

# Voices of the Community: Commentary

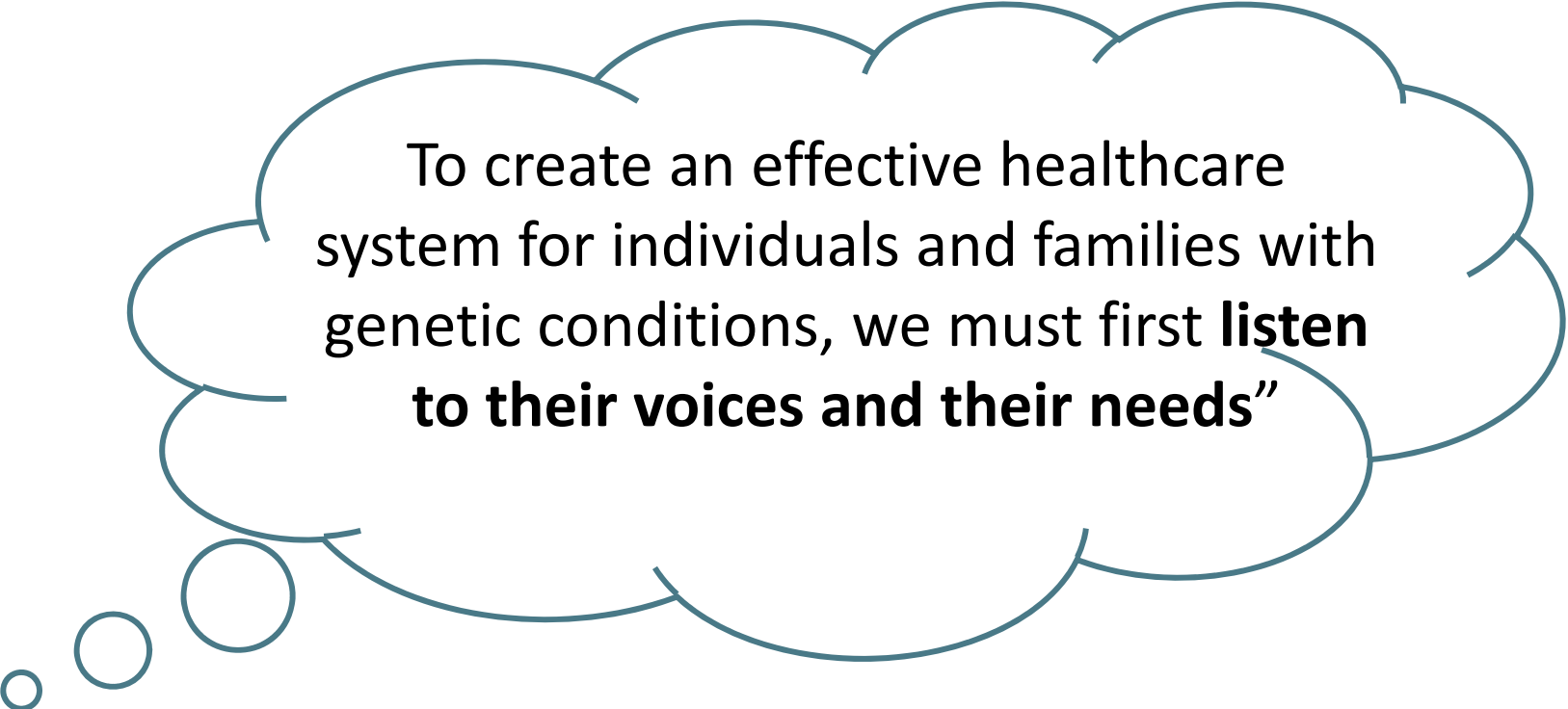


# Where We are Going

“There has been a shift in healthcare culture from a top-down, provider-centric system to a system focused on **patient-centered health outcomes**. Involving the patient in the healthcare and decision-making process is a relatively new concept. There is a growing recognition that involving the patient, or consumer, in decisions around their care **enhances the quality of care received** and **improves health outcomes**. Consumer involvement at all levels of the healthcare process is critical to the development and delivery of best practices.”

**A statement by the Consumer Advisory Group of the National Genetics Education and Consumer Network (2014)**

# The Patient-Centered Care Model



To create an effective healthcare system for individuals and families with genetic conditions, we must first **listen to their voices and their needs**”

## “Take Aways” from National Survey

- Majority receive care from **multiple providers**
  - Only 1 in 5 people had someone that helped **arrange/coordinate their care**
  - 31.% Very/Dissatisfied w/ **communication among doctors/other providers**
- 42% never or rarely received **social/emotional support** from healthcare provider/support group
- 33% **referred to support** by their healthcare provider

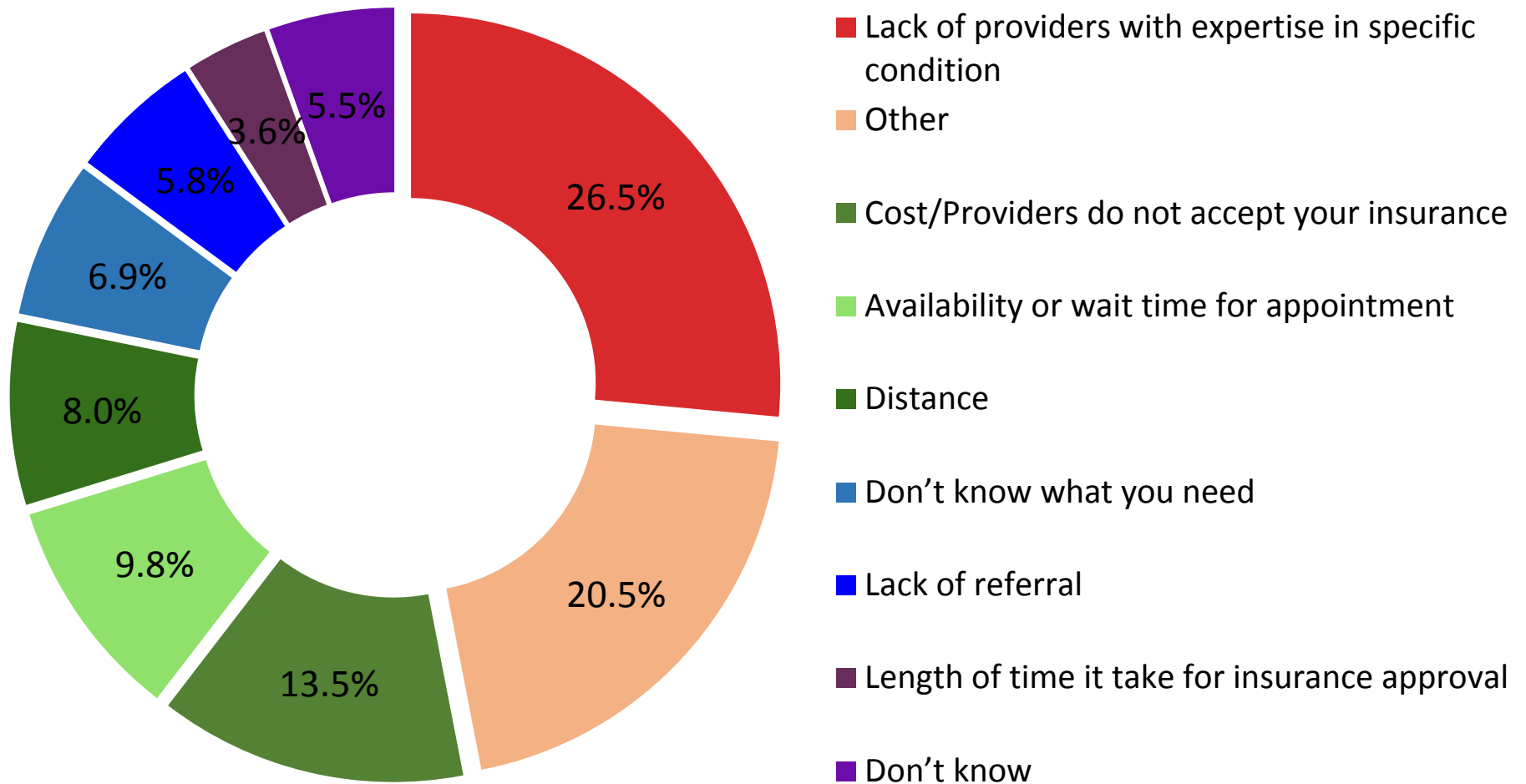
# Identification

## Time to Diagnosis By Age Group

	Children (0-17 years)	Adults (18+)
<1 month	15.3%	7.9%
1-6 months	15.8%	8.2%
6 months-1 year	15.8%	8.4%
1-2 years	13.1%	6.6%
2-5 years	14.4%	8.4%
5+ years	13.1%	47.2%
Diagnosed before symptoms	12.4%	13.2%
Average age at diagnosis	2.7 years (SD=3.8)	29.0 years (SD=19.9)

# Access to Care and Support

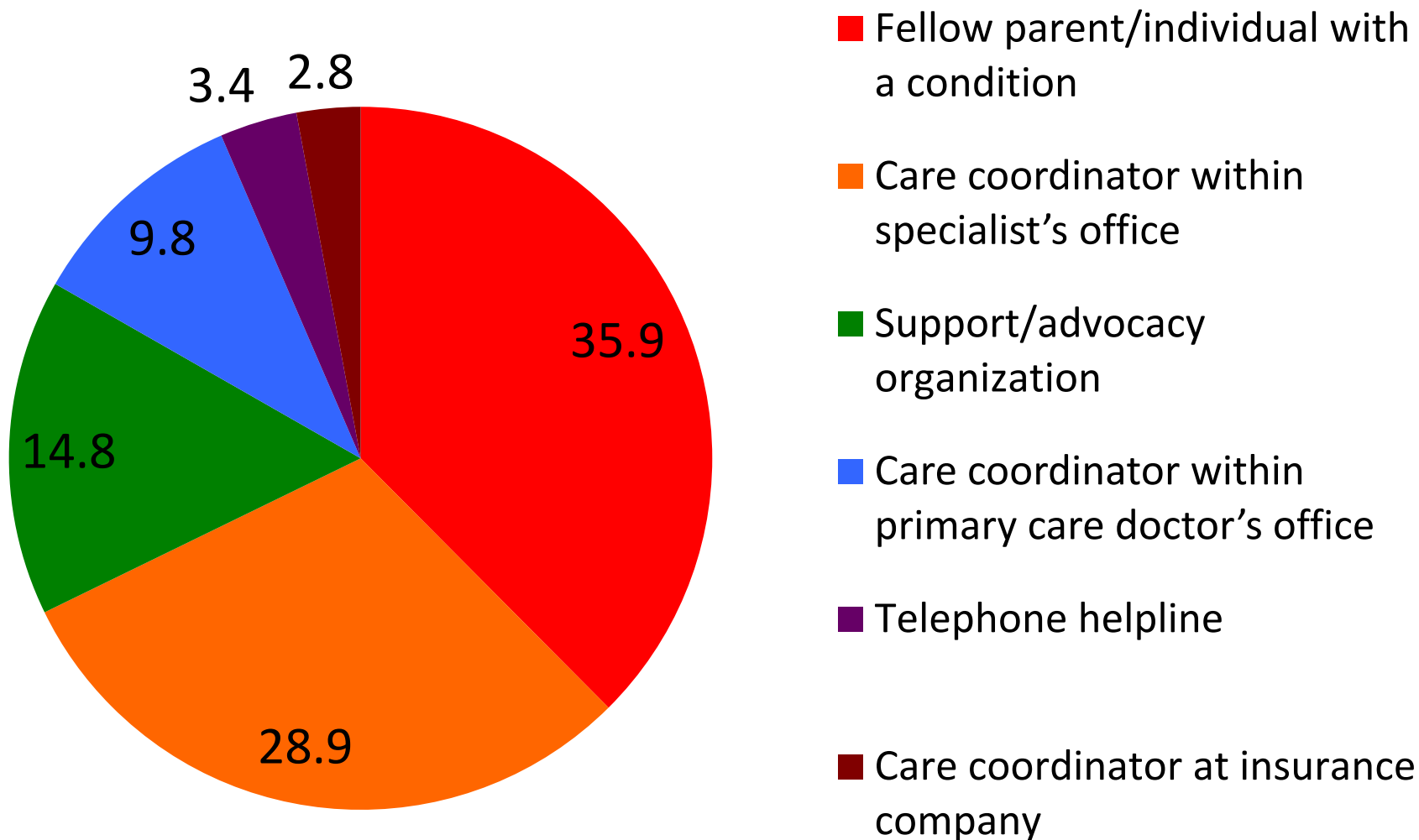
## Biggest Barrier Experienced Accessing Services (n=933)



21.7% of respondents did not experience any barriers

## Improving Access to Care

From whom they would be most comfortable receiving information (n=933)







## Acknowledgements

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