The University Of Sheffield.

Consanguinity and genetic risk: providing effective and culturally appropriate services

An overview for Birmingham HOSC

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Key messages -1

Current scenario (though shifting):

- Exaggerated risks of birth abnormality (not too dissimilar to older maternal age)

- Downplayed benefits, overlooked sociocultural context; pathologization of close relative marriage

- Responses: patchy, short-lived, alienating

- Infant mortality an inappropriate primary driver:
  overlooks lifelong illness and disability
  ignores other important risk factors for infant death, *and*
  threatens reproductive choice

Key messages -2

But, unmet need is real and persistent:

- Unmet need for genetic information and services
- Repeated unexpected births and deaths
- Risk clusters in families
- Significant social, emotional and financial costs

Service gaps:

- Misinformation from professionals
- Missed opportunities to refer
- Less than optimal genetic service encounters
- Inequitable access to information, support and technologies

Key messages -3

We can do better:

- Where enhanced, culturally competent services are offered – people respond positively!
- Good practice to emulate from East Lancashire, Greater Manchester, West & South Yorkshire
- Significant expertise and past experience in Birmingham
- Published national consensus (legitimate and guide action)
- Goals: [1] reduced service inequity; [2] informed reproductive choice

- Comprehensive set of statements from diverse group
- High levels of agreement across a wide range of issues
- Core themes:
  - Increasing **equity of access** to information and services
  - Cultural competence; empowering; co-design
  - Inter-professional working
  - Embed evaluation and knowledge sharing

→ Informing national policy developments and local action

A Four Stranded Approach

[1] Family-centred enhanced approach to provision of clinical genetic services

[2] Educate and equip professionals at the interface with the community (health visitors, midwives, GPs)

[3] Raise genetic literacy at community level

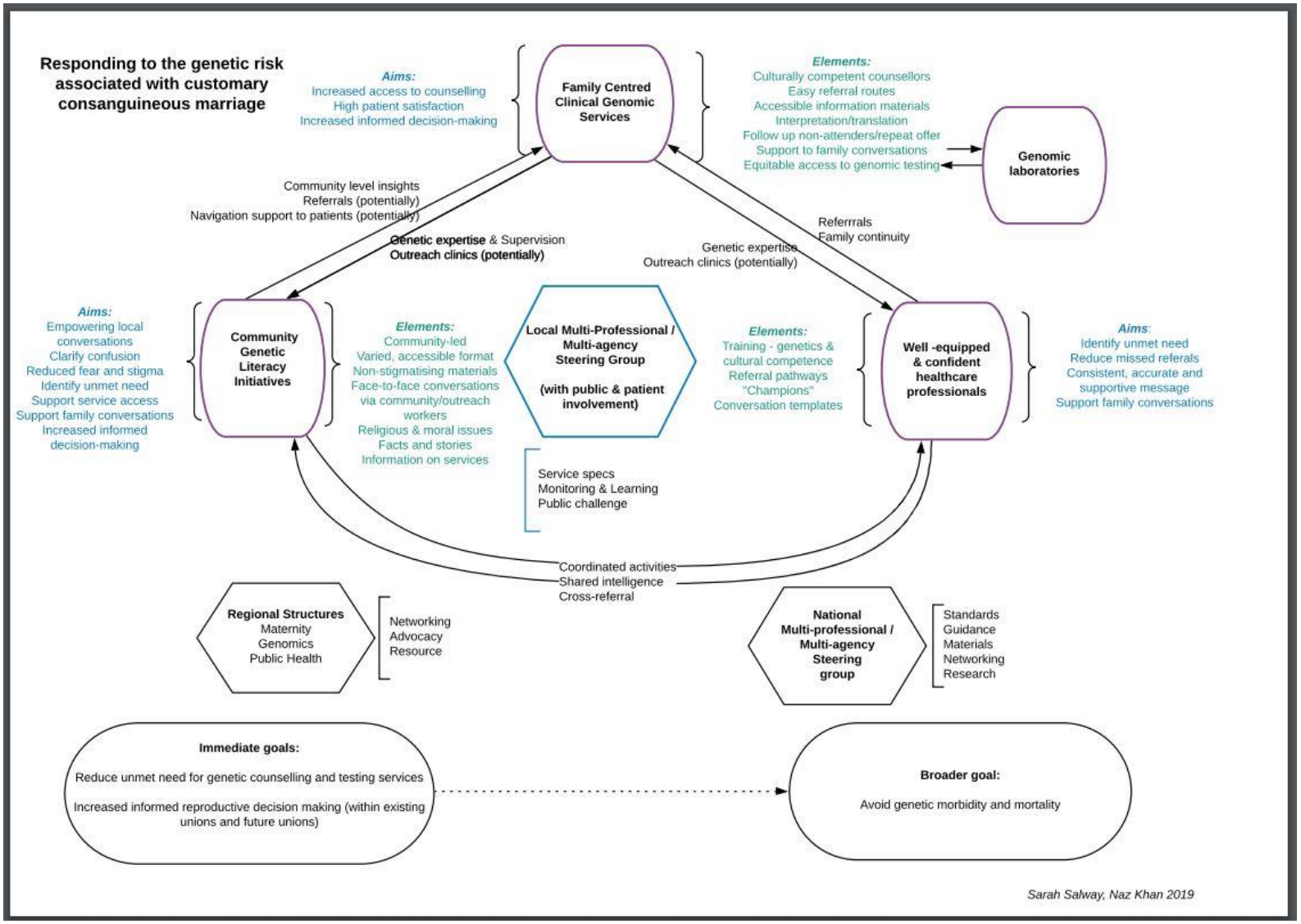
[4] Strengthen access to specialist genomic diagnostic services

Coordination via a multi-professional group with active community engagement

Building on:

Alwan A, Modell B (1997) Community control of genetic and congenital disorders. WHO Regional Office for the Eastern Mediterranean Technical Publication Series 24 http://www.applications.emro.who.int/dsaf/dsa21.pdf]

Four stranded approach



Recommendations

1. Support the adoption of the 4 stranded approach in Birmingham (ensuring appropriate adaptation to local context and building on local assets and expertise).

2. Support Birmingham colleagues' active participation in the national Steering Group.

3. Encourage further local data analysis and engagement with service users to ensure a comprehensive local picture.

4. Endorse the national proposal for new investment (across Clinical Genetics, Maternity, Health Visiting & Community Genetic Literacy) and seek clarification on its progress towards funding from DHSC colleagues.