

Adequate training of volunteers in understanding autism is more important to autistic people surveyed than volunteers being autistic themselves. Further understanding of what autistic adults would like volunteers to know about autism will be learnt through additional research. Once induction and training procedures are developed and tested as part of this project, they will be shared as best practice of how to take the needs of autistic adults into account.

Changes to peer support groups or activities

Closure of groups unexpectedly can unsettle attendees and cause them to give up on their routine activities altogether. Where possible, if funding/groups/activities are going to cease, giving attendees the most notice possible with explanation and offers of alternatives in the area could dissipate some feelings of confusion and anger in members. Ultimately, sustainability of activities should be the goal when starting groups.

Regularity of activities is key for encouraging participation. It's better to offer less frequent activity that is highly likely to happen than more frequent activities that are harder to sustain and may result in interruptions in availability.

Wider society

Many respondents mentioned the loss of social skills and increase in anxiety instigated by lockdown restrictions changing social and work routines. Increased understanding of autism by colleagues, friends, family and the public is essential for helping autistic people readjust to and build confidence in attending face-to-face activities when restrictions are lifted. Transition workshops or discussion groups may be helpful.

Positive effects on wellbeing were reported by those getting adequate understanding of autism and peer support in the workplace. Peer support does not need to be restricted to leisure and domestic activities to be effective in tackling isolation.



The National Autistic Society is here to transform lives, change attitudes and create a society that works for autistic people.

We transform lives by providing support, information and practical advice for the 700,000 autistic adults and children in the UK, as well as their three million family members and carers. Since 1962, autistic people have turned to us at key moments or challenging times in their lives, be it getting a diagnosis, going to school or finding work. We change attitudes by improving public understanding of autism and the difficulties many autistic people face.

We also work closely with businesses, local authorities and government to help them provide more autism-friendly spaces, deliver better services and improve laws. We have come a long way but it is not good enough. There is still so much to do to increase opportunities, reduce social isolation and build a brighter future for people on the spectrum.

With your help, we can make it happen.



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