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Commissioned by AADD-UK

Adult ADHD Support Groups survey UK

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Executive Summary

Background and context

This survey came as a result of the researcher's collaboration with AADD-UK¹ and his regular attendance to 4 support group which generated questions in relation to the development of adult ADHD support groups; how many groups are there in the UK, what is their membership and what do they do? The numbers of groups making contact with AADD-UK and its website has been growing in the last five years; they are very diverse in their organization, in what they provide and so are the local contexts in which they evolve. But they all have in common that they provide a much needed space for information, help and support for individuals who are or have yet to be diagnosed with ADHD as well as for their relatives and partners.

The aim of this survey was to provide an updated picture of the state of adult ADHD support groups in the UK; we hope this would in turn help individuals, families and professionals in accessing updated information on the AADD-UK website for better local signposting.

Summary of findings

The numbers of adult support groups has increased significantly since 2009, from 9 groups to 23 in 2013 with a peak in 2011 when 6 new groups were formed. We believe that there are a number of interrelated reasons² for this,

- The NICE guidance publication in 2009³ which set the procedures for diagnosing and treating ADHD in children and adults in England and Wales
- The Equality Act 2010⁴ which increased the visibility of adult ADHD in the employment and education area,
- The gap in local services that stimulate groups to meet and advocate⁵
- Changes in national policy towards the funding of local community groups⁶.

¹ This is part of a larger research project that has received ethical approval from the NHS and the University of London. For further information please contact Claude Jousselein directly.

² This is not an exhaustive list, there is likely to be local reasons too for the formation of support groups.

³ (NICE, 2009)

⁴ (HM Government, 2013)

⁵ See NICE quality standards for ADHD 2013 for services that should be provided so that best care is delivered.

<http://guidance.nice.org.uk/QS39/PublicInfo/pdf/English>

We were happily surprised to see that nine groups out of twenty three (39%) indicated that they receive funding, from local, national or European funds and this during a difficult economic climate. Seven of the nine funded groups were formed since 2009.

Three quarters of the groups are run by adults who describe themselves as having ADHD; most of the remaining groups explained that facilitators had family members with ADHD. The personal knowledge that facilitators have of the varied aspects of ADHD plays an important role for providing a nurturing and stimulating space that responds to the needs of individuals. Combined with their responsiveness and availability, this is likely to make support groups the first port of call for individuals seeking information.

The groups provide a wide range of activities, from peer support, a place to be with like-minded people and social events (9 groups), to advocacy and raising awareness of ADHD issues with statutory agencies (12 groups). Twelve groups (52%) provide also more structured activities, some with direct therapeutic applications such as mindfulness, counseling and coaching; others (6 groups) provide structured courses, such as life skills programs, anger management courses or strategies for living with ADHD. One group has developed a training course towards supporting individuals to return and sustain employment.

We believe these findings show a vibrant and growing community of support groups for adult with ADHD that are resourceful and determined to provide a safe place to share experience and information. In particular it is worth noting a possible trend for the more recent groups to seek funding and provide services. This survey highlights some of the common points between groups, of which an inclusive approach that welcome relatives, partners and for some groups also people with Asperger's is a crucial element. But the diversity between groups is also worth noting, each group is unique in its history and style and respond to particular local circumstances.

Limitations of this study: This is the first survey of adult ADHD support groups in the UK and aims to provide a snapshot of their numbers and activities; its findings need to be seen in that light. This report highlights some areas that would require further research;

- A growing number of groups are providing structured courses such as life skills program and training towards employment; more in depth research could help

⁶ (Hurd, Nick, 2011)

understand the training that facilitators require to deliver such course, what are the models used for the courses, what is the impact of these courses and members attending the groups?

- Groups play an important signposting role as well as providing a range of services; further research may highlight how these services are delivered and how they are linked to statutory organisations; what contact is there with local authorities and NHS services if any, what contact is there with local Voluntary Action Organisations?
- a growing number of groups are receiving funding; more research could highlight the good practice that leads to receiving financial support, what are the strategies put in place to liaise with local and/or national commissioners? Are support groups accessing funding available for charities or social enterprises?

Note: The complete survey questionnaire is included later in this document for reference.

Methodology

A list held by AADD-UK was used to make contact with groups by email as well as an internet search for other groups not already listed. This created a list of 37 contacts, to which were added 2 further contacts snowballed from existing groups making a total sample of 39. The contact details were checked using the groups' websites when available. Two groups had no email details available, their Facebook address was used.

A list of 10 questions was created based on conversations with groups and AADD-UK and embedded using an electronic survey; this was tested for functionality and content by sending to one of the group whose facilitator is also a founder of AADD-UK.

The electronic link was then emailed (1/05/13) to the 39 contacts with explanations that the survey was for groups catering for Adults with ADHD and contact details of the researcher for any queries. The email and link was resent on 2 further occasions (4/06/13 and 9/07/13) for the groups that did not respond with encouragement to participate.

23 groups filled in the survey during a period of 4 months. Of the 15 groups that did not fill in the survey:

- 4 responded by email explaining that their group was for children with ADHD and their parents, not for adults who suffered with ADHD
- 1 responded that the group had recently folded due funding withdrawal.

- The remaining 10 did not respond after 4 months.

Caveat: This survey is a representative snapshot of the situation of adult ADHD support groups in the UK in 2013 but cannot be considered an exhaustive list of functioning groups. The groups that did not respond may not have done so for a number of reasons and may be meeting regularly. Due to the rapid increase in numbers of groups in the recent years, it is possible that other groups may have formed that have not made contact with AADD-UK and not been captured in the internet search. It is also worth noting that a number of groups are organizing themselves as Facebook groups, some meeting for social events others not, and it is likely that this survey did not capture all of these groups.

We would encourage facilitators of support groups that have not been contacted for this survey to make direct contact with AADD-UK so that their details be added to the list of resources.

REPORTING:

A number of questions allowed for multiple responses , so percentages or reported numbers may not add up exactly to the number of respondents.

Six questions gave the opportunities to add comments; these have been included in the scale and scope analysis and highlighted as such.

Data analysis was completed using a mix of analytical tools made available on the Survey website, as well as Excel. Qualitative data drawn from extensive research fieldwork provided some further context for analysis.

The scale and scope of adult ADHD support groups

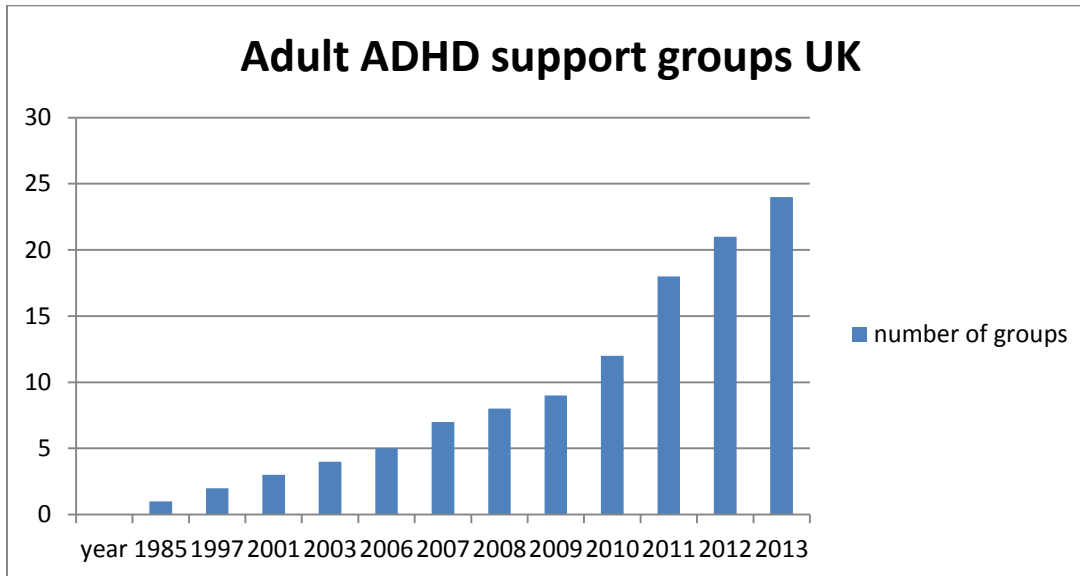
1. How many adult ADHD support groups is there in 2013 and their geographical distribution:

Based on the number of responses, there are 23 groups functioning in 2013 and they are distributed geographically in this way:

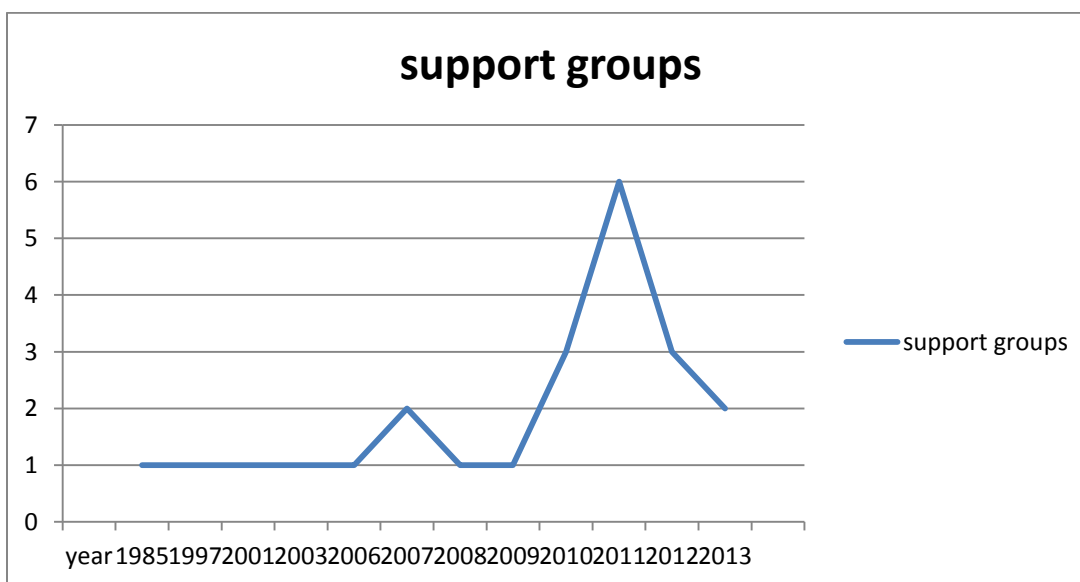


Chelmsford, Brighton, Belfast, Edinburgh/Glasgow/ Aberdeen,
Staffordshire, Dorset, Norwich, Cambridge, Central Lancashire,
Guernsey/Channel Islands, London – Harrow, Southampton, Liverpool,
Nottingham, London - Central, South Lincolnshire, Isle of Wight, Ryde, St
Helens, Oxfordshire, Manchester, Leicester ,Bristol

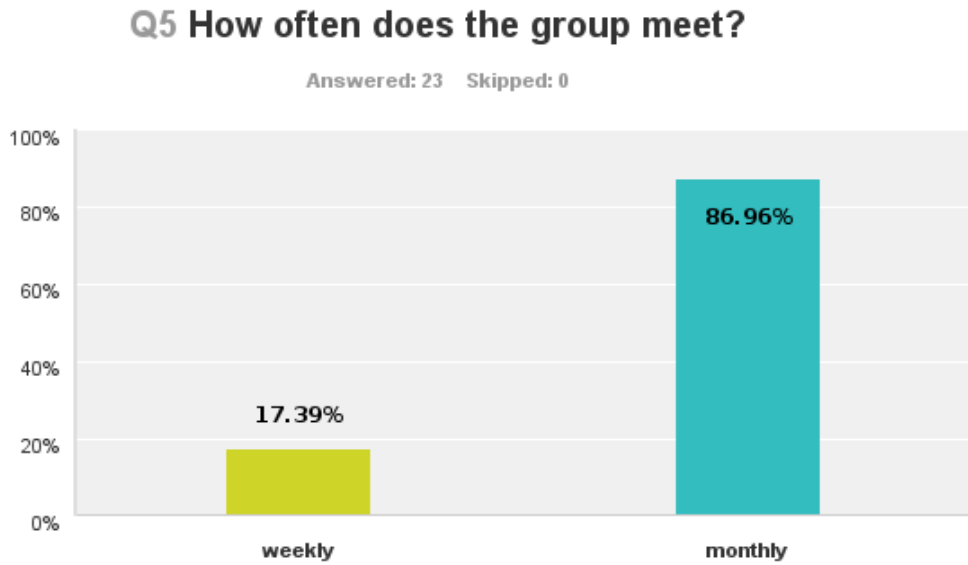
2. When were the groups formed?



The responses suggest a gradual growth of number of groups from 1985 until 2009 when 9 groups were meeting. There was a significant increase between 2009 and 2013 from 9 to 23. The year which saw the greatest of new groups being formed is 2011 as shown below:

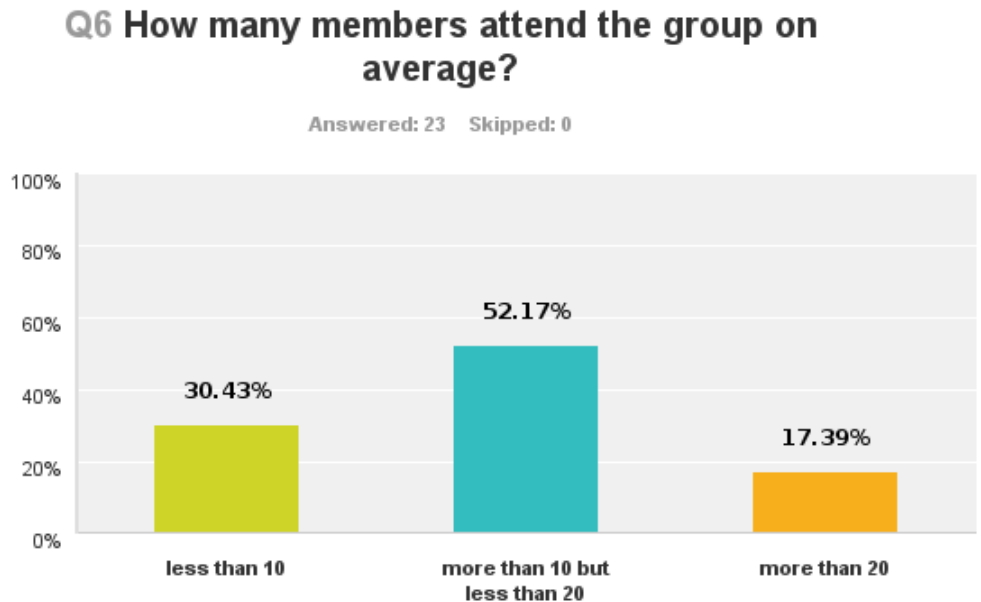


3. How often do the support groups meet?



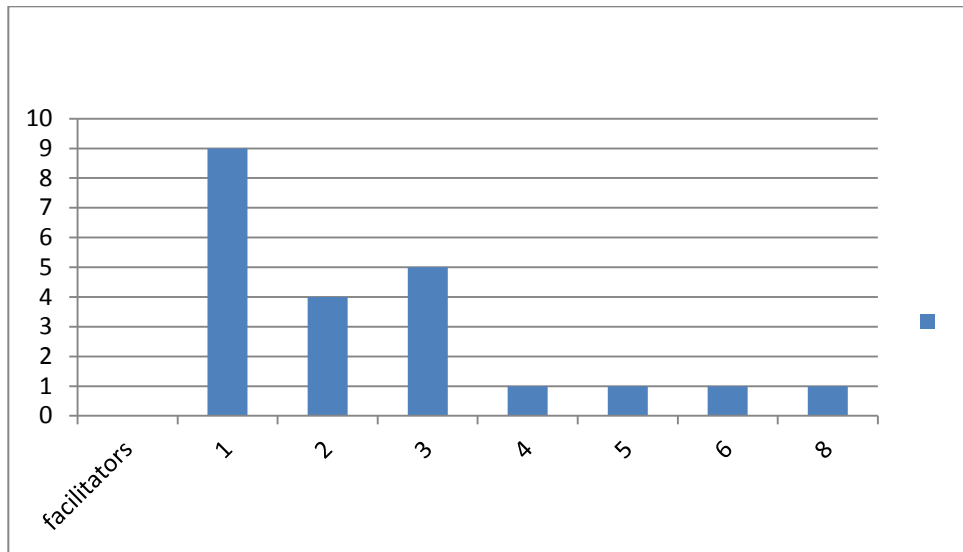
The Responses showed that 20 groups are meeting at least monthly and 4 groups meet weekly. The comments showed a slightly more complex and flexible patterns: Three groups meet fortnightly, 1 group six weekly and one during school holidays. One group also meets more frequently for special events and for organizational purposes i.e. annual board meetings etc.

4. How big is the attendance



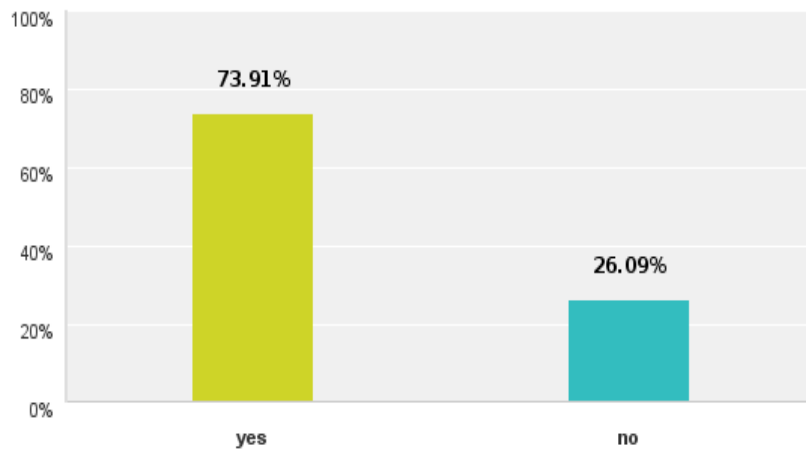
Close to $\frac{3}{4}$ of the groups (17) have 10 members or more attending meetings and 5 groups have on average more than 20 people attending. Comments highlighted that this can vary greatly depending on the time of the year (holidays etc.) and a recent group could not comment yet. Within the 4 groups the researcher attended regularly, the gender mix is about half and half with 48% of women attending; this is in line with research that has shown that whilst more boys are diagnosed with ADHD , the gender difference balance itself out in adulthood. ⁷

5. How many facilitators run the groups and how do they define themselves?



Q4 Do the facilitators identify themselves as having ADHD?

Answered: 23 Skipped: 0



⁷ See (Quinn, Patricia, 2011) for a recent review of gender difference in ADHD

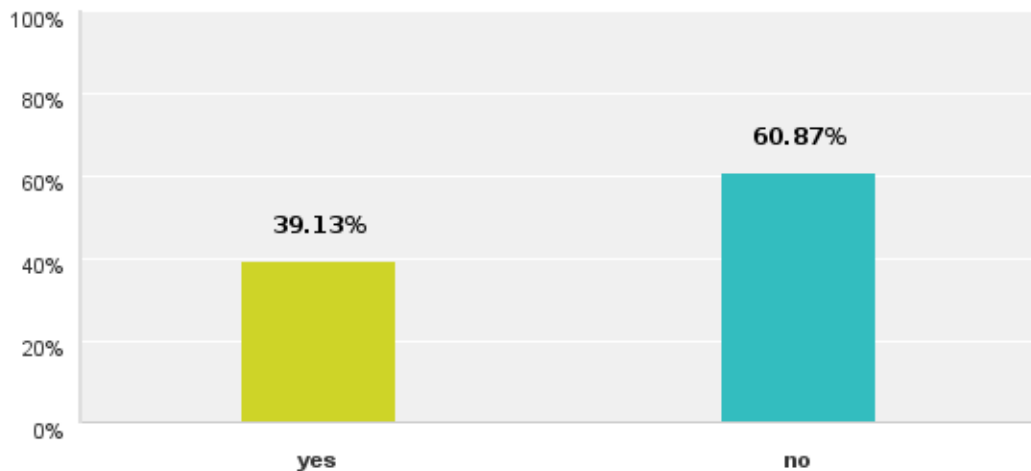
The majority of groups have between 1 and 3 facilitators but four other groups range between four and eight facilitators.

The majority of facilitators identify themselves as having ADHD, 18 groups out of 24; the 6 groups that responded negatively to the question explained that some facilitators had ADHD others didn't but that their family members had ADHD.

6. Funding

Q9 Do you receive any funding or support with resources? (please use the comment box if you wish to give details)

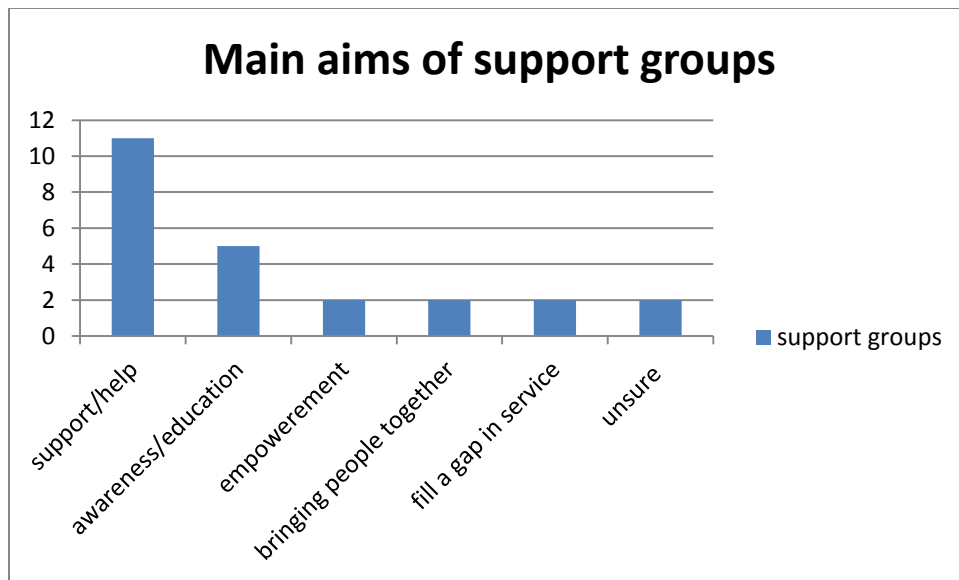
Answered: 23 Skipped: 0



37% of groups have responded positively to this question, that is 9 groups out of 23 receive some funding, and 7 of those 9 groups were formed since 2009. When groups have added comments they have described received grants to deliver courses, some local funding (COOP community funds), some national (DWP) and European too.

7. Aims of groups:

The groups described their aims in various ways which can be summarized in the following categories:



Half of the groups describe their main aim as providing support and help to adult with ADHD and their families:

“Bring similar people together”

“a place where people with ADHD can feel at home”

“Support for each other and to widen understanding for partners, families and friends “

This is clearly an important and valued element of the groups’ activities and is as inclusive as possible, bringing relatives and partners into the group as well as in some situations people with Asperger’s.

A quarter of the groups aim to raise awareness and educate on issues of ADHD.

“To increase awareness and understanding of Adult ADHD”

“Family social events, Information sharing, Raising awareness”

Other groups aim to empower individuals to improve their lives

“To empower people”

“Improve life chances of people with ADHD”

“To help people with ADHD to improve their lives”

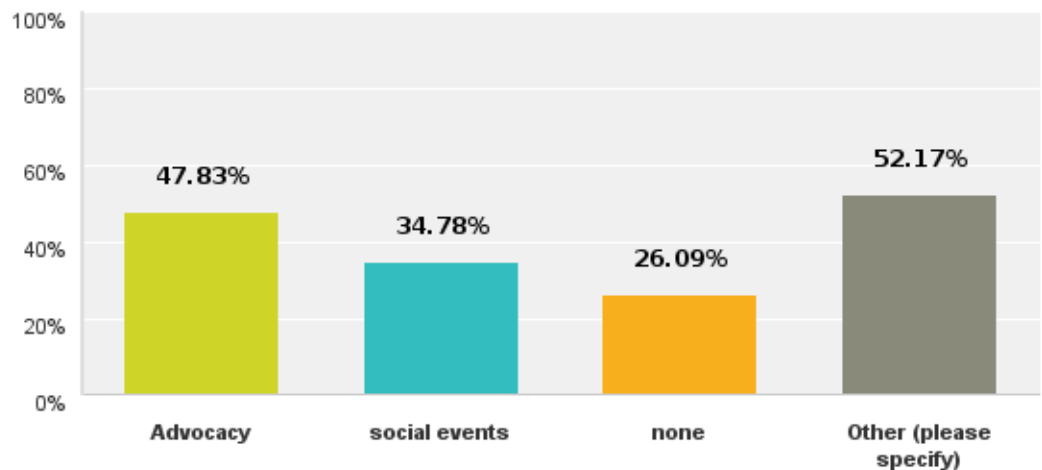
“To empower and help them lead productive and fulfilling lives”

The groups that were unsure about their aims explained that they had only formed recently or that they had too few members to have a clear strategy.

8. What do the groups do?

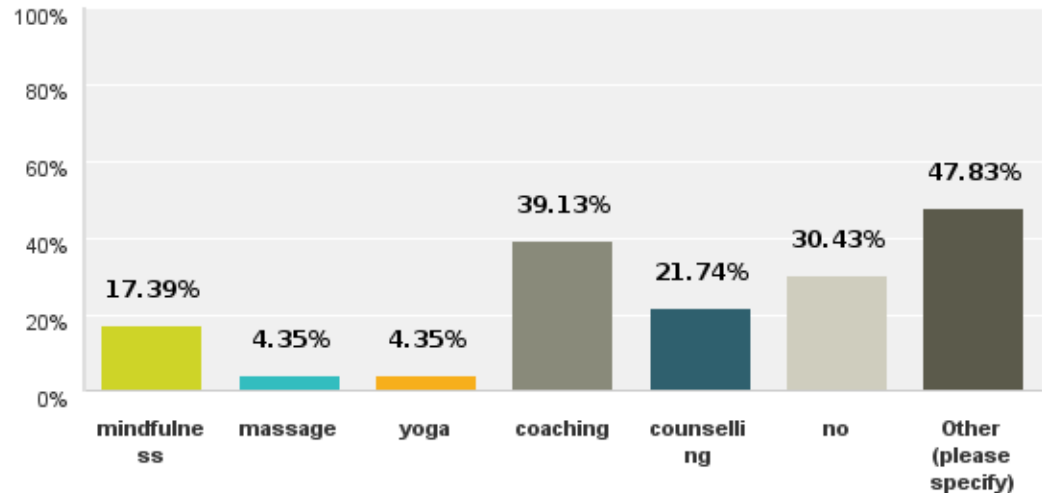
Q7 Do you offer any specific services? (please use the comment box to give details)

Answered: 23 Skipped: 0



Q8 do you organise any therapeutic events? (please use the comment box to give further details)

Answered: 23 Skipped: 0



Two questions were asked in relation to the groups' activities which were based on the activities of 4 groups I attended regularly;

Over 80% of groups provide advocacy and social events, but comments showed a much more varied approach with groups also providing phone and email support, and 6 groups were running courses, such as life skills, anger management, strategies for living with ADHD, training courses including for preparation for job application.

Coaching and counselling were the largest of therapeutic intervention including one group offering a specialist CBT program for adults. Mindfulness is also quite popular.

"We promote self-management by education and psychosocial interventions which help promote a better fit between the individual and society."

"One-to-one Support, Helpline 24/7, Training and Supported Housing for Young People with ADHD"

"Private ADHD Coaching/Psychotherapy"

"1:1 sessions, Coaching, Mindfulness, Anger Management, Empowering project"

"Specialist Coaches, family support, 10 week Life Skills Program, employment support and support with criminal justice system"

SUMMAR OF FINDINGS

1. Significant increase in numbers of support groups, starting from 2009, peaking in 2011 and an increase of membership.

It is worth noting a rapid increase in numbers of groups since 2009, but it is unclear if this trend will continue. Some groups have also folded in the last 2 years, mainly for reason of lack of funding and so the present economical context may make it difficult for some groups to develop or sustain their activities. An increase in membership has also been observed in the three groups the researcher has had contact with since 2009; the average attendance then was of 11 members per meeting, it is now in 2013 an average of 19 members per meeting with a gender mix of 52% male, 48% female.

2. 9 groups out of 23 , just under 40% , receive funding

There are more groups receiving funding than ever before, and the more recent groups seem very good at that. More data is required to understand how funding is accessed, if groups are set up as charities, social enterprise and how sustainable the funding is.

3. Three quarters of the groups are run by adults who describes themselves with ADHD.

Despite the difficulties that ADHD can produce the large majority of groups are run by facilitators that identify themselves as having ADHD, and some do this in partnership with people who do not have ADHD. Out of the 14 new groups that have formed since 2009, 13 of them have been formed by adults identify themselves as having ADHD. More research would help in understanding what their experience bring in the running of a support group.

4. Wide range of activities, including 6 groups providing structured courses.

The groups are adapting to the local context and the needs of their members with ADHD and provide more and more services that are not provided anywhere else. But the main activity the groups have in common is the support and help they give to each other through the sharing of their experience of living with ADHD.

The Survey

Hello,

My name is Claude Jouselin, I am a PhD student at Goldsmiths College University of London, I am conducting a research into the diagnostic process of adult ADHD in collaboration with AADD-UK (patient organisation) who have your contact details on their website.

I have been attending adult ADHD support groups in some cities in the UK , but there are now many more groups that I could possibly visit and it would be very helpful both to my study and to AADD-UK if you could answer this survey by clicking on the link below.

<http://www.surveymonkey.com/s/7DZFCDR>

It won't take more than 5 minutes of your time as there are only 10 questions; please do use the comments boxes to add any further information that you feel will help map the activity of adult ADHD support groups in the UK.

You can also use this email address to contact me directly if you wish to have further information about my study.

My study has received ethical approval from University of London and the NHS Research Ethical Committee; (clearance reference number is (REC)12/LO/0417 and (R&D) 2012/073).

I look forward to hear from you

Best wishes

*1. In which town/city is your group located?

*2. When did you start the group?

*3. How many facilitators run the group?

*4. Do the facilitators identify themselves as having ADHD?

yes

no

Other (please specify)

*5. How often does the group meet?

weekly

monthly

Other (please specify)

*6. How many members attend the group on average?

less than 10

more than 10 but less than 20

more than 20

Other (please specify)

*7. Do you offer any specific services? (please use the comment box to give details)

Advocacy

social events

none

Other (please specify)

*8. do you organise any therapeutic events? (please use the comment box to give further details)

mindfulness

massage

yoga

coaching

counselling

no

Other (please specify)

*9. Do you receive any funding or support with resources? (please use the comment box if you wish to give details)

yes

no

Other (please specify)

*10. what is your main aim for running the support group?

Done

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HM Government. (2013). Equality Act 2010: guidance - Detailed guidance - GOV.UK. Retrieved September 9, 2013, from <https://www.gov.uk/equality-act-2010-guidance>

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