

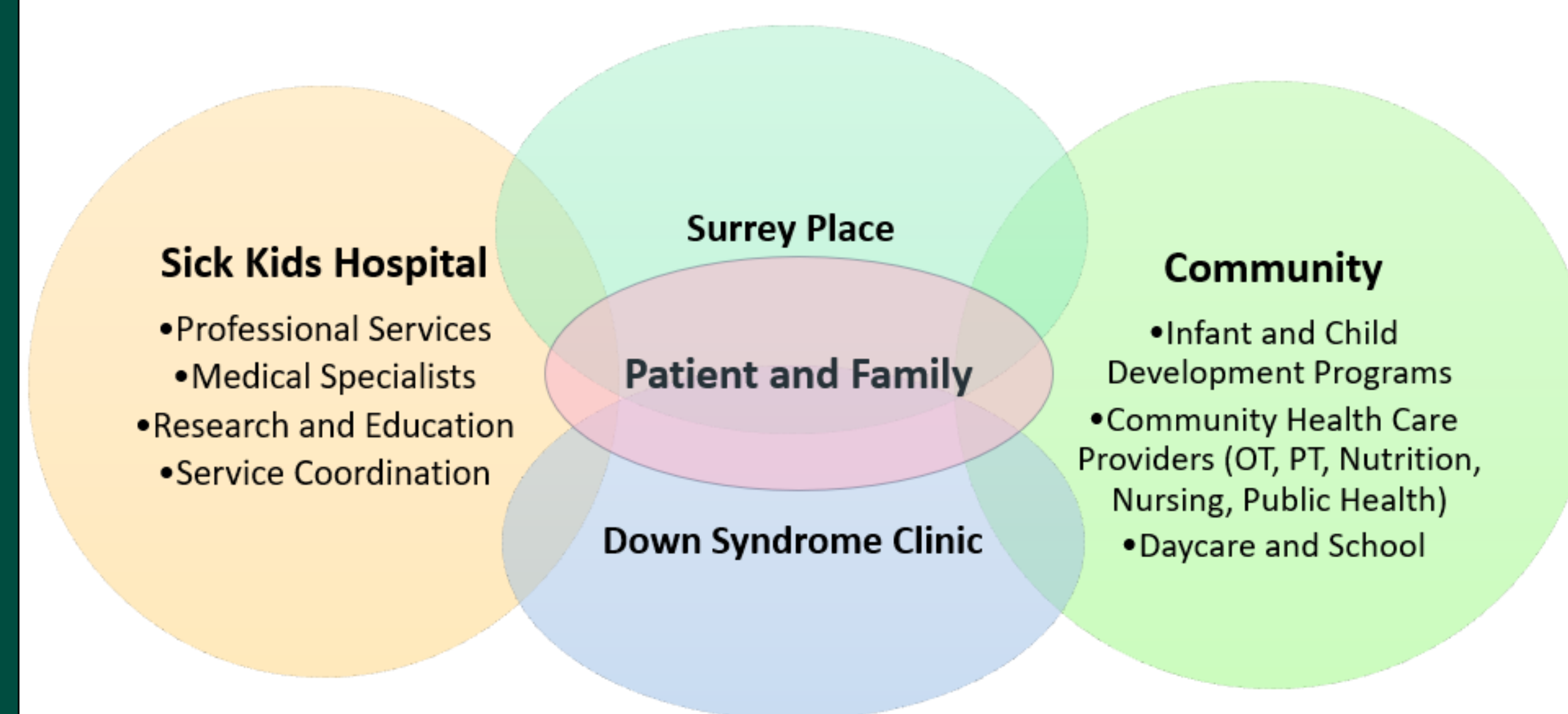
A new model of collaboration in the Down syndrome clinic at SickKids, which integrates community agency providers into clinic appointments, is allowing for positive perceptions of care by families of children with Down syndrome.

## Assessing Quality of Care Delivery The ABILITY Down Syndrome Clinic Experience: Assessing Quality of Care Delivery in a Novel Model of Collaboration between Community and Hospital Partners

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### INTRO

- The clinic uses a conceptual framework of “**child-in-family**”<sup>5</sup> as well as components of the **chronic care model**<sup>3</sup>. These frameworks emphasize that **the child and family reside at the centre of the “system”** and rely upon the resources, expertise and input of key services and organizations working in collaboration to **provide optimal comprehensive, coordinated care** for the child and family<sup>7</sup>.
- Coordination of care in a family centred manner is challenging**, and if managed ineffectively, results in: **long waits, untimely delays, fragmented communication, and inadequate planning. All of these can lead to poor health outcomes**<sup>3</sup>.
- Ongoing multidisciplinary follow up and early intervention has been found to minimize medical complications experienced in patients with chronic conditions<sup>4-6</sup>.
- Families are seen in a quaternary care setting with a focus on **inter-disciplinary care coordination, developmental assessments and integration into school**, and offered assistance with **health care navigation, funding support and bridging the gap between medical care and community**



### OBJECTIVE

Does this type of collaborative model of care which integrates community partners and addresses social determinants of health improve perceptions of care for families of children with Down syndrome?

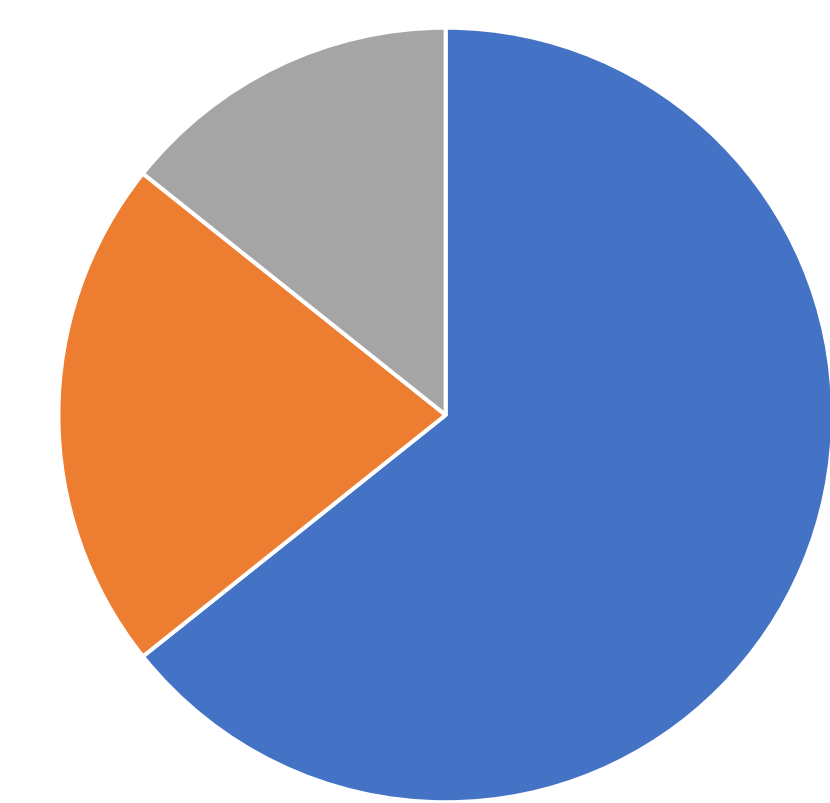
### METHODS

- The study received Quality Improvement Project Approval from SickKids
- Families of patients from the DS clinic were recruited in clinic, on the wards, and via telephone
- They were asked to complete a survey consisting of two components
  - Adapted Measure of Processes of Care (MPOC-20) questionnaire
  - Family feedback form (demographics, community services used, clinic satisfaction, funding supports)

### RESULTS

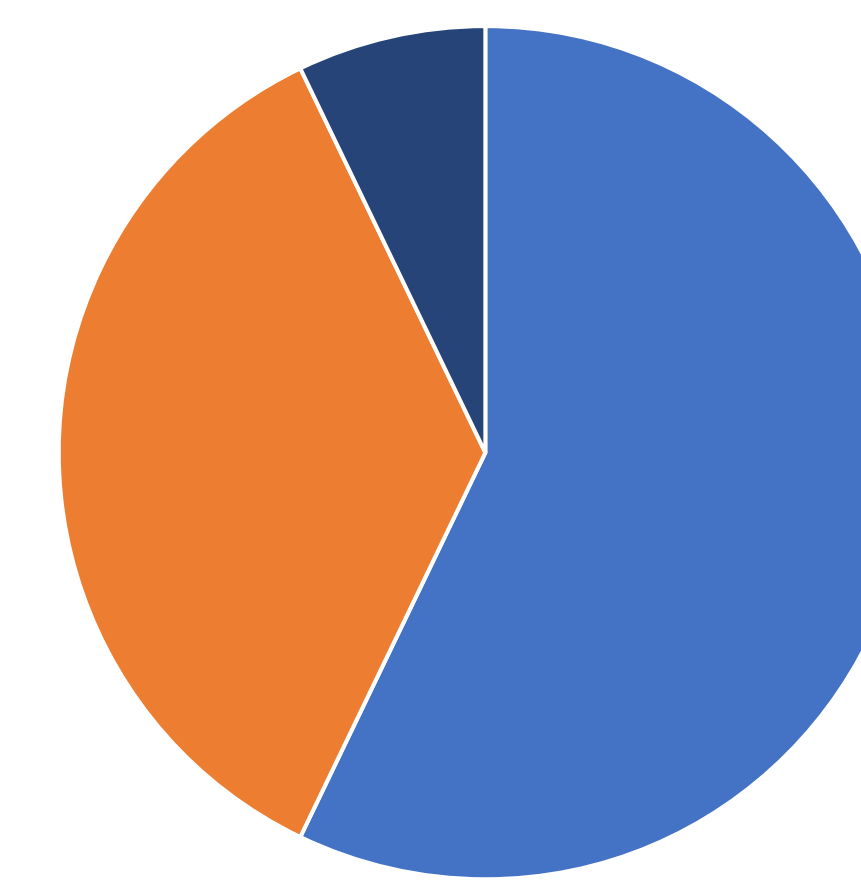
In the past year, to what extent do the **people** who work with your child in the down syndrome clinic...

...provide a caring atmosphere rather than just give you information?



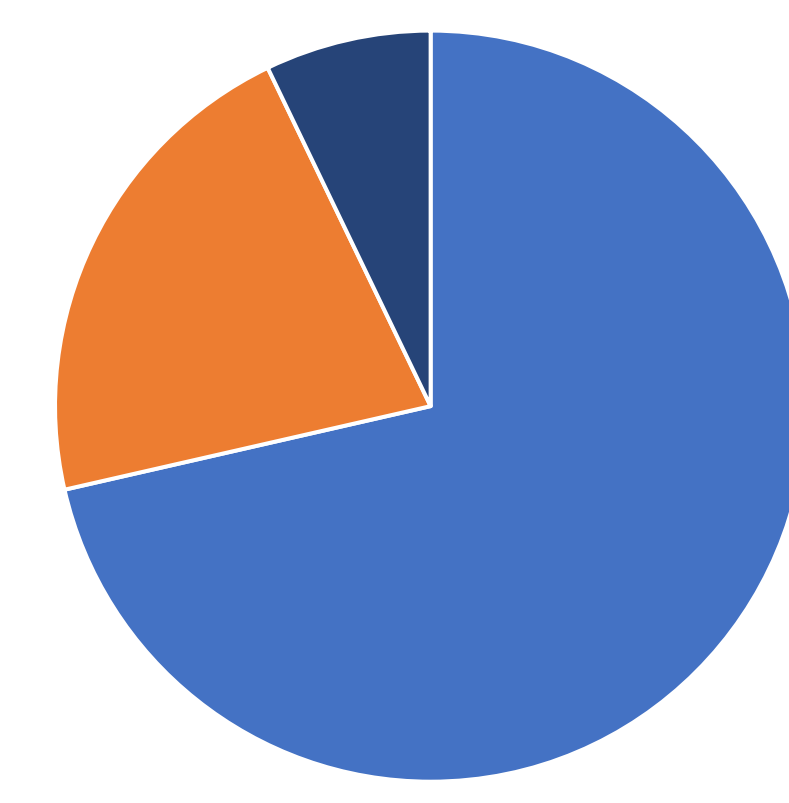
■ To a Very Great Extent (7)  
■ To a Great Extent (6)  
■ To a Fairly Great Extent (5)

...fully explain treatment choices to you?



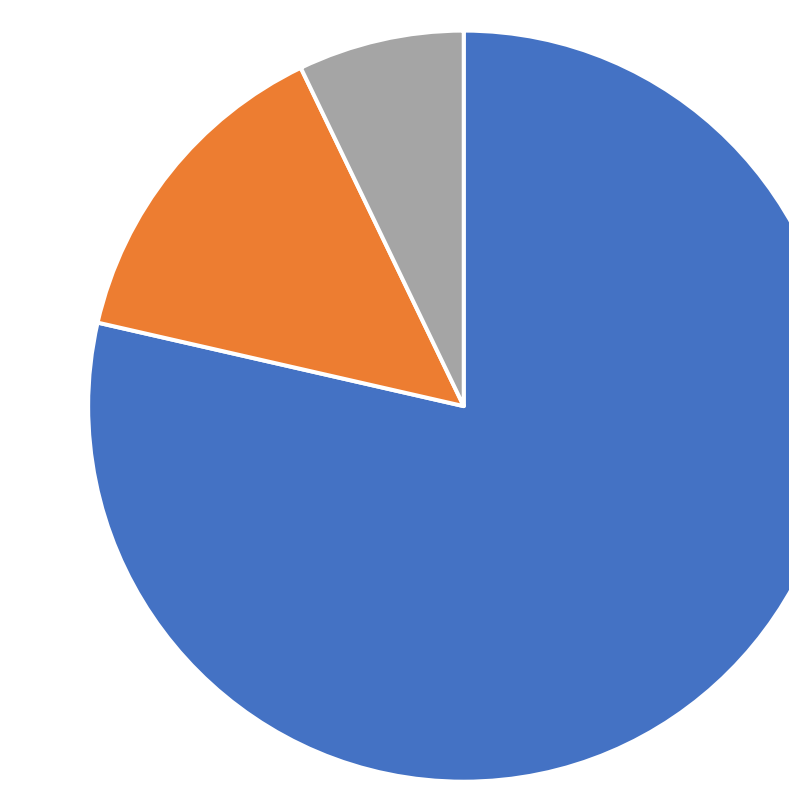
■ To a Very Great Extent (7)  
■ To a Great Extent (6)  
■ Not at All (1)

...look at the needs of your "whole" child instead of just at physical needs?



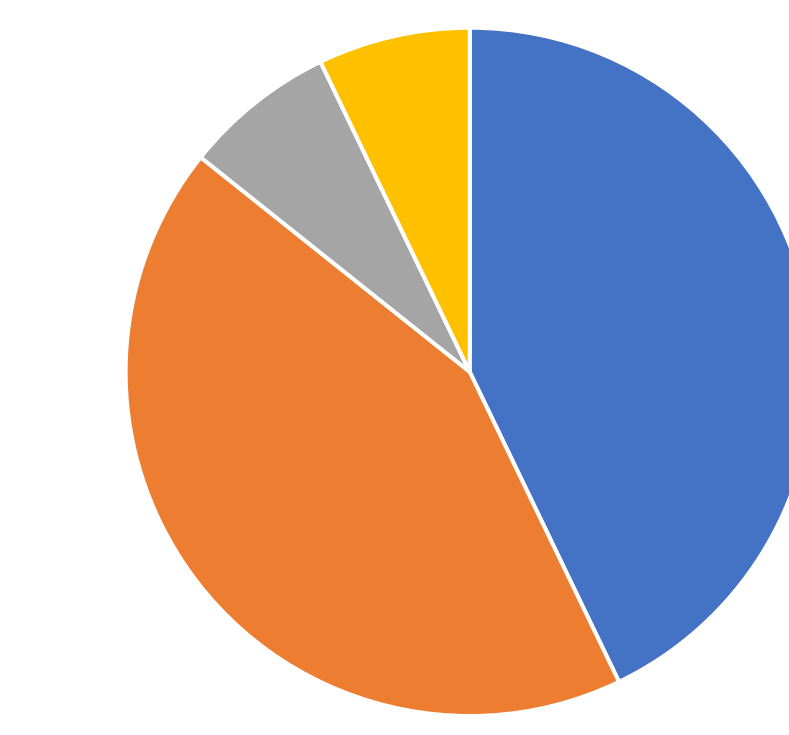
■ To a Very Great Extent (7)  
■ To a Great Extent (6)  
■ Not at All (1)

...treat you as an individual rather than as a "typical" parent of a child with a Down syndrome?



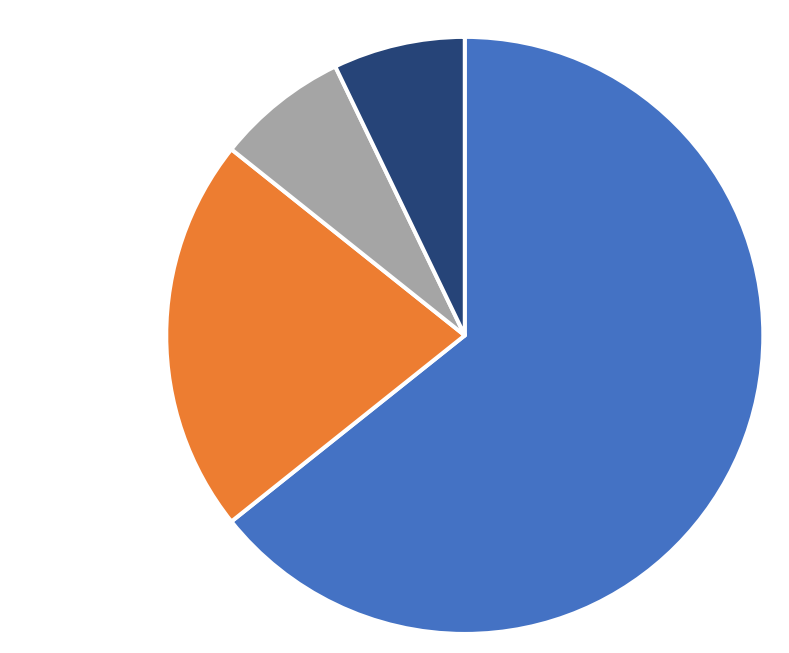
■ To a Very Great Extent (7)  
■ To a Great Extent (6)  
■ To a Fairly Great Extent (5)

...help you to feel competent as a parent?



■ To a Very Great Extent (7)  
■ To a Great Extent (6)  
■ To a Fairly Great Extent (5)  
■ To a Moderate Extent (4)

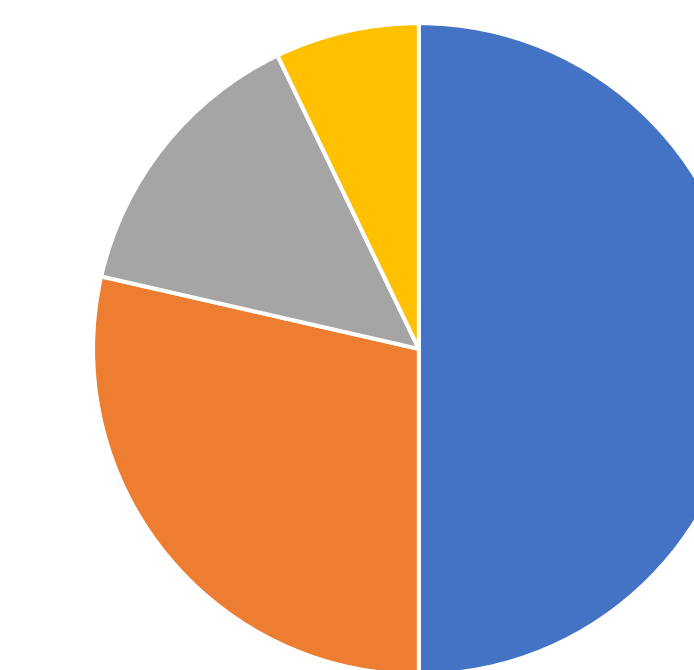
...plan together so they are all working in the same direction?



■ To a Very Great Extent (7)  
■ To a Great Extent (6)  
■ To a Fairly Great Extent (5)  
■ Not at All (1)

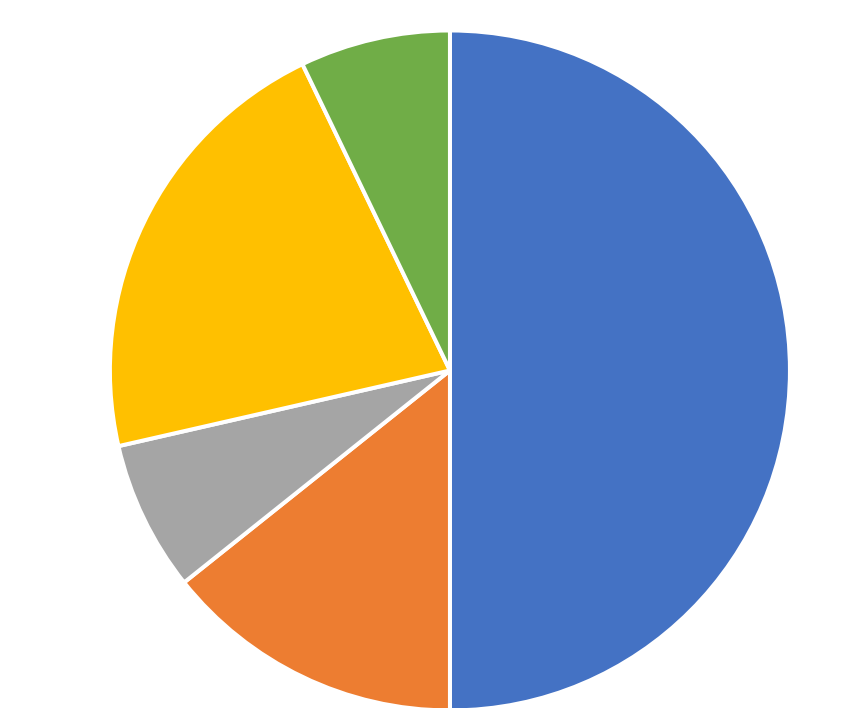
In the past year, to what extent does the **organization(s)** where you receive services...

...give you information about the types of services offered at the organization or in your community?



■ To a Very Great Extent (7)  
■ To a Great Extent (6)  
■ To a Fairly Great Extent (5)  
■ To a Moderate Extent (4)

...provide opportunities for the entire family to obtain information?



■ To a Very Great Extent (7)  
■ To a Great Extent (6)  
■ To a Fairly Great Extent (5)  
■ To a Moderate Extent (4)  
■ To a Very Small Extent (2)

### RESULTS

- 22 families have been approached and agreed to take the survey, 14 have completed the survey to date
- Median age of 3 years
- 50% diagnosed postnatally
- Overall, 93% of families said they are very satisfied with the services they receive from the collaborative DS clinic

### QUALITATIVE RESULTS

Parents were asked: “Overall, are you satisfied with the services you received from the Down syndrome clinic?”

*Emerging themes include:*

- Expertise
- Advocacy
- Acceptance

*Parent responses include:*

- “More than anything I am thankful for their trained eyes and their willingness to advocate for both [my son] and I”
- “[The Clinic] treat[s] their patients to the best of their ability”

### DISCUSSION

- 100% of parents feel as though they are receiving consistent care to a very great, great, or fairly great extent
- 100% of parents feel as though the people in the DS clinic provide a caring atmosphere rather than just give them information to a very great, great, or fairly great extent
- In comparison, complex care clinics that lack this form of collaboration have been identified to require improvement in the communication among the child’s care team (Cohen *et al.* 2009)

### NEXT STEPS

Next steps would include:

- Continuing recruitment of DS collaborative clinic patients
- Surveying families on the waitlist for the DS clinic about their experiences in non-collaborative clinics using the MPOC in order to understand parent perceptions on non-collaborative clinics