



HFNZ Community Needs Assessment: Preliminary Findings

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Outline

- Background
- Methods
- Demographic Results
- Service & Programme Feedback
- Areas of Focus
- Next steps

Needs Assessment Background

- Advances in medical care have changed reality of living with a even a severe bleeding disorder
- Needs of community could be expected to have changed
- Strategic Planning Meeting 2008
 - Assess members' needs
 - Align services with members' current needs
- Give members a voice in Foundation direction and decision-making

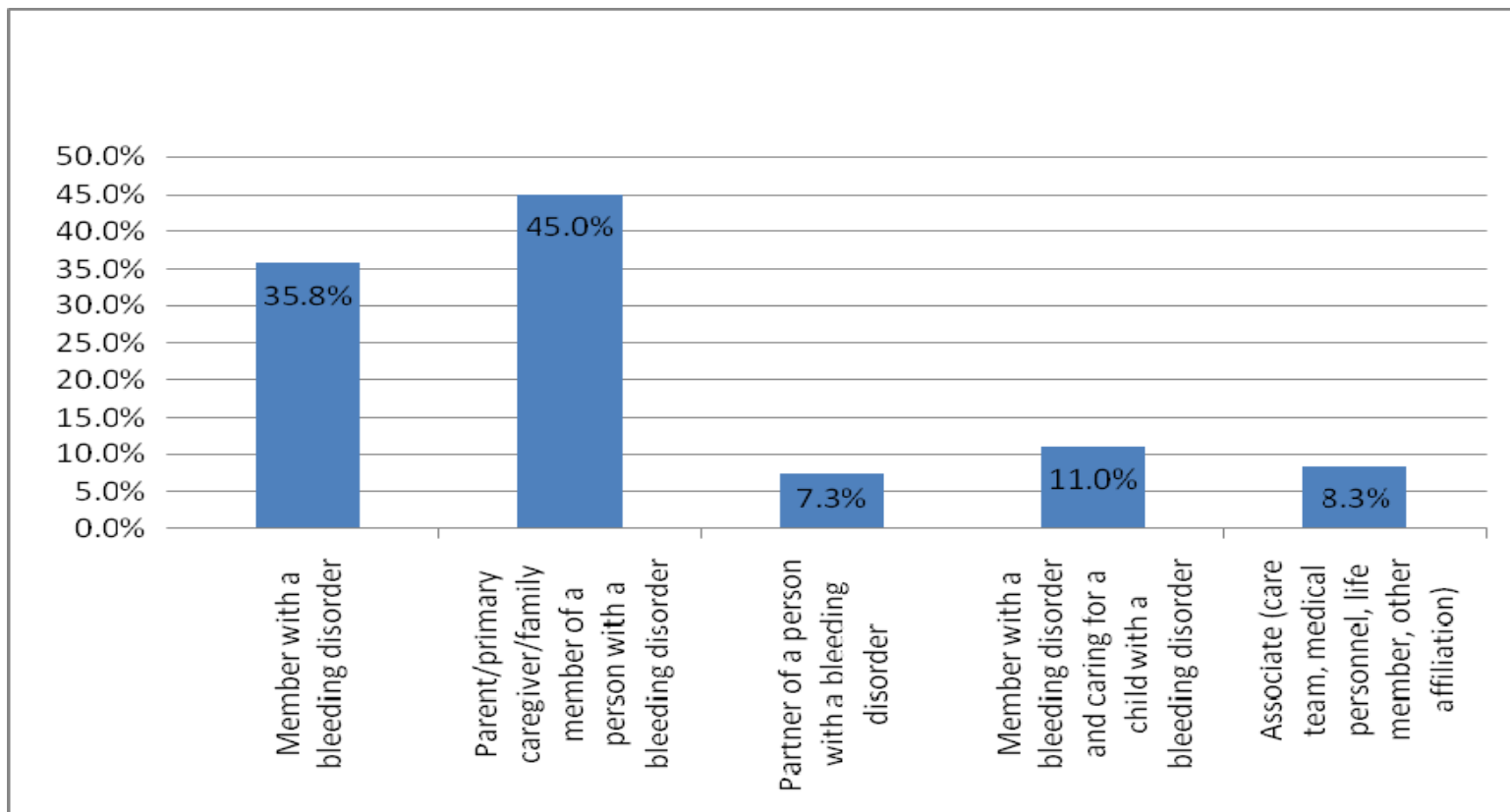
Needs Assessment Methods

- Research – consultation with a Canadian NMO
- Focus Groups
- Member Survey
 - Sent with June 2009 issue of Bloodline
 - Available online through Survey Monkey
 - All hardcopies entered into Survey Monkey for data analysis

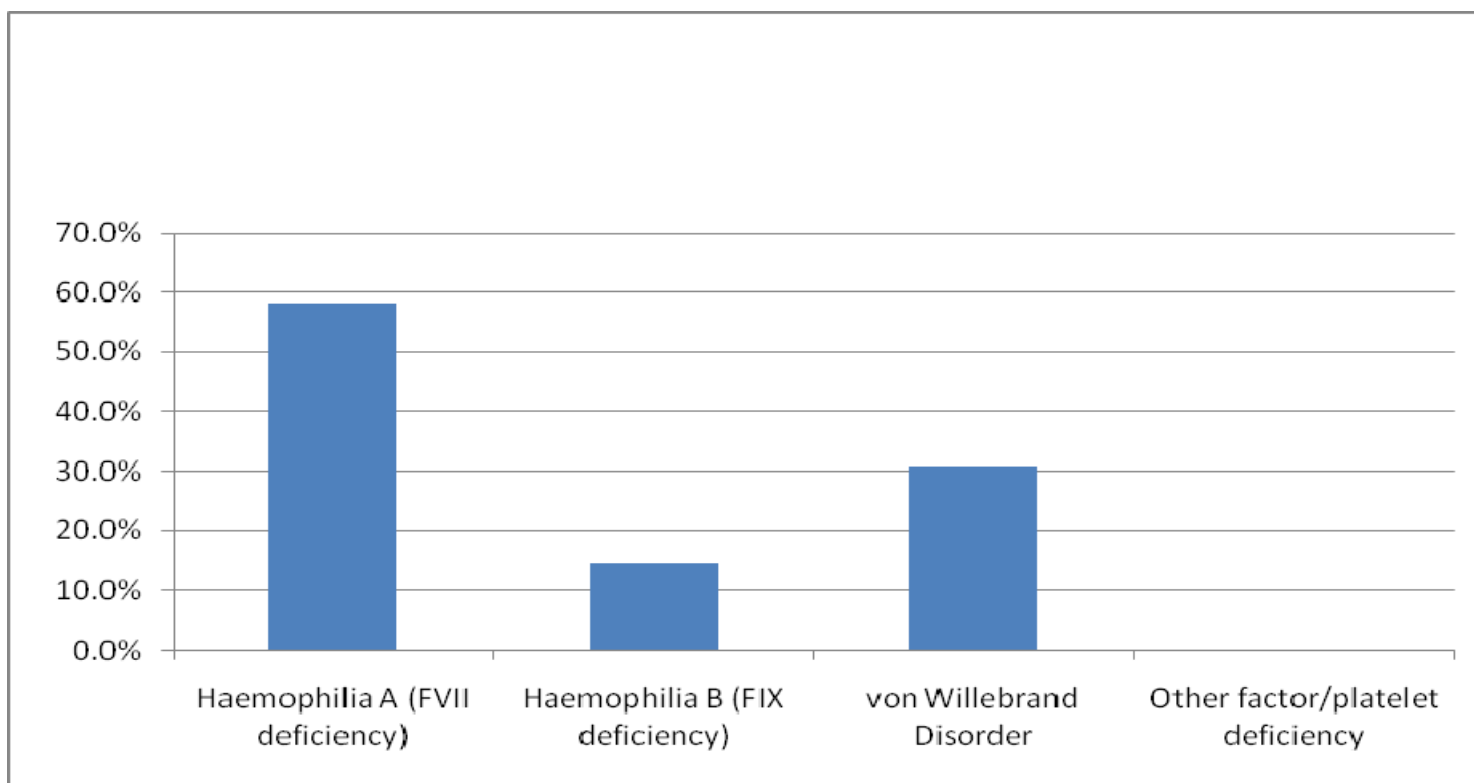
Initial Results

- 10-15 people per Focus Group
- 109 Surveys (94 hard copy)
- Fairly even distribution over 4 regions
- 1/2 lived in city with haemophilia centre, 1/3 in city with regional hospital and remainder in rural location
- 90% respondents over 30 years of age (37.6% over 50 years)
- 1/2 members of HFNZ >10 years

Type of Member (Survey)



Bleeding Disorder of Respondents



Programmes and Services

- **Most Valued**
 - **Outreach service – support!**
 - **Camps – educational and regional (social)**
 - **Education – via Outreach, camps, and newsletter or other written resources**
 - **Supportive Programmes – appreciated but not considered ‘essential’ by all**
 - **Advocacy – voice with govt and with health care providers**

- The connections made through the Foundation with other people with bleeding disorders or families were a key source of support and education for respondents
- This supportive network was considered essential to many people's journey with haemophilia and the main benefit being part of HFNZ

Service Utilisation & Importance

- Outreach, Bloodline and Educational Resources most used services and most valued services
- Utilisation and importance of others depended on personal need –
 - Utilisation highly variable but importance ranked fairly equally except for Defensive Driving lowest

Events & Educational Programmes

- In 2005, HFNZ switched to targeted educational workshops
- Attendance of survey respondents fairly low for individual workshops
- Attendance and desire to continue to attend highest for AGM and Regional activities (camps, Christmas party, etc)
- Reasons not attended:
 - Time commitments
 - Not applicable to current need

Areas of Focus

- Outreach Service – Essential
 - Need more 1-on-1 support

“Outreach Workers connect people, and their needs and information are the most important cornerstone of the Foundation. If the money dried up and we had to pay for/do with without support for shoes, swimming we would have to, but I would never want to see the Foundation lose the ability for connecting people for mutual support.”

Areas of Focus

- **Communication**
 - Better use of txt messaging, emails at all levels
 - Better dissemination of information from National Council
- **Resources**
 - More specific to NZ needed
 - Rare Disorders, Reproductive choices and vWD areas of need
 - Resources to help educate health practitioners

Areas of Focus

- **Support for Families**
 - Improved Outreach time
 - Help access other agency benefits
 - Day-to-day support, especially for those new to home treatment
 - Financial support for help with counselling, care giver support, etc.
 - Education for extended family (grandparents, etc) on bleeding disorders and how they can help

Areas of Focus

- Raising Awareness of Bleeding Disorders
 - With Public
 - Would increase understanding from friends, family, schools
 - Less explaining, less isolation
 - With Health Professionals
 - Better recognition of symptoms and diagnosis
 - Better treatment, especially for those treated outside haemophilia centres

Criticisms & Suggestions

- ‘Top-down’ approach
- More evaluation of current programmes than assessment of members needs
- No quality of life data
- In depth interviews with people at different stages of life

Next Steps

- Preliminary report prepared
- Community reviews in each region of preliminary report
- Final report published and mailed with December issue of Bloodline