

CLAPA Adult Engagement Roadshow 2018

Our Findings

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BACKGROUND

The 2018 Adult Engagement Roadshow was part of the Cleft Lip & Palate Association's (CLAPA) Adult Services Project. The roadshow was a series of 12 focus groups in different centres across the United Kingdom. These focus groups all consisted of the same structure, with variations in the delivery of the programme to best accommodate the audience that was present. With the exception of one event which was held for 4 hours on a Saturday afternoon, all events were 3 hours in duration and held in the evening. There was no compensation to attendees, nor were their travel expenses reimbursed. Although food was provided, it did not appear to be a motivating factor that drove attendance. Naturally the groups were set up in a way to encourage the development of new networks and friendships, as well as to provide an opportunity to share stories and reduce feelings of isolation. The focus groups were an opportunity for CLAPA to inform the adult cleft community about the Adult Services Project, initiatives that they may wish to be involved with and to collect data on what would be helpful as CLAPA moves to the next phase in developing their services for adults. It was free for people to attend. It was important to CLAPA to canvas a wide sample of adults from across the UK to better understand any regional differences so that these can be considered when developing future initiatives.

EVENT LOGISTICS

Events were held in Birmingham, London, Cambridge, Salisbury, Newcastle, Liverpool, Bradford, Bristol, Swansea, Belfast, Glasgow and Edinburgh. These locations were strategically chosen to be areas that are relatively densely populated, have an NHS cleft team nearby, and also are located in an area which is easy for people to travel to from neighbouring areas.

Initially additional events were planned for Manchester, Nottingham and Aberdeen. These were cancelled in favour of having increased numbers at neighbouring events. These locations are not precluded from future events.

Events were advertised in a variety of means including posters displayed by cleft teams, e-newsletters, organic and sponsored Facebook posts, the CLAPA website, word of mouth, personalised invitation and organic Twitter posts. Attendees were required to sign up in advance of the event using Eventbrite to register their place and advise of any dietary or access requirements.

Events were facilitated in conjunction with the relevant Regional Coordinator/Engagement Officer and the Adult Services Coordinator. They were often supported by a member of the cleft team and/or an additional member of CLAPA staff/volunteer.

ATTENDANCE FIGURES

There was a degree of non-attendance at the events. Many visitors commented on how they had really pushed themselves to attend, and had considered driving on without coming into the venue. It is very possible that some attendees did exactly that – it is important to recognise that face to face events such as this may be too much of a push for those with extreme anxiety, and additional interventions would be required to reach some groups of people. More women than men attended the roadshow, and there was a good age distribution with the youngest attendees being in their late teens and oldest in their 70s.

Attendance by location

Birmingham	Registered: 8	Attended: 6	Attendance rate: 75 %
London	Registered: 19	Attended: 15	Attendance rate: 79 %

Cambridge	Registered: 14	Attended: 8	Attendance rate: 57 %
Salisbury	Registered: 3	Attended: 1	Attendance rate: 33 %
Newcastle	Registered: 4	Attended: 4	Attendance rate: 100 %
Liverpool	Registered: 18	Attended: 12	Attendance rate: 67 %
Bradford	Registered: 2	Attended: 1	Attendance rate: 50 %
Bristol	Registered: 6	Attended: 4	Attendance rate: 67 %
<i>England Total</i>	<i>Registered: 74</i>	<i>Attended: 51</i>	<i>Attendance rate: 69 %</i>
Glasgow	Registered: 11	Attended: 9	Attendance rate: 82 %
Edinburgh	Registered: 11	Attended: 7	Attendance rate: 64 %
<i>Scotland Total</i>	<i>Registered: 22</i>	<i>Attended: 16</i>	<i>Attendance rate: 73 %</i>
Swansea	Registered: 12	Attended: 5	Attendance rate: 42 %
Belfast	Registered: 5	Attended: 2	Attendance rate: 40 %
UK	Total Registered: 113	Attended: 74	Attendance rate: 65%

Number of people for whom the roadshow was their first CLAPA event: 41 (55%)

ISSUES ARISING

GETTING A REFERRAL TO THE CLEFT TEAM AS AN ADULT

KEY FINDINGS:

- Not knowing the parameters of what they are entitled to as an adult
- Not knowing that they are entitled to treatment as an adult.
- Moving away and not knowing about cleft services in their new area.
- GPs not making the connection that some medical concerns may be cleft related.
- GPs not stating when they don't know what to do and instead bluffing their way through the appointment.
- *England* – Significant difficulties seeking a referral back into the cleft team. People reported a generally positive experience once they were being seen by the cleft team, but often struggled for two years or more to be referred to the correct place. Issues included: lack of GP and/or dentist knowledge about the cleft services in the region, referrals to incorrect locations, referrals being declined by referral panels. These issues were widespread throughout England and were the cause of a great deal of angst for many adults.
- *Scotland* – Changes to the cleft system at the start of this year, meant that some people had fallen through the gaps as they were active in the cleft care system during the transition. The cleft team are aware of this and are working on a case by case basis to resolve. The team are confident once the third surgeon is on board in November, the service will be able to run at capacity resulting in a smoother experience. The ability to self-refer in Scotland was viewed favourably by those in Scotland and England, although there is still a lack of GP knowledge to assist people in making referrals should they present via the GP.
- *Wales* – The ability to self-refer to the Welsh system was seen as a boon. Some of the older adults commented that they did not realise they were still eligible for care and treatment.
- *Northern Ireland* – Issues of this nature were not raised in Northern Ireland, however it is likely that an ability to self-refer would be of benefit.

RECOMMENDATIONS:

1. Development of a “Leavers Pack” for the point at which someone is discharged or no longer routinely seen by the cleft team. Such a pack would contain information on all UK cleft teams (since a lot of people move in adulthood and may wish to see a different cleft team) – including how to make a referral (self or GP/dentist), as well as information on eligibility to access services, and a letter which can be taken to a GP which explains how and where to send a referral (if required). It would also contain information on the types of things that adults may wish to seek further treatment for in the future as well as the ability to seek a second opinion from a different cleft team. The pack would be a physical pack that can be taken away and kept somewhere safe, but also an up to date electronic version would be housed on the CLAPA website. Some teams are already issuing something similar on a local level – the goal of this would be to have a consistent UK wide pack.
2. Advocate for acceptance of self-referrals in England and Northern Ireland. This has been introduced in Wales and Scotland and is reported to be working well and has drastically cut the wait time and frustration for people in Scotland who had to go via a GP or dentist. Despite the success in Scotland and Wales, this remains a significant barrier in England (and likely Northern Ireland) to accessing services. CLAPA should request the NHS consider adopting same approach in England and the HSCNI consider this in Northern Ireland.
3. Provide information to GPs and Dentists regarding making the right referral first time. Even with a successful self-referral system in place, it is important that GPs and dentists are well-

versed in making referrals for cleft related needs. A number of practicing GPs attended the roadshows who may be able to assist in disseminating information to GPs. CLAPA would benefit the cleft community by doing some work behind the scenes to provide information to GPs and dentists so that people are not reliant on knowing of CLAPA to be able to access health services in adulthood.

CLEFT TEAM APPOINTMENTS

KEY FINDINGS:

- Initial appointment – overwhelming to see so many professionals, not being prepared for it.
- Being made to see psychology prior to a surgical consultation.
- Not having access to psychology support in some areas.
- Treatment being declined by the cleft team.
- Some adults reported that they would like the opportunity to change cleft teams or to seek a second opinion.
- Cleft team dentists not attending to the health of the bottom teeth.
- Some adults mentioned that telephone consults for quick and/or screening appointments could be useful.
- Transition from paediatric to adult services was reported to either be seamless, or problematic. A seamless approach across the UK would be beneficial.

RECOMMENDATIONS

1. Better information on the initial letter confirming the appointment that explains the time scale to allow and who you will be seen by during the appointment. This letter should be generated by the NHS cleft team concerned and tailored to their particular service. Include an explanation of the rationale for seeing psychology as part of a surgical consultation.
2. NHS cleft teams to provide clear written information with the rationale in instances where treatment is declined to better enable the patient to process this information including any right of appeal.
3. CLAPA and others to advocate for psychology support across all UK cleft teams.
4. NHS cleft teams to consider telephone consults for certain things as an alternative to face to face visits for uncomplicated quick consults.

PERSISTENT MEDICAL & DENTAL ISSUES

KEY FINDINGS:

- A few adults reported chronic hip pain at the site where their bone graft was taken in childhood.
- Many adults across the UK reported that they felt they were considerably more susceptible and regularly ill with colds and ear infections.
- A seemingly high prevalence of hearing loss relative to the general population.
- People are unsure what they should just “learn to live with” versus seeking treatment for.
- Grey areas around what may be considered “cosmetic treatment” and stigmas around this.
- People often feel unsure of the pros and cons of different treatments and interventions.
- There was a wide variety of age groups at the roadshow, and people often felt ill-informed of some of the changes in techniques and treatment pathways over the years, as well as having an idea of what future interventions may look like.
- A feeling that alternatives are not presented for particular treatments, and that decisions may be made by health professionals based on financial interests.

- A great deal of fear and anxiety surrounding going to the dentist.
- Recognising that they have had a significant amount of time out of school and that this has likely impacted negatively on their education and/or social development.
- Issues with dentists not referring to cleft team, instead referring to private practices (sometimes their own) and charging significant amounts of money for work that would've been free through the cleft team.
- Many adults felt that they were asked to make difficult medical decisions at any early age and didn't necessarily have the skills and experience to make these decisions. Some people discussed a 'fear of the unknown' and being asked to place faith in the expertise of the health professionals.
- Many adults report a fear of losing their teeth as they get older and wondering what happens when that happens – what options do they have?
- A significant number of adults reported having a persistent fistula that they are unsure as to whether to get fixed, or if there are other non-surgical options (e.g. obturator). People report also avoiding certain foods as it is painful or problematic for fistulae, teeth and jaws.
- Some people mentioned anxiety regarding anaesthetic induction.

RECOMMENDATIONS

1. Professional advice at the November 2018 Adults Conference about medical issues that can occur in adulthood – having this video also available online.
2. Professional advice relating to the progression of medical issues related to cleft in adulthood- i.e. can fistulas become worse? Does dentition get worse? Do treatment options change over time?
3. Developing a register of dentists who are confident and knowledgeable in dealing with cleft and are effective at alleviating anxiety and fear.
4. Online and/or face-to-face sessions with a Q&A for people contemplating jaw surgery, and another one for rhinoplasty.
5. Online information about the anaesthetic induction process.

MENTAL AND EMOTIONAL WELLBEING

KEY FINDINGS:

- Mental wellbeing was routinely discussed on the roadshow with most attendees recognising that their mental health had been impacted at some point.
- A number of people recognised that support to manage expectations would be beneficial – e.g. the limitations of surgery, the possibility that surgery could make their situation worse etc.
- A lot of older adults felt that they had never had an opportunity to talk to someone impartial about their experience, and that they did not wish to burden their parents.
- A higher than proportionate amount of attendees to the roadshow did have unresolved mental health issues which did lead to escalation and safeguarding incidents (in some cases). Some people reported as they got older that their coping strategies became less effective.
- People did not feel they always knew where to turn to for support.

RECOMMENDATIONS

1. Further promote and recruit for the peer support service.
2. Psychology input at the 2018 conference regarding mental and emotional well-being.
3. Curate some coping strategies for people to cope with bad days/bad news.

BULLYING/DISCRIMINATION

KEY FINDINGS:

- Most adults, although not all, reported that instances of bullying declined in adulthood. Many however were still left with emotional scars from the bullying that had occurred in earlier years. People generally feel that a greater emphasis on reducing bullying when they were younger would have helped them – education in schools was felt to be important.
- Secondary school was reported to be the hardest, although some recounted severe bullying at primary school also. It was felt that teachers don't always help the situation.
- Cyberbullying – some of the younger attendees reported relentless online bullying, particularly from female perpetrators.
- People found by the time they reached working life, most people are respected for who they are and what they can do rather than their appearance. That being said, there was a perception that they have to work that little bit harder than their “unblemished” counterparts to be treated equally.
- Those who lived in small towns or villages reported a greater intensity of bullying compared with those who lived in larger cities.
- Some people in public facing jobs felt that they were discriminated against by members of the public and some had received inappropriate comments relating to their appearance from members of the public.

RECOMMENDATIONS

1. Continuation and expansion of CLAPA and Changing Faces' programmes in schools targeting discrimination and bullying.
2. Development of a confidence course for adults who were born with a cleft to improve their confidence and self-esteem. It would be envisaged that this course would be facilitated by trained professionals and delivered over a period of time (e.g. one session per week for eight weeks). The confidence course would be broadly focussed enabling adults to work towards improved confidence in various situations – e.g. standing up to bullying/discrimination, making friends, performing in the workplace and establishing romantic relationships.

DATING/RELATIONSHIPS

KEY FINDINGS:

- Entering and remaining in abusive relationships as they were looking for acceptance, forgiving behaviours feeling that “I couldn't do any better”.
- Promiscuity – using sex as a social currency, sleeping with people and “being easy” was a way to be accepted.
- Not asking people on dates due to a fear of rejection. Assuming rejection is because of cleft.
- Being unsure at what point to disclose that they have a cleft, particularly with online dating – do they put it in their profile? Tell them in chat? Tell them on the first date? Not tell them?
- If cleft palate only and speech is good, it's easy to put off discussing the subject and then becomes too awkward to raise.
- A perception that prospective partners are interested in the perfect body rather than personality and can be very judgmental.
- A feeling of missing out – particularly in the teenage years when everyone else was dating.

RECOMMENDATIONS

1. Expert presentation on the additional challenges of dating/intimacy when born with a cleft at the November 2018 conference.
2. Development of a confidence course as described above.
3. Social events that provide opportunities to interact with other people and reduce some of the anxiety and barriers with talking to other people (these are not speed-dating or singles events, rather these would be meetup groups designed to bolster confidence).
4. Telling the stories of those who are in fulfilled relationships with someone who was born with a cleft – explaining how the cleft is not the primary thing that defines their partner.

DECISIONS TO HAVE CHILDREN

KEY FINDINGS:

- Wanting to know the likelihood of having a child with a cleft.
- Receiving genetic counselling, but then being unsure as to how to interpret that information – e.g. I was given a one in five chance, what decisions do I make now?
- Some adults reported that they would not be concerned if their child had a cleft, as they felt that they would be in a good position to raise that child having known what the journey was like, whilst others felt that a cleft is not something they would wish upon their enemies, let alone their own children. Some adults had chosen not to have children out of concern that they would be born with a cleft.
- Unique set of circumstances where “the whole world comes crashing down” when you are told that your child is going to be born with a cleft – you are given lots of information about cleft (which you already know), but no support to process the unique feelings that come with being an adult with a cleft about to become a parent of a child with a cleft – greater support is needed – a different intervention strategy that provides tailored support.
- A number of people would consider terminating a pregnancy if their child was born with a cleft.
- Feelings of guilt and responsibility when their child is born with a cleft. Some adults had even felt that some family members had assigned blame to them.
- It raised the issue that people did not know what had caused their cleft and they had a desire to know.
- People were keen to know about the environmental factors associated with cleft as they felt these were things that they may be able to mitigate better than the genetic factors.
- People felt they hadn’t seen many stories of people being born with a cleft and having had a child with a cleft.
- Feelings of disappointment at not having the perfect child that was expected was reported.
- A lot of adults with a cleft have a lot of anxiety around having a child with a cleft – it is felt that this isn’t generally recognised and therefore the first 20 weeks of the pregnancy are very stressful.

RECOMMENDATIONS

1. Expert presentation on genetic counselling and the genetic aspects of cleft at the Adults Conference in November 2018.
2. Information on CLAPA website regarding decision making regarding having children.
3. Provide information on syndromes.
4. Recommend NHS establish a protocol that provides a referral to psychology on the cleft team when a diagnosis of cleft where one of the parents also has a cleft.
5. Recommend NHS have psychology support following genetic counselling to help people determine what to do with the results.

6. Stories on CLAPA's website of adults with a cleft having a child with a cleft that specifically discuss this experience.
7. Balanced information on termination vs continuing a pregnancy. Some people felt that they would feel unwelcome in the cleft community if they terminated a pregnancy when they had a cleft themselves.
8. CLAPA to present more honest information about the bumpy emotional journey with cleft to reduce the element of surprise when times are difficult.
9. Information on environmental factors which could reduce the risk of having a child born with a cleft.
10. Recommend NHS ensure radiologist and midwife understanding of the unique position that people find themselves in when having a child diagnosed with a health condition that they too were born with.

SOCIAL ANXIETY

KEY FINDINGS:

- A reasonable proportion of attendees reported that they found meeting new people to be difficult. A number of people self-reported that they were shy, and there was a perception that others are judgemental. Some mentioned using alcohol to assist in social situations.
- A number of people reported that their difficulties with speech make some situations such as making telephone calls quite difficult.
- A number of people likely did not attend the roadshow due to social anxiety.

RECOMMENDATIONS

1. Advocate for psychology support for adults in teams where this is currently not available – e.g. Northern Ireland, Nottingham
2. Development of a confidence course as described under bullying/discrimination above.
3. Group sessions with other adults who were born with a cleft to encourage social interaction in a safer environment – hopefully the confidence gained would generalise to other settings.

MEDIA

KEY FINDINGS:

- Many people felt that the media had played a negative role in their perceptions of themselves. They felt that they were consistently comparing themselves to an artificial standard depicted in film and television.
- Many people also felt that the media did not cast “people like them”, or that people who looked different were often portrayed as weird or outcasts. It was felt that the media could do a lot more to improve viewers self-esteem.

CONCERNS WITH CLAPA

KEY FINDINGS:

- A reasonable number of adults felt that the messaging used by CLAPA could be improved upon. Many felt that it painted a picture that was overly positive and hence they did not always feel that their feelings were validated.
- A number of people with cleft palate only felt a sense of being an “imposter” at CLAPA as they did not have a visible difference, and a lot of CLAPA’s work is focussed around the appearance aspect of cleft.
- Regional work – some people felt that CLAPA had not given regions that same attention and that some services were only available in London or other big centres. There were also some concerns about branch and funding structure which predates, and is outside the scope of, this project.
- The Welsh language is not utilised as part of our services in Wales. The adults at the roadshow are keen to support this happening.

RECOMMENDATIONS

1. CLAPA to investigate messaging and how a more balanced message can be transmitted where it relates to adult services.
2. CLAPA to provide more information specific to cleft palate only to ensure that this group feels equally involved and included in the cleft community.
3. Continuation of the Adult Services Project hybrid approach where services are delivered in a combination of UK-wide and more regional initiatives.
4. Use of the Welsh language in literature, online and at events wherever possible (in Wales).
5. 2019 Adults Conference to be held in Scotland.

ADDITIONAL WORKSHOPS/INTERVENTIONS PEOPLE WOULD LIKE TO SEE FROM CLAPA

- Online panels/forums
- Q&A panel for people contemplating jaw surgery/rhinoplasty

FEEDBACK FROM ATTENDEES ON THEIR CLEFT EXPERIENCES

Some quotes have been paraphrased for clarity.

WHAT DO YOU FEEL ARE THE MOST POSITIVE THINGS THAT HAVE COME OUT OF THE FACT THAT YOU WERE BORN WITH A CLEFT?

- | | |
|---|--|
| • Resilience (stated >50 % of the time) | • High pain tolerance |
| • Empathy/Compassion/Kindness being able to relate to others (stated >60 % of the time) | • Increased confidence |
| • Being less judgmental (stated >30 % of the time) | • A resolve to do more and work hard |
| • Led to a fulfilling career (stated >10 % of the time) | • Awareness of cleft |
| • Nothing (stated >10 % of the time) | • Determination (stated >30 % of the time) |
| | • Strength |
| | • Perspective – not sweating the small stuff |

- CLAPA groups and residentials
- Met friends who saw beyond the cleft
- Being witty
- “Made me who I am”
- Spent extra time with parents going to hospital visits etc.

WHAT HAS BEEN YOUR MOST SIGNIFICANT LEARNING FROM YOUR CLEFT EXPERIENCE?

- A lack of awareness in society of cleft
- The NHS is a wonderful thing
- Not all disabilities are visible/obvious
- People are judgmental and the world is obsessed with looks
- Learning about cleft
- “That the barriers you put up are often not really cleft related.”
- “You have to do things for you and not others.”
- “Appreciating that inside I’m just the same as everybody else and a cleft isn’t something to be ashamed of.”
- “Looks aren’t everything.”
- “Develop resilience to bullies.”
- “People’s perceptions aren’t always what you think.”
- “Not everybody is going to understand it.”
- “Not everyone respects difference.”
- “I’ve been born with this for a reason, so I need to do something with it. My cleft has affected me in ways other people are not affected and that has made me who I am.”
- “To overcome fear.”
- “Don’t judge others – we all have problems.”
- “People may not understand, but it’s not their fault. Own it, don’t ignore it. I’m not a victim.”
- “Tooth care is vitally important.”
- “There’s a lot more people with cleft than I ever realised.”
- Persistence in dealing with emotional matters etc.
- “People are thoughtless.”
- “Everyone’s different, so nobody’s different.”
- Others don’t see me any differently.
- “That you don’t have to be what people think you are, and that there’s always a light at the end of the tunnel. It’s ok to be different.”
- “Keep trying to get help.”

WHAT HAVE BEEN THE HARDEST THINGS THAT HAVE ARISEN FROM HAVING BEEN BORN WITH A CLEFT?

- Childhood bullying (appeared regularly)
- Absence from school (appeared regularly)
- Shyness / lack of confidence (appeared regularly)
- Having to go through surgery
- Making friends
- Being severely deaf
- Chronic pain
- Being judged by people / reactions from others
- Speech Difficulties
- Worry about the impact of surgery
- Lack of female role models who look like me in the media
- Acceptance
- Understanding why I was born with a cleft
- Operations taking up time in my life
- Abandonment
- Assumptions about my intellect and education which was problematic for employment and promotion

- Mental health and my relationship with cleft
- Always knowing you're different
- The possibility of passing cleft onto my children
- Thinking no one would ever love me and want me
- Effect of my cleft on my children
- Work discrimination
- "Being called retarded because of how my voice sounds."
- Accepting how I look
- Not knowing how this will end – what will the outcome be?
- Low self-esteem
- Many, many appointments (appeared regularly)
- Breathing/sinus problems

IF YOU COULD GIVE ONE PIECE OF ADVICE TO YOUR 10 YEAR OLD SELF, WHAT WOULD IT BE?

- "You are in a small pond. You won't always be. There's a whole world out there. Look for the good people and stick with them."
- "Everybody is different, take no notice of teasing."
- "Stay true to yourself."
- "Try and find coping mechanisms for bullying, rather than just having to bear the brunt and internalise the stress."
- "Let it go, stay strong."
- "Don't worry."
- "Don't stress about it."
- "You are beautiful, things will get better."
- "Don't be shy! Don't let it stop you doing what you want to do!"
- "You do look different, and that's okay."
- "It's about to get really bad but then it's so much better and you'll deal with all of it (most of the time) ☺"
- "Keep smiling – every smile tells a story."
- "There is someone for you out there."
- "Don't worry what anyone thinks."
- "Talk!"
- "Relax – don't feel lucky to have the affection of the undesirable. Learn what constitutes a good relationship. Don't rush into relationships."
- "Be determined and follow your dreams – school is not "real life" it's better when you leave. You'll be valued for you, not your cleft."
- "You will go months/years on end when you don't think about it and don't see it in the mirror anymore!"
- "You have your whole life ahead of you."
- "Brush your teeth."
- "Don't judge yourself against everyone you meet."
- "Be strong – you are normal and you will achieve your aspirations."
- "Be kind to yourself."
- "It all works out in the end...patience!"
- "The only person that's holding you back is you!"
- "Let people know how you feel – stop pretending everything is ok to protect the anxieties of others. Tell someone about the bullying."
- "Hold your head up high instead of looking at your feet all the time."
- "Be yourself and be confident."
- "Your best friends now will be your best friends in 25 years!"

PERCEIVED VALUE OF THE ROADSHOW

The feedback from the roadshow was overwhelmingly in favour of the roadshows as a worthwhile exercise and people felt that these roadshows were a useful opportunity to come together with other adults who were born with a cleft. For many adults, this was the first time that they had met other adults with a cleft, which was a positive (albeit emotional) experience for some to be in a room with other like-minded people who “get it”. There was a desire expressed by some of the attendees that they would appreciate a greater emphasis on social events in the future (e.g. meetups in a pub), whilst others would prefer structured events with a common goal. It is likely that a combination of these could be offered in the latter years of the project to cater for different preferences. People appreciated the regional nature of the roadshow and the ability to make local connections – many people recognised that their ability to travel is limited and that they would not have considered attending events if they were considerably further away. This being said, now that people have engaged with CLAPA, they generally feel more prepared to travel as they perceive the work we are doing to be worthwhile. Some attendees have proactively exchanged contact details with other attendees to coordinate their own informal meetups, as well as engaged with CLAPA’s Facebook community which are positive steps. If money and logistics were no object, it was evident that people would have favoured an even wider expansion of the roadshow.

There were however some areas with poor attendance (Salisbury, and perhaps more surprisingly Bradford and Bristol) which is good to be aware of for future event planning in these regions. Greater engagement with partner organisations in these areas could be of benefit.

Attendees have indicated that they would attend another roadshow if it were offered (no current plan). This bodes well for engagement and would suggest that future events would attract even higher numbers. Although future events would likely be different in style (most likely focussing on one or more key topics rather than a broad general discussion), a continued focus on regional events in addition to UK-wide events will be important. To this end, the 2019 Adults Cleft Conference is planned to be held in Scotland. Other workshops would likely be rotated around the UK from time to time to work towards more equitable access to CLAPA’s services.

Those who attended the roadshow were predominantly white and predominantly female. It will be interesting to see how this correlates with data collected from the survey – perhaps events of a different nature may be more appealing to a different audience. Additionally, CLAPA’s existing database of adults is predominantly female – this is fairly typical in the charity sector where women are generally a lot more engaged than men; it would be good to bring more balance to this.

NEXT STEPS

Following the conclusion of the roadshow, the next step is to corroborate a lot of this data with that captured through the Adults Survey. This will provide a more robust overview of many of the issues that adults perceive across the UK. Once this data has been analysed, a series of further recommendations will be made and plans developed to deliver on these ideas in the second/third years of the project. Additionally, recommendations for the NHS and others are likely to arise and these will be presented to the relevant parties.

*Report prepared by Kenny Ardouin, Adult Services Coordinator.
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