"Don't leap in with your cape flying, going: 'Hi, I'm here to change your life'"

Case studies of health promotion with seldom-heard groups

chances4change Wellbeing Portfolio



Picture courtesy of Get Active (also known as Leisure Opportunities for People with Learning Disabilities)







Executive Summary

This is one of three legacy papers produced by Building Blocks, funded by the BIG Lottery through the chances4change portfolio. Building Blocks was a capacity-building project, where one aim was to develop and communicate learning from the other chances4change projects.

This paper presents three case studies of chances4change projects that worked with groups considered 'hard-to-reach', or 'seldom heard' and are known to have poorer health than the general population. These projects were:

- Naturally Active, who ran a successful walking group with members of the Sikh community in Dartford;
- Get Active (also known as 'Leisure Opportunities for People with Learning Disabilities'), who developed sports opportunities for people with learning disabilities in Buckinghamshire; and
- Health Activists for Gypsies and Travellers, who ran health promotion activities and recruited community health activists from Gypsy and Traveller sites in Berkshire.

Case studies are based on evaluation of the project and in-depth interviews with key staff. Each case study outlines key stages of project development, why it worked and what they would do differently if they started again. Key findings across projects included the importance of being able to improvise and adapt sessions, of taking time to understand group and individual needs, to take time developing your project and to value small steps of progress. Both projects working with ethnic minorities emphasised the importance of building trust through volunteering in non-project related activities and through being vouched for by a trusted member of the community.

Other papers available from chances4change are:

- <u>Legacy 2</u>: Accessing social capital in later life: the social benefits of walking groups.
- <u>Legacy 3:</u> Growth against the odds: how four projects continued their work in a hostile economic climate.
- A chance to change: results from the lifetime of the chances4change portfolio 2007-2011.





 These and further project- and portfolio-level summaries of the work of chances4change projects can be downloaded from www.wellbeingsoutheast.org.uk by the end of January 2012. Memory sticks containing this information may be requested by emailing chances4change2@yahoo.co.uk



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Structure of this report

A brief introduction describes the context of chances4change and the aims are outlined. The methodology, which is based around three case studies of projects working with hard to reach or seldom heard groups, is explained. Detailed case studies form the main section of this report. A summary of key findings is made and followed by broad recommendations for projects hoping to engage with hard to reach or seldom heard groups.

Introduction

chances4change was a £5.6m portfolio of 62 projects in the South East of England, funded by the Big Lottery Fund Well-being programme. It aimed to redress the hidden health inequalities and improve the health and wellbeing of people in the South East, targeting 'at risk' groups across the region.

The key aims of chances4change projects were to:

- 1. increase physical activity, fitness levels or motivation to be more active in the future; and/or
- improve mental health through preventative approaches, including, as agreed, benefits on proxy variables (available on request, but including factors known to increase wellbeing, e.g., goal attainment, increased social contact) or awareness of mental health needs; and/or
- 3. increase knowledge and skills around healthy eating, having greater access to healthy food or increase healthy eating; or
- 4. build capacity for other projects to improve their performance in specified areas.

<u>Aims</u>

This legacy paper aimed to capture learning from projects that had experienced some success in developing health promotion activities with groups traditionally considered as hard to reach.

Methodology

The three projects examined here were chosen for their ability to provide rich, in-depth information (Patton, 2002) about engaging with a group of people traditionally considered 'hard to reach' or 'seldom heard'.





Existing evaluation information was used to develop an outline of the key successes of the project.

In-depth, semi-structured interviews with key staff were carried out in settings convenient for the interviewees – this included offices and a community cafe. The questions included taking a chronological history of how the project developed in order to aid recall of key challenges faced and strategies taken to overcome these. In addition, projects were asked a set of questions aimed at eliciting what they would do differently with hindsight, advice they would give to projects starting to engage in this kind of work and strategies they thought were crucial to their success (see Appendix One for the full interview schedule).

These interviews were transcribed and analysed for key themes with the aid of the qualitative software program, NVivo.

A case study approach has been taken because this is allows examination of how the project operated within a "real-life context" (Yin, 2003, p.1).

Each case study outlines:

- Why there is a need to develop health promotion work with this group
- The activities of the project
- Evaluation results
- Key stages of project development
- Challenges and strategies used to deal with them
- Advice to projects on what they think a new project needs to consider

Each case study finishes with a reference box of key learning points.





Findings

Case Study One

Naturally Active's healthy walking scheme for members of Dartford's Sikh community



Picture courtesy of Naturally Active

Why work with this group?

Members of the Asian community have some health inequalities when compared with the majority white population in the UK. For people whose family is from India, who form the largest ethnic minority in Dartford, there is a slightly raised prevalence of obesity as compared to white groups (Butland, Jebb, Kopelman, McPherson, Thomas, Mardell & Parry, 2007).

About Naturally Active

This project ran a range of activities in urban green areas and countryside of North West Kent for groups experiencing health inequalities, including the local Sikh community. The health walk for Sikh women in Dartford ran for approximately two years.

Results of the project

The membership of the group has increased from three to over 25 women, due to the inclusive nature of the walk, the trust built up by the walk leaders and their commitment to tailoring the walk for the specific needs of this group of women. The group they have worked with have significant and chronic health problems, which have become less severe over the period of their engagement with the walk.

In a group of older walkers, including those from the Sikh community, 100% reported an improvement in general health, 83% a reduction in diabetic symptoms, 83% an improvement in mobility and 61% weight reduction.

Having an organised walk is very important for this group of women, who face significant barriers to walking independently, with this group providing the only access to weekly exercise for some more isolated women.

Key stages in developing the project

A. Making links within the Sikh community





The project were not able to start working immediately within the Sikh community as they did not have pre-existing links or contacts, and these were difficult to establish:

I would say, certainly for the first six months, it proved very difficult to find the links

They felt it was crucial to build trust before offering activities – being mindful of the experiences of racism that some people had experienced locally:

the [Sikh] ladies here, there is still a lot of racism that they get living in their own street... when you first start, because you are white... you're quite unique when you walk in the temple, you don't see many other white people in the temple... they're really welcoming, but... you're now the minority... when you're working in that community

They described a number of strategies they used to develop a link into the Sikh community.

1. Targeted networking, getting 'known' and building trust

the more people you know, the easier it is to get things done or to get assistance or to open doors. So... one of the first jobs I did when I came here... [was] network, and I try to draw a line between useful meetings and networking and pointless ones...

Useful networking was with organisations with a good reputation where there was scope for a genuine, equal partnership:

I think people quickly learn, in the community, and you hear it on the grapevine... who's worth investing time with and who's not. There are plenty of people who describe partnership as a two-way process but don't actually deliver

They found it was most helpful to partner with other small teams who could exchange complementary benefits:

most of the people that we partner and work with are really small teams... everyone recognises that by working together... you can deliver a lot... each... bring different skills and resources, we have transport, now that's quite a big resource, we have certain equipment that other people don't have. And then another project will come along... and can do a lot of foodie stuff...

Providing general help was an important strategy, well worth the investment of time:





our project succeeded... because we worked in partnership with organisations who were already targeting mental health for the Asian community... we attended a number of Asian events, not particularly selling what we do, but helping, even if it was moving tables and saying hello to people, just so they got to know who we were

[So] that's your first step, you get known.

Through building up a good reputation and getting known as people who were flexible and helpful, staff were able to develop a good relationship with a crucial contact:

...our breakthrough, I think, came working with [a local community contact], because we'd had a good relationship with her anyway, we were working in partnership [already]

And then when she picks the phone up to us or someone else picks the phone up to us and says 'You couldn't help us with this, could you?' if we've got a couple of hours or whatever, we'll go out of our way to try and help them and that's how it works.

This approach also meant that when she introduced them to other contacts they already had a good reputation in the community:

And... when [she] finally introduced us to someone, they said 'Oh right, yes, yes, you've helped with this'... we [had] worked with a young girl's group who did Bangla dancing. And the youth worker that worked with us said 'Oh yeah, it would be good to get them out, they don't get out much' so we facilitated that and slowly, slowly, we managed to sort of get in...

B. Building interest and working with gatekeepers within the Sikh community

Staff talked about the importance of striking a balance between meeting their own targets and meeting partners' needs:

it works far better when the staff are motivated and want to work with you. [It] worked really well, [but] we suddenly realised that if we weren't careful, they would become reliant on us being there each week... we had to... [keep increasing numbers of beneficiaries] to make sure that we were delivering our contract

Staff reported that encouraging people to join took the longest time, but that this was common to other community projects outside the Sikh community:





[It was] very slow to start off with because the groups don't know... you... [or] whether they can trust you... but... I'd say this was universal... taking the first step is the hardest step.

They also found that their offer of activities in green spaces inspired less interest in younger rather than older members of the community. They felt this was due to less interest in green-space activities among younger people as well as more alternative opportunities being available:

[Young people]... were already being fairly active in dance groups... perhaps... [they] have more doors open to them...it's probably not just true of the Asian community, you know, if you look at activities young people do...[t]he number of young people that might want to... go on a hike and sleep out overnight is probably a minority

Getting it right first time

They emphasized the importance of ensuring preliminary work was of a high standard:

You've then got to make that group work well because that will be your reputation within that community.

There were a number of strategies they used to build interest and a good reputation in their initial delivery of work with a group from the Sikh community, described below.

1. Providing a unique and accessible service

The project staff felt they could offer similar activities to other established groups, but in a way that might feel more accessible:

our walkers enjoy what [another local walk agency] would do, but they want to do it in our format that is... more open to them... it's somewhere... they feel comfortable

This accessibility was built on working with the group's needs and being willing to adapt around them:

You try to provide what they want, you can't provide everything that everybody wants, but it's good to listen to what they want and try and provide those things, but then we adapt to everybody... if it's pouring with rain, there's no point in walking in an open landscape... the majority... wear some of the silliest shoes going, no arguments... that's where we're at, so you have to think about that before you take them up a muddy path.

2. Taking a gentle, individualised approach to promoting health





Rather than branding the walks as 'healthy' they emphasised having fun:

it is health by stealth, people don't realise... you're actually getting healthy, which is great because they're having fun while they're doing it so they don't mind doing it.

This led to a committed group attending each week:

[People enjoyed] the social thing of seeing everyone each week as well and almost feeling like they're missing out if they don't come.

They were also sensitive to different people needing different kinds of motivation:

the way you deal with different people varies upon the individual. [A project worker]... needs to be quite perceptive to that sort of thing... some clients... [need] a more softly-softly approach, some need more support, some like to have a laugh and a joke and I think that's quite key...

3. Reaping benefits from the success of early initiatives

They were able to provide evidence of people enjoying the walks, which they hoped would address fears about what it might be like:

it's useful to have a few photographs of a group going out and enjoying that and other people see it and think 'Oh right, okay, so it's not new and other people have enjoyed that, so maybe I'll look at it.'

However, it was through word of mouth that they had the most success:

...it is still by word of mouth, that's how we recruit more people... [In] June of last year, we... [were] inundated with [requests]... we could run this project just on... delivering to the Asian community.

They felt this was due to walkers feeling a sense of ownership:

I think it was them... being confident with each other as a [walking] group, then being confident to invite other people along through word of mouth and actually, having a sense of ownership of 'This is our walking group...

Advice to other projects

Why did it work?





1. Staff skills and experience

a) A good, proactive networker is needed for the start of the project:

You need someone that can network quickly and make the links you want. Many projects can take six months or more just to network... if [you] have to find... [your] audience... you need someone that can go out there and open the doors... [Then] you could almost snatch that person out and put someone else in...

This part was seen as crucial to the later success or failure of a project:

it's the groundwork that makes the project work and if you don't do that properly, the project won't move forward

Their advice for anyone starting this process was:

go and find a friend quickly, help someone that might be in a good position and then let them introduce... [you] to other people

b) Someone who has a good reputation and existing community networks

One way of achieving this quickly is to employ someone who already has a good reputation:

If you bring people onboard that [have] that experience... Because [the local networks] know you, they trust you, so if you're bringing them something new, most people will think 'Well, that sounds interesting, we'll have some of that.'

c) A good 'salesman'

The initial person involved has to convince people of the benefits of taking the first step into a new activity:

You've got to be a salesman; you've got to be able to encourage people to get going

d) Experience of working with people with disabilities or health problems – or sensitivity to this – and taking a flexible, empowering approach:

[One member of staff] also works for Riding for the Disabled, so she's done a lot of work with disabled kids which means she's able to adapt, you know, you're an unknown quantity when... you come along and join the project.



Picture courtesy of Naturally Active





2. Attitude and approach

a) Be reliable

With partners:

They know... we're reliable... If your reputation is rubbish, people won't work with you and in this community... [we] are well-known and well-respected for what we do and people come to us, we don't have to look for work, we haven't done so for ages...

With those attending the project:

if there's a bank holiday... [we will rearrange sessions] so that... [the Monday group] don't feel they lose out. And we try not to take our holiday[s] at the same time

b) Be sensitive and respectful, learning about and adapting to cultural and individual differences:

Don't patronise the community, treat them as you would treat everybody, learn about their needs, get an understanding, you know, if it's about males and females not going out together, respect that, understand that... you have to be slow and careful about your approach.

Show an interest in... [people's] culture... we... have some quite open discussions about... life in Britain, life in India ... whatever you do, do it nicely, do it... in the same way that you would chat to your own family in a nice way or your own friends in a nice way, certainly have a good sense of humour... you don't have to live in the community, you don't have to be there 24/7, but take time to stick your head in the temple once in a blue moon and eat with [people]. They really appreciate it, you get to have a nice meal, it... just works.

you need to be adaptable and flexible and actually, have a bit of an understanding of the culture and of actually, how different people's lives can be before you go in and try and say 'Oh, you know, this is what you should be doing, why aren't you doing this? Why haven't you done this?'

c) Take a slow approach with small steps:

go in slowly... [don't] leap in with your cape flying around in the air going 'Hi, I'm here to change your life' because you're not. Suggest work slowly and then I think it becomes very rewarding





our walks have gradually increased in length without them really even noticing and we've gone to more challenging places as their confidence has grown in walking and in us, knowing that actually, if they are tired, we'll find somewhere to stop for five minutes, get your breath back, collect yourself and we'll go again. There's no, you know, set pace that we have to go at, the group will stay together ... so it's about being approachable for people and... [making] small steps, [having a] little goal, so that people enjoy it along the way and it doesn't become a chore.

What would they do differently?

a) Work in a more holistic, joined-up way with partners

I would like to see... a greater link of partners to provide a more rounded service for clients so that if I can't work with you twice a week... [if] I can only do once, we... get other projects doing different things that you could link people in... we have done that, it would just be nice to do that on a more regular basis

In particular, the team saw a need for more targeted mental health work:

I would quite like to target mental health... because... [that's an area] that... [doesn't] get the resources and there's a great deal could be done.

b) Finding ways of capturing broader benefits for clients:

[We need to] try and pick up on what we hear on a daily basis and be able to feed that back because... when you're out walking, people just seem to open up to you. But you don't have a pen and paper in your hand at the time or, you know, you can't quote it, but...I know what differences we make to... [their] health, mental wellbeing, just offering them support and just generally... it makes a huge difference... [so you should be finding appropriate ways to] monitor... that as well.





Key learning points

Staff qualities

- Good networker needed for start of project
- Someone able to work sensitively and respectfully and to adapt activities in an empowering way
- Someone with good 'sales' skills to convince people to take the first step to be involved

Key successful strategies

- Target your networking to those committed to genuine partnership working
- Offer general help to 'get known' in the relevant community and make new contacts
- By listening to what your first group want, build a unique service that is accessible, suitable and adapted to suit their needs
- Promote your activity in terms of what is most appealing ('health by stealth')
- Understand and respond to what motivates different members of your group
- Build in a sense of ownership so people feel happy to invite others
- Be reliable and flexible for partners and clients
- Take time to learn about and understand cultural and individual differences so you can adapt your service to suit
- Take a slow approach with small steps to build confidence

Suggestions for new projects

- Work with other partners in a holistic way to provide a seamless service
- Develop evaluation techniques that allow you to capture ad hoc compliments and observations (with consent, of course)





Case Study Two: Get Active – providing opportunities for people with learning disabilities to engage in sport



Picture courtesy of Get Active (also known as Leisure Opportunities for People with Learning Disabilities)

Why work with this group?

14-20% of people with learning disabilities die from Coronary Heart Disease, (Emerson & Baines, 2010). This is likely to be connected to the very low levels of physical exercise taken by adults with learning disabilities:

[o]ver 80%... engage in levels of physical activity below the Department of Health's minimum recommended level, a much lower level of physical activity than the general population (53%-64%) (Robertson, Emerson, Gregory, Hatton, Turner & Kessissoglou, 2000; Messent, Cooke & Long, 1998; Emerson, 2005; all cited by Emerson & Baines, 2010, p.8).

About Get Active

Originally known as Leisure Opportunities for People with Learning Disabilities, this project provided opportunities for people with learning disabilities to participate in sport and physical activity by employing a project coordinator who created, supported and developed a series of activities using community-based sports facilities and trained staff and volunteers to be more inclusive.

Results of the project

83% of people evaluated reported being more confident about taking part in sport and physical activity.

For most of the participants the main reason for attendance is to be involved, be part of a team and meet people, although being healthy and better movement were also reported as being important.





It's helped me a lot. I've been able to get about... easier than I would have done [without it].

Key stages in developing the project

A. Reaching people

The project found it difficult to establish links with people with learning disabilities initially:

we knew they were out there, but we had very limited ways of actually... tapping into them.

They approached this problem by looking for gatekeepers in the wider local community:

it's not just parents and family carers and day services and residential service providers and supported living people... it's also trying to find out... [about] other... social groups that are around...

B. Working with gatekeepers

Once this contact had been made, the project had to work on gaining the trust and commitment of these gatekeepers before they could work directly with people with learning disabilities.

This was a key difficulty they encountered, specific to working with this group:

when you're working with adults with learning disabilities, you kind of have to work twice as hard as you would working with anybody else in an adult population because you've got to persuade the adult with the learning disability that they want to do an activity... [a]nd... whoever's working with that adult... because... they [may]... need that support to... get... to that session...

it's been... a long, slow, drip-by-drip process and... some of the day services... [have] been... very proactive in seeing Get Active as a real opportunity... And others... have... picked service users that would really benefit... And others haven't really engaged at all and that's despite... [us] going and visiting... [them] and talking to the... teams... and really making a case for what we're doing... With regards to colleges, we haven't had a ... very good... take-up... but I think that's because, in the past, they've always had money to run their own sports programmes, so it hasn't been a problem for them





They felt that engagement could sometimes be affected by a difference in philosophy about community participation:

the philosophy of Get Active has always been about accessing the community and accessing a load of services within local areas, whereas a lot of the colleges want things delivered on their site for their group... and they don't want anyone else to be involved with that... And several of the day services had that kind of mentality as well, so we've kind of said that's not what we're about, we put on stuff in the community that you can... use if you want to, but it's not for... putting on something for you.

Wanting activities to be very close was identified as a possible problem:

it's just possibly been that things haven't been local enough for [some people] to do, so there are some day services that are in some of the more rural areas, so where there's been an activity that's been near them, they've engaged with that, but if it's a little bit further, then they wouldn't, which is, I guess, more about logistics rather than what's on offer.

However, they had also experienced problems in engaging with local providers.

They gave one example of how a gatekeeper could (perhaps unwittingly) dissuade engaged people from attending sessions:

two young men... used to come regularly... and they were brought by a care manager who was... really, really enthusiastic and joined in and got these two young men really excited about being active and really enjoying the sessions. And he moved from that house... and the new care person... came along... about twice with these two men ... and then ... we never saw them again... we [heard]... that the care manager... they [have now], didn't like sport... didn't enjoy going to the sessions... didn't want to join in and... sat on the side and looked grumpy the whole time. And that meant that this young man didn't want to upset the care manager... [or] want her to be unhappy, so he said he didn't want to go, but... it was... [because the member of staff] didn't want to.

The project was also aware that gatekeepers could be (understandably) suspicious and risk averse when a new organisation offered a new activity.

They tried a number of strategies to deal with these concerns and the difficulties surrounding engagement.

1. Face-to-face approaches





speaking to people face-to-face is ... a key thing because... they want to be sure that what's on offer is going to be appropriate and safe and ... run by bona fide people who are not going to just take advantage of... [someone]... I think that that kind of a thing is quite important and I think probably more so... for this population... that parents [and the individual] trust the people that are providing the opportunity...



2. Providing 'taster' sessions

That's where some of the taster sessions and the festivals have come in very handy, is because they can see, straightaway, the type of thing that's on offer and the level of the coaches and that the coaches can adapt the sessions to suit whoever turns up and... that that person is not going to maybe sat on the sidelines doing nothing, that they will be included and I think that's a... key thing.

Picture courtesy of Get Active (also known as Leisure Opportunities for People with Learning Disabilities)

3. Attending events for local providers to promote project activities

[We] took loads of Get Active literature and ... and... found... that a lot of the people... were... at the management level and... [had] heard about Get Active, but having the chance to go and speak to them about what it's all about and ... impress on them the... importance of filtering that information down to the level of the individual houses and the individual care workers.... And... we got a whole range of new people to put on our mailing list of professionals, but also... direct [contacts in]... the house[s]

4. Working with disability clubs to encourage them to develop their own activity sessions

...saying to them 'It's not that difficult to set up some sports activities and that your members and potential future members would really benefit from... being involved...' And I think we have got a lot of people on our programme, through going to those groups and doing... a taster session with them and then handing out lots of leaflets and so I think it will just be a kind of a step on from that to support them to... set





up their own activities. And I think... without having wads of cash, that's going to be the only way that you can... move forward

C. Genuine involvement of people with learning disabilities

Although many people they worked with were available during the day, they found that breaking routines could be a real issue for some:

quite often it's been that we've just had to go with whatever timeslot a facility had available, which hasn't always been the most conducive time to get people doing activities. Cos one of the things that... we've found out since working with this population is that routine is very important... and to try and break out of that routine is quite difficult for some people and it causes a lot of anxiety.

As a result, they did their best to ensure that routines were respected:

[we tried] to find slots in facilities that kind of means that people can be doing activity and then do what they usually do and it fits in with their routine

The project staff also spoke of the particular needs of people with learning disabilities, which made more common forms of consultation difficult:

[W]ith this particular population, because of the communication needs, and also, in some cases, it's ... memory and remembering things... it's quite hard to consult... in the way that you would with anybody else, you can't just send... a questionnaire

The project used two strategies to deal with consultation difficulties:

1. Trying things out

The project found that the best way of involving people in making an informed choice was through providing taster sessions to try things out:

So a lot of our work has been kind of trial and error and put on a ... short block of activity or a few taster sessions or some multi-sport-type activities and then people can do lots of different things and then decide what they like or what they don't like.

2. Making questionnaires more accessible

We've also done very simple questionnaires with lots of pictures, so each question has a picture and easy-read writing and a lot of participants can... fill those in, either themselves, or with support from a carer. And we've done all kinds of different things ... a lot of smiley





faces and flip-chart paper and just canvassing people's opinions on ... what they think of the activities that they've done.

D. Working with providers

The project had some helpful leisure providers, who offered some venues free of charge or at reduced rates.

for some of our sessions, we've negotiated either free or reduced rate access to facilities... So... the only cost is the coach to go along... [as] you need a qualified coach... somebody who can deliver a quality session, otherwise people won't come... we've tried to negotiate with all the facilities to see what... we can do in that respect and whether there's any other ways that... we can work, because we generally do a lot of activities during the daytime and centres are traditionally quite quiet then...

The project managed to negotiate this with commercial providers as well as social enterprises:

It's through commercial leisure providers, but one of them is... a social enterprise so they have a slightly different attitude to some of the other leisure providers... [and were] one of the partners in the project right at the beginning... Some of the other leisure providers have let us [have a much reduced rate]... as they've also been involved from the... beginning. But I think they see the value in having the disability group accessing their centre and it looks good for them to say 'We've got disabled people coming in'... cos a lot of... the District Councils or the people who set up the contracts... put in targets around community use and voluntary sector use and usually [but not always], disability and underrepresented groups is one

However, this was not always the case, as they found when there was a change of provider:

the new company that's come in is a lot less community-minded... in respect of our projects... we've invited them to steering group meetings and nobody's come along and we've been down and met them and sat down with them, telling them what... the project is all about and they still charge us the going rate... for all the facilities, which is a little bit of a shame, but... it's one of the things you have to work on.

E. Working with coaches

Initially the project staff found that coaches could be anxious about working with people with learning disabilities and were unsure what to expect:





at the beginning, finding coaches who were keen and willing to just work with this particular group [was a challenge]; I think it's quite daunting if you say it's a session for adults with learning disabilities. I think people have a particular image in their head of what that population looks like and what they might be like and how on earth do I coach these people? And it's like well, actually, they're people, they just want to do an activity

They took a number of approaches to dealing with this initial uncertainty:

1. Provided learning disability awareness training

[We]... put together a... little learning disability awareness training specifically for sports coaches, just talking about what a learning disability is or the fact that you might not know, to look at somebody, that they have a learning disability and... that it comes in a really broad spectrum of ... of ability level. And... we also do a little bit of a practical with them about adapting activities and making them easier in the way that you explain an activity, it might be slightly different.... And really just simple ways of making it a little bit easier for them... And the people... who've done the training have said that it was really helpful

2. Provided the chance to come to an initial session or co-coach at the beginning

more recently... because we've got coaches doing it and because we've got activities going, we can say to people 'Just pop along [to a session]'... And some of the festivals and stuff we've had, we have coaches who... maybe haven't done it before working alongside coaches... who've been quite experienced in working with adults with learning disabilities, so that's worked quite well.

3. Working with people who can improvise

I always say to new coaches it's like you plan a session and you turn up and you need to have that little trick up your sleeve so that if the session doesn't work or if something doesn't go according to plan, that you can just pull out your little spare bit and ... and change it or adapt it. And... it's about being confident enough to do that... But with this client group, it... doesn't matter if it doesn't progress according to plan, it might take some people six months to get to the end of your session plan... and it's just being able to adapt it and change it and be responsive to the people. And I think, for a lot of coaches, that's a real big 'Oh' so it's like... a different mindset and a different way of working...



Advice to other projects

What made it work?

1. Management staff were open to working with different partners

at a... management level, it's... having a bit more of a flexible attitude and being... open to... new things and... possibilities when they come your way... like the... housing fair... and I think it's being more open to that kind of thing... even though it's not sport-related... I think... a lot of people... working in sport find it very hard to... work outside their own little area. And... when you're working with hard-to-reach groups, you have to... go to where they are and find out about them and their lives and how you can bring them into... your world

2. Having allies and supportive management

My...line manager here and the boss of [our organisation has] always been very supportive of ... disability sport, so we've had the kind of ... well, not exactly free rein, but we've been able... to kind of mould and shape the project as... it's gone along... And I think having people like that who... support you and... look out for you and stand up for you... is really valuable.

3. The team had a mixture of professional backgrounds

I'm from a sports background... and... have a limited... experience of social care. Whereas [the other member of the team] has come from a social care background and so she knew a lot of the ins and outs of social care and how it all works and... having both aspects of it has been very... beneficial... And... I think what we... would [also] need... is somebody from a... housing support [background]... to... influence things

4. Removing cited barriers for providers

Quite often, when you speak to sports clubs about getting involved in disability sport generally, the first thing they say is 'Oh, we don't know anything about it, we wouldn't know where to start, we don't know where these people are...' and you just get... barrier after barrier. And I think we've... got to the stage now where... we can help to... get round those... we've got a mailing list of people who are interested in being involved in sport and physical activity and we've got ways of consulting with people. We've got links in the community [to where people]... spend their day... [or] live... so... we've got something that we can offer.

5. It's worth the effort





it's one of the most rewarding projects that I've done... because you go along and you see... the people who are attending and... the smiles on the faces... [and] that they're so engaged in what they're doing... and I just think it's worth all the... hard work and the... frustrations when you see that...

What would they do differently now?

1. Find out where to find people before the project starts

I think you need to have a bit more of a clear idea of who your target audience is going to be and how you can reach them... I think that was one of the pitfalls that we had...

2. Get more organisations involved from the start

I would try and get more leisure providers onboard from the beginning and I'd also try and get more than just Social Services onboard at the beginning... [to] tap into some of the other local organisations [like]... the supported living providers... [and] groups like Mencap... half of the problem was that... you don't know whether you're going to [win funding bids] and you don't know... who your key partners are going to be... I don't think we quite realised some of the... issues that... we'd have and some of the... the gatekeepers that... we'd have to... find and then work out ways of dealing with... [so]... picking your partners and your allies... at the start is quite helpful.





Key learning points

Staff qualities

- Coaches who are able to improvise around a session's aims
- Management who are open to working outside the sports world with a range of partners
- Line management allowing experimentation and trial and error approach with sessions
- Having a team with a mixture of professional backgrounds such as sports, housing and social care

Key successful strategies

- Engage a wide range of gatekeepers, such as disability leisure clubs and colleges as well as social services, day centres, family carers and residential service providers
- Make face-to-face approaches to promote activities
- Provide taster sessions for people and carers, support staff and coaches to test out the activity with an established coach and meet the team
- Network with local providers at specialist events (e.g. housing fairs) to promote your activities
- Support existing disability leisure clubs to include more sporting activities
- Run sessions in slots that fit into people's existing routines where possible
- Use accessible materials in consultation and evaluation
- Try negotiating for reduced fees from venues
- Provide learning disability awareness training to coaches
- Listen to then systematically remove the barriers cited by providers

Suggestions for new projects

- Get more organisations involved at the start of the bidding process
- It's worth the effort this is very rewarding work





Case Study Three: Health Activists for Gypsies and Travellers – engaging with two sites in Berkshire

Why work with this group?

Gypsies and Travellers have worse health overall than any other ethnic group in the UK (Parry, Cleemput, Peters, Moore, Walters, Thomas & Cooper, 2004). Detailed information about cause of death is not available yet in the UK, but heart disease and diabetes are likely to account for the highest mortality rates, as in the population as a whole (Aspinall, 2005; Bhopal, 2007).

About Health Activists for Gypsies and Travellers

This project aimed to train a number of health activists in the Gypsy and Traveller communities who will identify their own specific health needs and provide feedback to inform strategic planning. These volunteers were expected to offer support, advice and information in their own communities and work with health care professionals to improve access to services.

Results of the project

- 172 people from the Gypsy and Traveller communities have taken part in the project in two sites.
- Two people from the Gypsy and Traveller communities have been trained as Health Activists.

Outcomes to date

- Adults want more physical exercise and healthy eating activities for their children.
- Liaison has been improved with children's services and some health visitors.
- Children enjoyed tasting different fruit and making smoothies.
- Children learned about the importance of 5-a-day.
- A few Traveller mums have accessed the local Children's Centre (a first for this particular community). The Children's Centre will continue to outreach and encourage the mums to attend with their children.
- Both Health Activists have enjoyed having the opportunity to access training and work opportunities.

The work continues in the short-term through another agency.





Key stages in developing the project

A. Gaining access

The team were aware that they couldn't go in 'cold' to make contact with the community, so they made use of local, trusted contacts in order to gain access.

we set up a steering group with [people from the] Council and one of their other workers, [who worked in Traveller Education Support and Liaison]... [a member of our team] spent quite a lot of time... going through an... induction with [the] Council as they... had so much involvement on the two sites and really piggy-backed on... to a lot of their work to try and build relationships.

In particular, their worker was able to join a mobile bus run by this team:

[the] mobile bus... has been used for... mums and toddlers on a weekly basis in term-time... goes onto both of the sites, a morning on one and afternoon on the other... but it was really handy for me to go along, even as a woman going onto the mums and toddler bus... The idea... is to encourage... play with the children and... [eventually to encourage the] use [of] the local services and the local Children's Centres... [our contact] knew many of the Travellers, so rather than me going in cold and nobody knowing me from... Adam, and also, because the bus is there... every week, they get to know the bus... [and] the people there, then they gradually got to know me.

B. Seasonal impact

The project found it difficult to develop engagement initially because of the cold weather and lack of shared facilities on the sites:

From October, right through to... about March/April, it was very cold... cos a lot of the activities often would take place... outside and... there wasn't a shared facility... that we could use, which was really unfortunate... you got to a stage where you thought 'I can't do any more door-knocking, I can't ...' it's just embarrassing because you have to be sensitive to where you're trying to encourage people to do things and where you're actually being intrusive.

They also found that Christmas was a bad time to start something new, as people were so busy preparing for it:

[At] Christmastime ... there's not too much happening because... all the focus is on Christmas, it's... quite a big thing, the Christmas shopping and doing things around Christmas. So... [there was] quite poor attendance [at activities on the bus].





C. Gaining trust

it seemed to be... very slow-going, but they did warn that it could be... because... people take time, you know, in that community, it does take a long time to build up relationships and build up trust. And... I was doing something completely new and I was a different face and it was different to what [our contact] had been doing, so I... just organised some activities and one of the mums helped a little bit because she'd... also been involved with [our contact] in a previous role

One of the early challenges was needing to have one of the mums at every session she put on.

you need one of the mums there... otherwise [a session] couldn't happen

The project team identified a number of different strategies they used to build trust:

1. Offering wider sign-posting

that took a long, long time to really get to know who you were ... they got to know you as a person, as a face, but [as for] what you're actually doing... but even so, you were a point of contact that they could trust and they could ask you for advice, even if it was benefits advice and I've got lots of different leaflets with me like the ... CAB have got a special Traveller helpline... So [by being] on the Easter bus... as well as me doing... the healthy activity/healthy eating sort of stuff... it was a great opportunity cos the weather was nice. And... from then, [I] began to get to know people a little bit better and so from then onwards, I suppose you could say things started moving a bit more.

2. Offering Traveller-only sessions at the local Children's Centre

the Children's Centres are trying [to engage the two sites] ... I have arranged times for just the Travellers to come along... [although]... it's... a balance... not to exclude them from other things... [however] it's... where... they are at the moment... [b]ecause it... breaks down those initial barriers of suspicion and it... really makes the communication so much better [in general]... [J]ust to get them into a different environment is very hard, so... [to] expect them to come along to one that's already existing... with other people there... is expecting quite a lot... and it just... wouldn't work, you know, it would be trying to jump it... too much





3. Working separately with each site and being aware of existing animosities

the two sites don't mix because there's quite different families on [them], so you couldn't organise one thing and say 'This is for Travellers... come along' you have to do one thing for one site and one thing for the other site... you have to be [even-handed]... and... if you have one person employed on one, you couldn't use that person to work on the other site because they wouldn't accept it... And even within ... there's an... Irish family on one of the sites and... there is even a bit of tension between the Irish family and the other families... So there's these little tensions going on as well and it's all quite political...

4. Following up contacts in different settings

this lady, she was helping out [our contact] ... on the evening for... two or three hours or something and she was actually working in a café at the time [run by] her mum... and that was... quite useful because it was a point of contact, I could stop and have a cup of tea there and start... chatting to her.

5. Offering a day out

we did organise a [subsidised] day out... we charged everybody... a token fee of £5... to book it because otherwise, everybody could put their name down and nobody turn up... but actually, they... did all turn up and... because I had to talk to them about it... I had an excuse to go on [site] and that turned the tide on that ... site, it really opened it up that you were doing something for them. And it was something they wanted and it was the mums and the children and a couple of the grannies as well, they took their grandchildren and we had over 40 [go]... They really enjoyed it, they were really appreciative... most of them don't actually have that opportunity to go out... so I think... that really broke a lot of ice and... it's much easier to go on site now...

D. Generating interest

The project had repeated problems with people agreeing to attend events and requesting activities, but then not turning up:

people said that they would like to do some exercise classes... [but] nobody came... and... I think it's because there... [were] three [people] that were quite interested but unless they all go, then nobody... goes, so there's that lack of like real confidence.

Although the project weren't always sure about why this happened, they had a number of theories, which included the importance of the whole group





attending together, literacy problems, events like christenings or funerals and other family commitments.

A couple of strategies that helped to increase engagement are detailed below.

1. Focusing on children's health

the mums are always very enthusiastic about you doing work with their children about healthy eating... they love their children, they're very family-oriented... the families support each other. [In]... all the evaluations and things coming back, the mums are always so pleased and want you to do stuff with the children.

2. Avoiding over-reliance on written materials

[we found that people] might be able to... read... or write basic stuff, but they would say that they can't read or write because they can't understand it... so... you can't have [sessions be] too heavy... [and you need to use] lots of pictures

E. Employing people as health activists

The project was successful in employing two health activists after a long period of engagement and trust building. However, they encountered bureaucratic barriers to getting them registered to work, which led to long delays.

because of the process of all the changes here [the PCT changed from being a provider to a commissioner of services] and having to get permission to employ somebody, even though the money was there... the whole process, people being off on summer and then, finally, getting the interviews and everything going. Then from the travellers... it's taken them so long to get their ID together, so one is employed and the other one is still waiting for different ID to come back because she'd lost her driving licence... she hadn't got her marriage certificate, she had to send off for another one and she hadn't got her National Insurance number card or anything... So she was waiting for three pieces of ID to come back because normally, she wouldn't need those... she's never... worked before... Whereas the other lady who's already started... has... had quite a few different jobs

I... really... had no idea that it would take so long. Especially reading about Pavee Point in Ireland... but... [that] was such a massive project... they trained up... 18 people and then they employed about eight from that to go round and be health community workers... ... it just seems that there's so much ... that's holding us back and so many procedures and policies in place that aren't supportive.





What made it work?

1. Perseverance – and valuing small steps of progress

[the project worker has] been brilliant and just kept going and kept getting on with it

you've got to recognise that small steps that you do make are huge steps and it's only reflecting on that that we've learnt that... but, you know, even when things... didn't go right... we thought 'Well actually, that was a really good tool to get to... talk to people'. And... you'll learn from every step that goes along.

2. Ability to improvise

being able to think on... the hoof as well because things can change... And to be ready if they're ready for a session, just to be ready with that and to go with it

3. Being sensitive around gender etiquette

[With a male worker] you'd have to have another lady with the mums... because of the etiquette of... the Travellers. Because the women are quite protected and the young girls are quite protected and... you don't talk about sexual things, although I've heard a few... [bawdy] jokes... but generally, you wouldn't talk about that sort of thing with... both [men and women]... or with children present.

4. Being introduced by an established team

for the first month, I only went in with [our contact]... I think the first month, he had organised a Saturday event for ... for the youth and he took them out... on a minibus... so, I went along with him to be introduced to people.... And then after a month, I started going in on my own... and just explaining further what I was doing and... could do... The bus also was used as a youth bus in the summer holidays and in the Easter holidays, so... [our contact] organised lots of helpers to come onboard doing crafts and sports, computers, lots of different things. And... [I brought] in some stalls and... [made] some fun activities around healthy eating, doing quizzes and games and different sorts of... things. So... that's how it started

5. Need to work in a holistic way

there's such a lot of foundational work that needs doing... it's all part of wellbeing, isn't it... and confidence and... it ... touches on so many things rather than a focus on just eating... Whereas if you get





somebody's confidence and improve their literacy, then they're more likely to want to know ... more about... reading a healthy eating leaflet

6. The bus

In addition to being a venue to use when the weather is bad, and a natural meeting point, there were other benefits to using the bus:

because there's no venue [on the sites] the bus is [available and] mobile and... if you do get any political [issues], the bus is mobile and can go from here to there, it's not in one place... [you can] use that as a bridge

Advice to other projects

What would they do differently now?

1. Medium term commitment to funding/time to develop

it has been really difficult and I've toyed with the idea quite a lot... my concern was that if we do go in for a year, we're going to do more harm by building relationships and then having to break them. So I think we need to have some sort of commitment that you've got a three... [or] five-year project, that there's... some ongoing funding

2. Strong commitment and strategic support

you need to have a huge amount of support, whether it's in your policies and strategies and here, we have got a lot of strategies around reducing inequalities of health ... but... I've been in a difficult situation in that my role changed partway through and ... also, our lead for inequalities went on maternity leave and that role wasn't replaced. [You need the] right... amount of force... championing it... you need people behind you... [need] their commitment from the start and... maybe even to have a wider steering group than we did [to share] the responsibility

3. Health bus/health checks for the whole family

one thing we haven't done that we would like to have done is to have had a health bus for health checks and I know when we went up to the Roma [bus] in London ... the whole family were there and they were taking the opportunity to have health checks. And... all the men were... having health checks... so... that is one thing that would be nice, to get men involved... that would be looking really quite long-term, but it's mainly the women that will [otherwise get involved].





4. Get community involvement at bid stage

if, from the start, when the... proposal was put in... [there was]... some way they could have got [the community] involved... [we'd]... have had... a bit more insight. Because... what was planned in the original bid was that... there would have been a person in my role [who would] have just gone in there... [to recruit Travellers] who... [would be]... all... willing and ready... and then they would have all just got on and run it ... which was just [unrealistic].

6. Try to sustain into mainstream work

it's got to be sustainable... it's not very likely that a project like this will continue to get funding. And I've told you about the problems of fixed terms, that it can't keep going year-on-year, but... it's such a forgotten group that I think awareness-raising needs to be done with all the other agencies [so] that they know it's their responsibility to be working with this group as well.

The project lead suggested that it might fit into the new, shared Public Health responsibilities as part of the Health and Social Care Bill (2011):

this kind of project will fit well when local authorities take on more of a public health role





Key learning points

Staff qualities

- Perseverance
- Ability to improvise in running sessions
- Need a very supportive wider team and commitment at strategic level

Key successful strategies

- Working closely with a contact who had gained the trust of people on the local sites
- Volunteering with existing work streams to get known
- Providing signposting to other forms of support
- Being sensitive to any political issues between and within sites
- Offering a fun day out to show they were willing to give something to the community
- As with wider health promotion work (e.g. change4life) a child health focus helped to engage families
- Avoiding over-reliance on written materials
- Using a bus as a base as there were no permanent venues on site and it was not site-specific

Suggestions for new projects

- Start the project in the warmer months of the year unless you have indoor facilities available that are already used by the community
- Avoid developing your project in the lead-up to Christmas
- Allow as long a time as possible to build trust go for three or five year funding rather than year-on-year grants
- Don't expect people to engage with wider services immediately try Traveller-only sessions first
- Be aware that employment can take a long time to set up if people don't have the relevant forms of ID
- Value small steps
- Be sensitive about gender etiquette
- Work in a holistic way around health, wellbeing, education and advice
- Consider using a family health check bus in the longer term
- Make all agencies aware of their responsibilities so there is a longer term exit strategy
- This could fit into the role to be taken on by local authorities as outlined in the Health and Social Care Bill (2011).





Summary of findings

As would be expected with such different target client groups, projects and activities, the key learning points for each case study differed. However, all projects faced setbacks in developing and delivering their projects with these seldom heard groups in sometimes surprising ways, such as facing difficulties in working with gatekeepers. The stages of development described by each project may resonate with other projects through describing some situations they recognise and may provide suggestions for alternative ways to deal with similar difficulties.

There were some areas of learning that were very much related to the client group the project worked with (which may also apply to a number of other client groups, whether considered 'seldom heard' or 'hard to reach' or not). Working with people with learning disabilities presented particular challenges in terms of developing meaningful ways to consult with and learn from people about what they want from a service. In working with two Gypsy and Traveller sites, staff found they had difficulties in gaining commitment to attend sessions and had to be particularly mindful of familial commitments and different sets of expectations. The project working with the Sikh community in Dartford had to be sensitive about working with people who had experienced sustained racial abuse from other parts of the community.

In addition to these very specific learning points, however, there were some findings where at least two projects concurred, which may reflect more general strategies and considerations in engaging with a group considered to be 'hard to reach' or 'seldom heard'. These are highlighted below and are overlapping considerations.

1. The ability to improvise and adapt sessions

All projects described ways they had changed and tailored their work to ensure it fitted the particular needs of the group they worked with. This is a part of wider project practice that may not necessarily be limited to working with a 'hard to reach' or 'seldom heard' group, but may help projects in demonstrating the relevance of their work to a wide range of sectors of the community.

2. Taking time and 'small steps'

All projects emphasised the importance of having time built in at the beginning of the project to network, build trust and develop and tailor sessions and support that fitted the group they were working with. Two projects specifically mentioned how important it was to have a management team that would tolerate this period of experimentation before the bulk of project delivery activities took place.

3. Taking time to understand your client group





All projects, through some of the approaches described above, took time to try to understand and then adapt to the needs of the group they were working with. Sometimes this could be difficult, but through perseverance and allowing time to build up trust and develop activities and ways of working that really suited and appealed to their target group they were able to overcome most of the difficulties they faced.

4. Finding a good contact and 'getting known' through wider workBoth of the projects working with ethnic minorities described the importance of finding a helpful local contact who could vouch for them and introduce them to the community, but also of the importance of 'getting known' by providing general help at events or other sessions, even if this was strictly outside the remit of their main project work. This combination allowed them to develop trusting relationships with the communities involved, which had both experienced racism in the wider community.



Recommendations

Every project is different and each case study has highlighted very specific learning that may be of greater or lesser importance to different projects working with different groups considered 'hard to reach' or 'seldom heard'. However, as described above, there were some approaches that were particularly helpful to projects and could be useful considerations for projects planning work with 'seldom heard' or 'hard to reach' groups.

- Allow a long lead-in time to develop networks, build trust and develop and tailor your activities and support for the specific group(s) and individuals you are working with
- Don't be overambitious in terms of what a short-term project might achieve. Allow for small steps of development
- Know something about local need and have some key contacts when you start, or allow time to develop these when you do.



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Appendix One

Interview Schedule for Hard to Reach Legacy

- Which strategies did or didn't work for reaching groups, engaging with them and doing successful health promotion?
 - Good practice guidelines for engaging with groups.
 - Ingredients for success
 - Recommendations for other projects starting up leads and project workers.

The story so far...

First of all, can they take me through the journey from where they started to where they are now... how did it happen? (How has the role/project developed and changed from the original bid over the lifetime of the project?)

What types of challenges and barriers did they have to negotiate?

What do they think were the key things that helped in moving things forward?

What do they think were the most successful strategies for engaging people? (What was most attractive about the project?)

Were there any strategies didn't work as you expected them to? (Engagement, but also delivery)

What do you think happened and how did you deal with this?

What have been the key achievements of this project/role?

Learning for the future

If you were starting this project again, what would you do differently?

What would you keep in place?

What do you think needs to be in place for someone starting a job/project like this?

What kinds of skills are essential for this kind of work?

If you had one piece of advice to give to a project trying to work in this way, it would be....

Is there anything else you'd like to say that we haven't covered?



