

# BRADFORD COMMUNITY GENETICS PROJECT



## Progress report

Challenges and achievements

August 2012

## FOREWORD

“ The Every Baby Matters Steering Group leads the work across 10 key recommendation areas to improve maternal and child health and reduce infant mortality rates across Bradford district. The Infant Mortality Strategy and Action Plan developed to reduce infant mortality rates includes ‘Recommendation 7’ which is focused on increasing awareness and understanding of congenital anomalies, which include genetically inherited conditions, within communities.

We know all communities can be affected by genetically inherited diseases e.g. cystic fibrosis and we also know that some communities and individuals in Bradford district are more at risk of rare autosomal recessive conditions which may result in serious illness or death in infancy or beyond. These rare conditions are more common in the district than other areas nationally and the Bradford Community Genetics Project was set up as one part of the Infant Mortality Action plan under Recommendation 7. This project is focused on training staff who have regular contact with communities at risk on a ‘hub and spoke model’ in order that they have a deeper understanding of the issues and challenges for communities they already work with. The aim was to equip staff with the knowledge and confidence to engage with communities and individuals at risk in a useful and positive way and thereby ensure they have an understanding of their potential risk and how they can seek help and support from their GP or specialist services.

Staff involved in the project developed their skills and knowledge and were able to engage with families to pass on this awareness. In addition, useful feedback from families has provided pointers to future direction of work for the Recommendation 7 group.”

~ Shirley Brierley  
Consultant in Public Health  
Chair of Every Baby Matters Steering Group NHS Airedale Bradford Leeds





## CONTEXT

In 2006 the Bradford District Infant Mortality Report identified five key areas for future work to improve maternal and infant health and reduce infant mortality:

- Reducing poverty, improving housing and increasing meaningful employment
- Improving access to high quality health and social care services
- Improving the nutrition of mothers and young infants
- Tackling smoking and substance abuse, particularly during pregnancy
- Raising the public's understanding of genetics, genetic inheritance patterns and the risks of inheriting severe anomalies within diverse communities.

Since the publication of that report, twelve steering groups have been set up to develop services to support these areas of development. These 12 groups take forward work under the ten recommendation areas of the Infant Mortality Action Plan. The Recommendation 7 steering group is taking forward the work to embed an understanding of the importance of genetic inheritance as a potential cause of ill health within both local communities and the local health and early childhood services. This group is a multi-agency working group chaired by the Stronger Communities Engagement lead from the Bradford Metropolitan District Council (BMDC). A key aspect of this work is the pilot project reported in this document that was set up with the following aims:

- To engage communities to promote an understanding of different patterns of genetic inheritance and the risks of inheriting congenital disorders
- To help empower individuals to make full use of the services on offer
- To develop the foundations for future community development work in this particular subject
- To challenge negative stereotyping of the practice of consanguinity and choice of family structure with accurate information on the added level of risk to infant health that might occur.

The key messages to be understood and disseminated were:

- Consanguinity does not cause genetically inherited disorders : it is the presence of two recessive genes that cause the disorder. Consanguinity raises the risk that parents will both carry the same recessive gene.
- The risks of having a child with a recessive disorder is approximately 2% in the general population and this doubles for parents who are related to each other as first cousins.
- The risk associated with consanguinity is not uniform – there will be some extended families that are at greater risk than others within a community

depending on their history of recessive disorders.

- Once it is known that two parents carry the same recessive gene, there is a one-in-four chance of having a child affected by the disorder for each pregnancy.
- To understand an individual or family risk, people will need to see their GP who might refer them to a genetic counsellor for a detailed family history.
- There are a number of genetic counsellors who hold outreach clinics in Bradford to provide information on future genetic risks to families who are affected by a genetic disorder in their immediate or wider family.

In return, the recommendation 7 group were keen to hear back from communities on their experiences of passing on the messages and on the experiences of families accessing health services for more information.

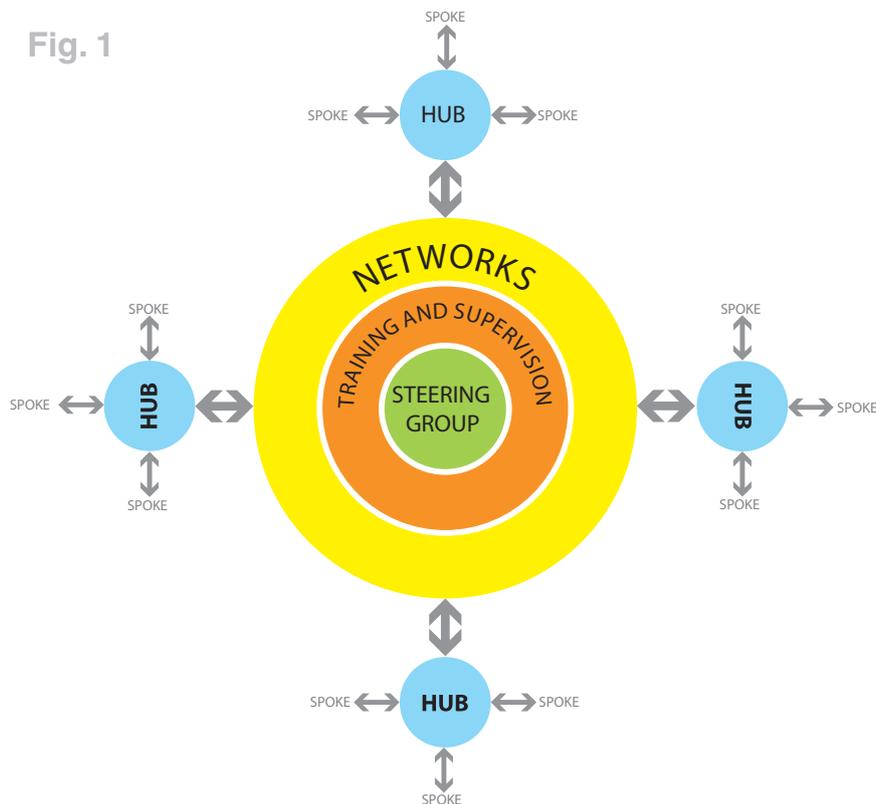
## PROJECT OUTLINE

Four areas of the district were identified Barkerend (BD3); City and Little Horton (BD5); Manningham and Girdlington (BD8) and Keighley. The localities chosen had large south Asian populations, a community significantly affected by inherited disorders that have a severe impact on life expectancy or quality of life. Four organisations were chosen, one in each area, for their location plus their history of active engagement and community development. The organisations were Barkerend Children's Centre (BD3), St Edmunds Children's Centre (BD8), Trident (BD8) and KAWACC (Keighley). The organisation chosen in BD3 had previously run an active Genetics Interest Group in response to local need. Each organisation had a willingness to take part and the capacity to dedicate a paid worker for one day a week to take the project forward. The workers identified had either a family support or community health development remit enabling them to embed this project into current work practices.

As well as the lead organisations, an additional 3 were chosen in each area to also engage on the project. The community projects were grouped on a 'hub and spoke model.' The lead organisation (hub) was given funding to enable them to release dedicated staffing time and were expected to deliver the bulk of the community engagement work. The other community projects were offered the training and support to facilitate partnership work with the hub organisation. This was to allow the organisations to work together to maximize access to families in the targeted areas.



Fig. 1



## COMMUNITY ENGAGEMENT

The project identified as the 'hub' was provided with training, sufficient funding and contracted to deliver the following requirements;

- » To cascade information to other staff in their organisation.
- » To deliver awareness sessions with individuals or groups within their organisation.
- » To offer dedicated one to one work with families affected by issues using identified tools.
- » To network/support the satellite centres by liaising with those colleagues who attend the training. Share resources and build on opportunities to promote community engagement and awareness raising.
- » To participate in a district wide awareness raising event.
- » To refer families to appropriate medical and support services.

The projects identified as 'the spokes' were provided with training to deliver the following requirements.

- » To identify at least one worker who will attend the training.
- » To cascade information to other staff in their organisation.
- » To liaise with the hub organisation, signposting to their services or delivering sessions at own centre with hub support
- » To use the resources provided to maximise any opportunities to promote community engagement and awareness raising.
- » Refer families to appropriate medical and support services.

## TRAINING

Training was commissioned to a local organisation - Genetics Communication Diversity (GCD) - and was delivered to achieve the following learning outcomes:



### Genetics Communication Diversity (GCD):

A training and consultancy organisation that specialises in issues concerning genetic service delivery to families and communities that have partners who are related by blood (consanguineous).

- » To understand the global and UK context of diverse kinship patterns and marriage preferences, their relevance to genetic support services and the social significance of cousin marriage
- » To be able to contextualise current concerns in the media about cousin marriage within a sociological framework.
- » To gain an understanding of recessive inheritance and the impact of cousin marriage on the prevalence of recessively inherited disorders in communities that marry close relatives.
- » To understand the central role of accurate information in genetics and consider the pitfalls of misinformation
- » Participants to understand basic concepts of genetic inheritance including autosomal recessive inheritance.
- » To be able to support individuals and groups from diverse communities to understand genetics, consanguineous marriage, and inherited disorders.
- » To be able to explain to individuals and families what specialist services are available to Bradford residents, what procedures may take place for families and where to go for further information.
- » To know the boundaries and responsibilities of their discussions on genetic inheritance and what other services are available for individuals and families.

### **The training was designed to provide opportunity for participants to :**

- » Consider and be encouraged to reflect on societal attitudes to risk associated with recessively inherited conditions in communities marrying close relatives in relation to other risks on infant health, eg, Down's syndrome.

- » Be encouraged, through time-out activities, to reflect on personal and professional encounters with issues relating to cousin marriage and disability.
- » Consider termination of pregnancy in the context of dealing with genetic risk in a religiously diverse population.
- » Consider the boundaries and responsibilities of their role in discussions related to cousin marriage and genetics and understand how to access help for individuals and families through available services.
- » Receive and learn how to use purposely designed resources \* as a tool for community engagement and communicating information. (see below)
- » Receive photocopied resource materials for reference and be referred to further reading. Ideally, participants will take away with them tools and resources to support accurate and comprehensible information sharing, for example, diagrams, glossary of terms, leaflets and contact details of services, reputable websites FAQs and answers.

## SUPERVISION

The trainer (Genetics Communication Diversity) attended and delivered the first session where feasible by each organisation to provide support, guidance and feedback. Supervision was provided on a one to basis by the trainer including email and phone support. In addition regular meetings provided:

- ▶ Peer support,
- ▶ Direction from steering group
- ▶ Informal supervision from trainer

In addition, informal links with the Regional Genetics Service were established.



\* Cousin Marriage and Children: The Facts. A booklet for professionals and families G-C-D 2010

## MONITORING

The Hub organisations were required to provide evidence of community engagement and outcomes through regular monitoring sheets, project evaluation reports, photographs and case studies.

## OUTCOMES OF THE COMMUNITY ENGAGEMENT PILOTS

Out of the four organisations, three different models of delivery emerged:

- ▶ One-to-one sessions
- ▶ Mix of group awareness raising sessions / one to one support
- ▶ Training to other staff members

All organisations signposted families to additional services, for example the local GPs and the Imam at BRI.

## HOW MANY PEOPLE ENGAGED WITH THE PILOTS?

### ANALYSING QUANTITATIVE DATA

Across the project the organisations were in contact with 195 people. Each person was only counted once though may have received support or attended sessions on more than one occasion. The majority of people were female, and from a Pakistani heritage with the next largest group being White British.

(Please see charts & figures overleaf)

Fig. 2

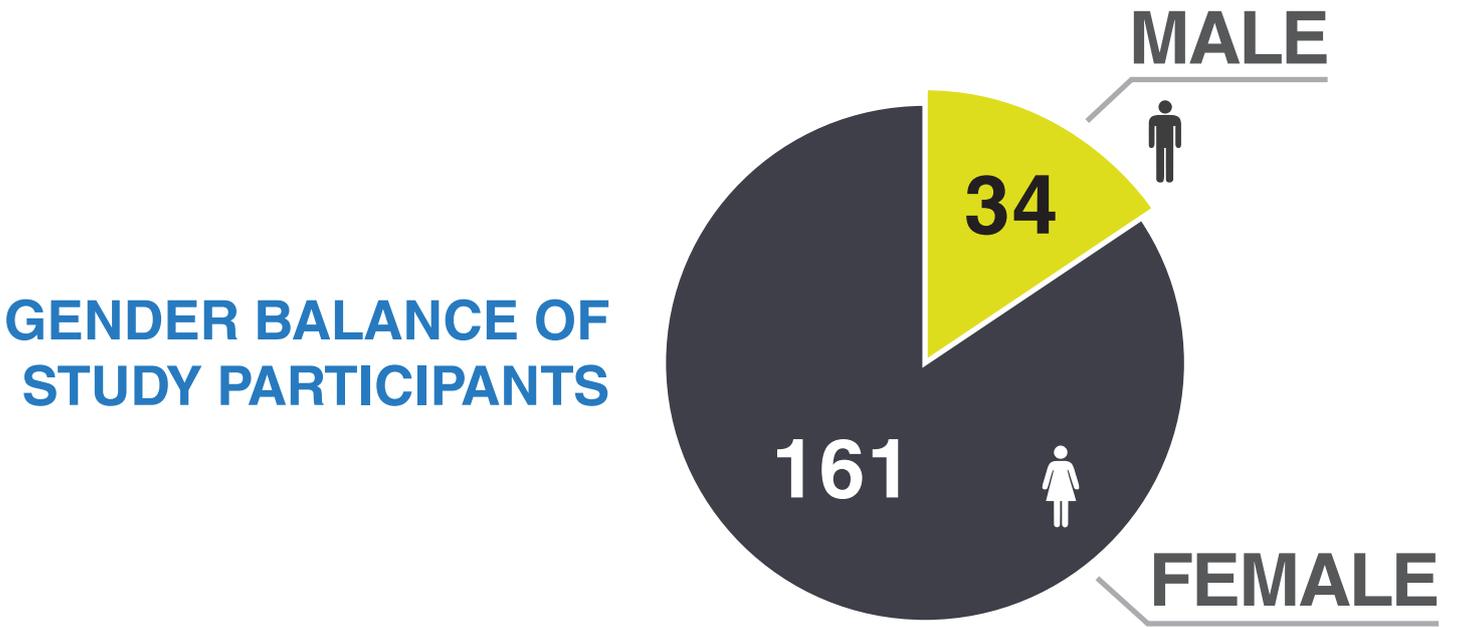
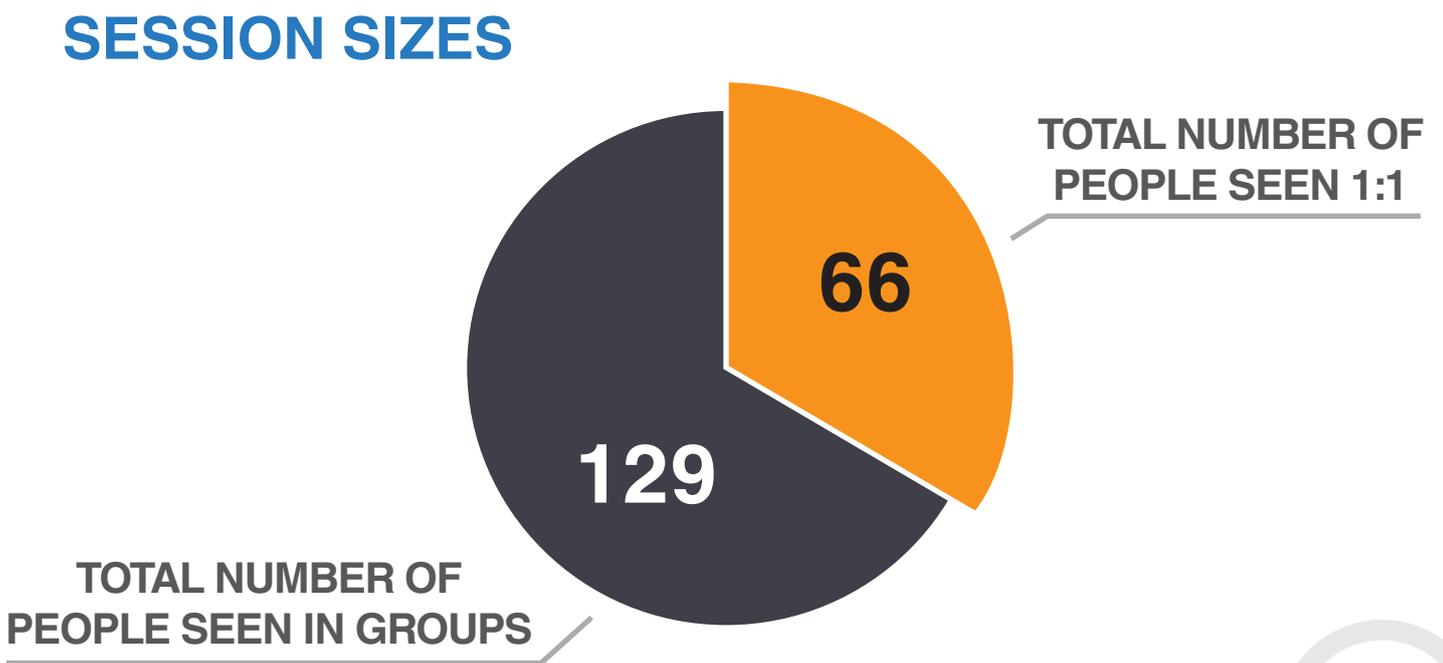


Fig. 3



**Ethnic breakdown of participants:**

Group	Detail	Nos
White	British	23
	Irish	
	A8 Accession States*	1
	Other white	
Mixed	White & Black Caribbean	2
	White & Black African	2
	White & Asian	4
	Other Mixed	2
Asian or Asian British	Indian	3
	Pakistani	143
	Bangladeshi	8
	Other Asian	2
Black or Black British	Black Caribbean	4
	Black African	
	Black Other	
Other Ethnic Groups	Chinese	1
	Other – please specify	
<b>TOTAL</b>		<b>195</b>

\* includes Czech Republic, Estonia, Hungary, Latvia, Lithuania, Poland, Slovakia, Slovenia

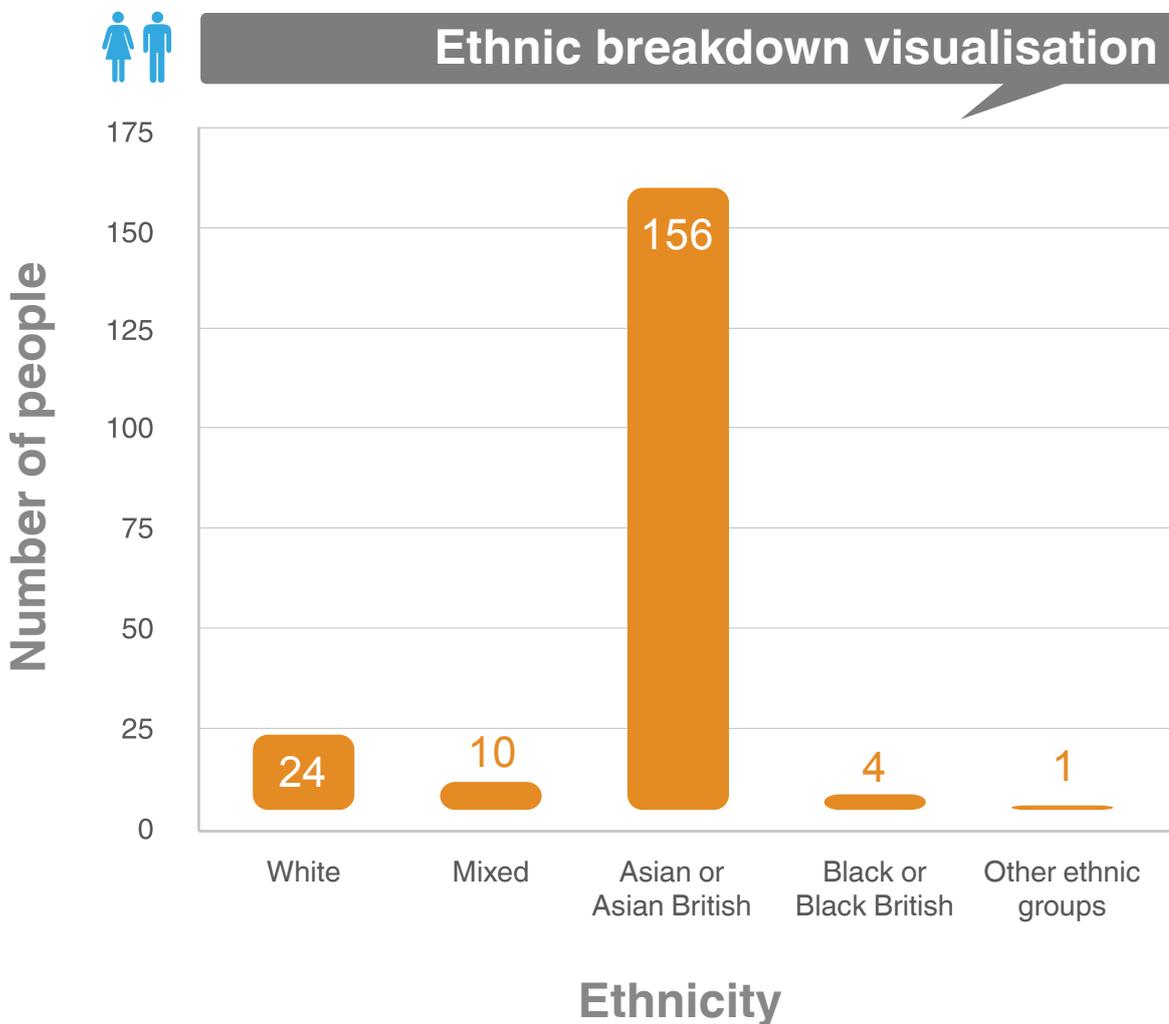


Fig. 4

## WHAT HAVE THE PILOTS ACHIEVED?

**The four Hub workers were asked to identify the positive aspects of the intervention.**

- ▶ The provision of purposely designed tools enabling ease of communication
- ▶ Families wanted to engage with project and understand the genetics of inherited disorders
- ▶ Being able to respond to families who wanted to engage with the project and understand the genetics of inherited disorders
- ▶ Working with hub and spoke model and being able to exchange experience
- ▶ Personal professional development
- ▶ Working to integrate the project into existing community development
- ▶ Networking and profile raising
- ▶ Still significant interest in project with public wanting further sessions

**There were challenges that each hub addressed during the course of the pilot. These were identified as:**

- ▶ Mistrust from community members about project due to previous negative messages related to consanguineous marriages.
- ▶ Tools currently only provided in English – needs to be in other languages including Braille in order to meet the needs of our community.
- ▶ Access to tools/resources - that the booklet was covered by copyright meant workers could not reproduce it in other forms for their teaching and discussion groups.
- ▶ Resources work better on one to one or small group basis. Additional training resources would be useful for larger groups
- ▶ Sometimes difficult to liaise with spokes.
- ▶ Families need to go through their GP to access counselling services
- ▶ Referring on for further support, eg Imam at BRI, RGS etc not straight forward sometimes difficult
- ▶ Sometimes difficult to engage men
- ▶ Only staff who attended 2 day training were able to deliver sessions
- ▶ Organisational challenges to running the pilot alongside mainstream commitments

### Key Learning Points

- ▶ Robust training needed for staff and specially designed tools
- ▶ Continued support, supervision and dialogue between practitioners is needed
- ▶ Flexible approach invaluable – able to respond to need and preferences ie one-to-one or group sessions

- ▶ Strong existing links into communities by staff delivering on project
- ▶ Staff trained also able to respond to need to provide on going emotional support
- ▶ Tools translated into different languages and formats
- ▶ More staff from each organisation need to receive the training to continue the project
- ▶ Better understanding by all of how communities can access personalised information for their situation when it's wanted and needed
- ▶ The hub and spoke model needed additional infrastructure support to ensure effective collaborative working.

It became apparent during this project that many members of staff involved had to undergo considerable personal development. The project challenged previously held concepts, some of which were identified as being detrimental or even contributing to the issues being addressed. These concepts were raised and explored through the training but staff needed on going support to take them through that transformational change. If the project was to be rolled out more work would be done with line managers to ensure an appropriate level of support for staff. An additional and integral part of the project delivery were the regular meetings of all project staff and original steering group. This provided a safe space for continual reflection and re-evaluation of both personal and professional concepts and of the practical delivery of the project.

An important key to the success of the project was having purposefully designed tools and robust training which enabled workers to have clear and safe communication about the topic of genetic inheritance. The tools also helped to ensure the workers kept within their remit, engaging families, exploring the issues and signposting to appropriate services.

It was also key to have the right workers. Staff who had an existing remit of community development. It enabled the new knowledge to be incorporated into an existing organisation service. It took a long time for the person who was trained to gain confidence in talking about what they had learned, and in doing so it began to trickle out through the organisation and so change occurred within the organisation, eg – to Health Visitors, line managers, fellow Family Support Workers.

## **Future Sustainability**

This section explores the concept of presenting the Community Genetics Education project as a general family support intervention. It can be developed as a 'toolkit' available to support the work of community based front line professionals. Learning from the project so far suggests that the tools can be used flexibly in both one to one or in

group contexts. As a Family Support intervention the toolkit would provide information, a resource for building awareness and support signposting to specialist support. The model could also be linked to Family Support/Community Engagement worker professional competencies. Presenting the project in this manner, could provide a robust model for embedding the project into the future and ensuring its continuation.

The model relates to all populations. However, particular attention was centred on local communities where consanguineous marriages are practiced. Wider integration of the approach could 'normalise' the language, strengthen the support processes available to wider professionals to enable them to start dialogues on this sensitive subject.

The model relates to all populations. However, particular attention was centred on local communities where consanguineous marriages are practiced. This approach could 'normalise' the language, strengthen the support processes available to professional to enable them to start dialogues on this sensitive subject.



### ***Why consider a Family Support intervention in a Children's Centre?***

***The answer from a Children's Centre manager:***

*"Sure Start Children's Centres now have a "CORE PURPOSE" with a number of main focuses. The principle focus being, improving outcomes for young children and their families, with a particular focus on the most disadvantaged families, in order to reduce inequalities. Family Support and Parental Outreach remain a core service already embedded as early intervention and preventive support.*

*The training delivered by GCD, provides information about the medical, scientific and social phenomena underling genetic diseases. As a Family Support intervention the key principles underpinning the approach would include advocating and developing empowering dialogues; developing community, individual and group support; signposting to specialist services.*

*Family Support services in Children's Centres provide a continuum of support for children, families and communities with additional needs based on integrated services. This would provide the potential to develop further as an intervention that links the delivery of a public health message with support services embedded in Children's Centres and community based provisions.*

*Family Support in Children's Centre is underpinned by a shared framework promoted by the Local Authority and intended to support good effective practice. This includes a shared guidance on professional competences and continuous development. Government guidance places an onus on Children's Centres to deliver evidence based intervention. The project will need to continue to collect evidence of effective outcomes to strengthen its value."*



## **Why consider a VCS intervention?**

*The answer from a VCS health partnership manager:*



*"The Voluntary and Community sector (VCS) is highly diverse but it is this breadth and flexibility that is the core of its strength. The VCS often comprises of small community groups, usually formed around a single issue or neighbourhood. Organisations are able to respond creatively, quickly and effectively to the needs identified in local areas and by local people.*

*The VCS frequently has specialist knowledge of communities and a deep reach into those often not accessing other services. The VCS has a strong history of engagement with diverse communities including BME and refugees through trusted relationships and networks.*

*The VCS are well placed to engage and inform communities about issues, support them in making informed choices and signpost them into specialist services.*

*In a time of continued cuts, diminishing resources, and ever growing workloads, the opportunity to deliver truly people centred health and social care is an increasing challenge. Partnership working is the key to stronger engagement, effective use of resources and the best outcomes for services users. The importance of a multi-agency approach to tackling entrenched health inequalities was highlighted in The Marmot Review, Fair Society, Healthy Lives. The VCS are also recognised as a key player in public services reform in the government's Big Society initiative, designed to empower communities. A positive impact is achievable when effective partnerships are formed to create whole system approach."*

## CONCLUSIONS

The strong message that came from the interventions was that there are families who were keen to engage with more information about recessive inheritance, consanguinity (cousin marriage) and the associated risks of inherited disorders. In addition, family support workers and community health workers were able to deliver provided they had clear communication tools and support.

The component that was lacking from this project was a proper sense of the pathway for families within communities to the NHS services that provide information on an individual's family situation. A clear pathway, with named local individuals from the NHS to receive people who want to know more could ensure continued engagement within communities.

Community based organisations within both the network of Children's Centres and the Voluntary Sector have clearly demonstrated the potential to create a wider network of partnerships to promote information on genetic inheritance and inherited disorders. A positive impact is achievable when effective partnerships are formed to create whole system approach which includes communities, maternal and infant health services and primary health care teams.

## RECOMMENDATIONS

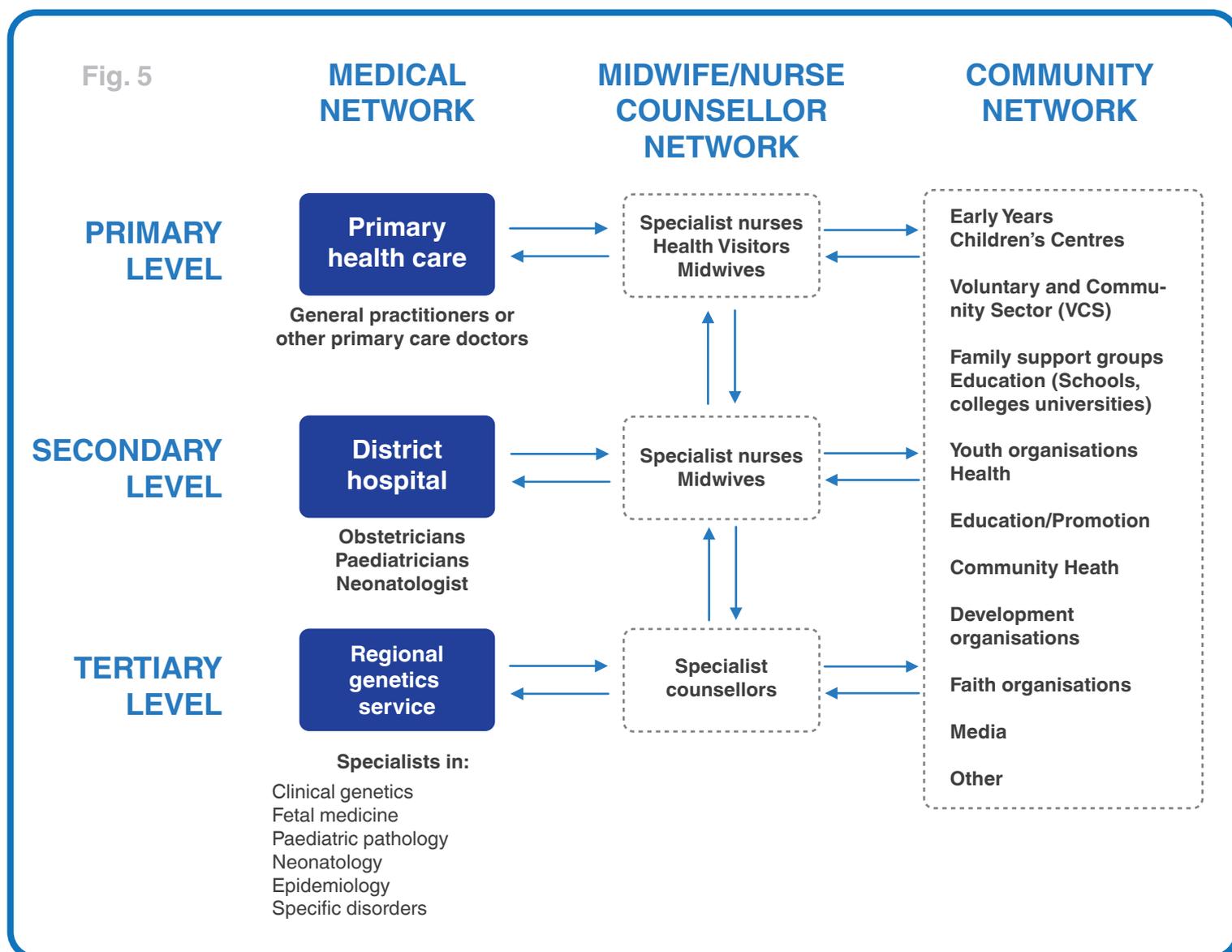
1. That there is continued training and engagement of community workers to deliver basic messages on genetic inheritance.
2. That these messages are expanded to include information about the services available to support families to obtain greater understanding of their genetic risk and the choices they may need to make.
3. That FSW employed within non-NHS organisations are recognised as a valuable resource to support families to understand information on genetic inheritance risks and the services available
4. That there if further development of primary care pathway to genetic counselling services and consideration given to developing expertise among the primary health care teams.
5. That families are supported through the pathway to ensure they attain the information and service required from the NHS



## A FINAL THOUGHT FROM DR. AAMRA DAAR

The infrastructure and strategies, needed to translate advances in genetics into services for people at risk for or affected by inherited disorders, are still in the development phase. Recent guidance from the Department of Health's Human Genomics Strategy Group cites community engagement as an important strategy in increasing the genetic literacy of the public, so that individuals and families are empowered to make informed choices about their genetic risk and use of services. To achieve this, the report also states the need for an appropriately trained and equipped workforce to respond to the specific genetic needs of local communities.

~ **Dr. Aamra Darr BSc, PhD**  
 Committee Member: Education, Training and Engagement sub-group  
 Human Genomics Strategy Group  
 Department of Health  
 Director, Genetics Communication Diversity (GCD)



Adapted by A Darr for NHS Bradford & Airedale from:  
 Modell B Kuliev AM, Wagner m (1991) WHO regional Publications, European series, No 38.