

# SNUG camps for children affected by rare diseases: A dose of respite

February 2010



# What is it?

- A 5 or 6 day camp for the whole family
- Fun activities
- Outdoor adventure (canoeing, climbing wall, giant swing, archery, low ropes)
- Student volunteers



# Who is it for?

- Families of children with special needs from rural and regional NSW
- Focus on rare conditions (not exclusively)



# A family holiday





# A break



# Meeting other families



# Rejuvenation





# Learning from each other





# Medical appointments



# Who organises SNUG?

- The Family Action Centre at the University of Newcastle.
- A steering committee composed of a group of professionals who work with families with children with special needs
- Funded by Steve Waugh Foundation



# Goals of SNUG

- Improved access to dental and medical services
- Support networks for families created
- Improved resilience of families
- Students gain experience in understanding the issues faced by rural families with children with special needs.





# Improved access to dental and medical services

- Attended 94 medical and related health appointments including
- Dental (50)
- Music therapist (13)
- Paediatric neurologist (10)
- Massage (7)



# Improved access to dental and medical services

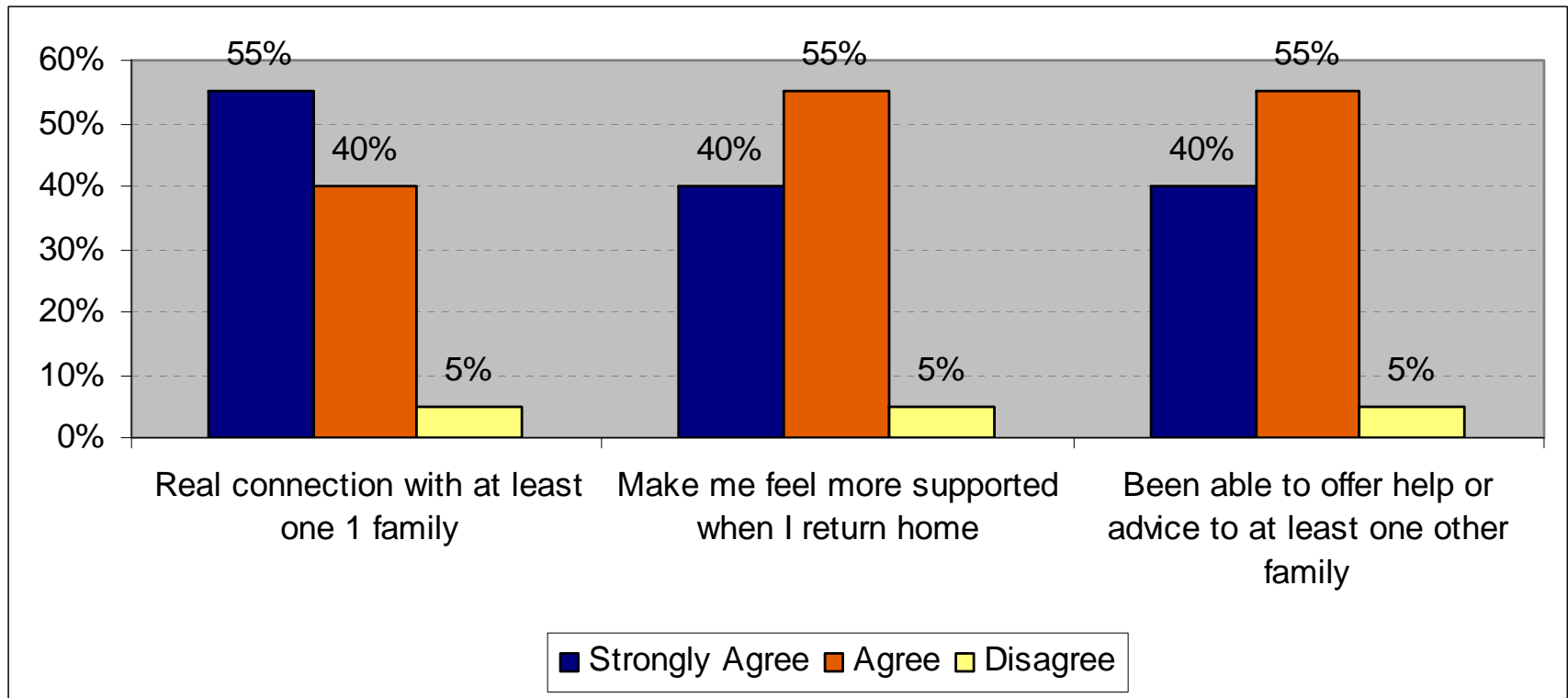
- 37.8% parents agreed or strongly agreed that “The health and community services in my local area can meet the needs of my family”.
- 80% strongly agreed that “SNUG allowed my family to access health services I would otherwise not have been able to access”. (The rest agreed.)
- All of them agreed (31.6%) or strongly agreed (68.4%) that the services they accessed were helpful.

# Support networks for families





# Create support networks



# Create support networks

- *Beth: There's a couple of families here that we've made a bit of connection with.... We quite often go, 'Oh yeah', you know, 'same for us', we've had similar experiences. You don't have to do the big explanation thing trying to get them to understand when they can't. (Camp 3)*

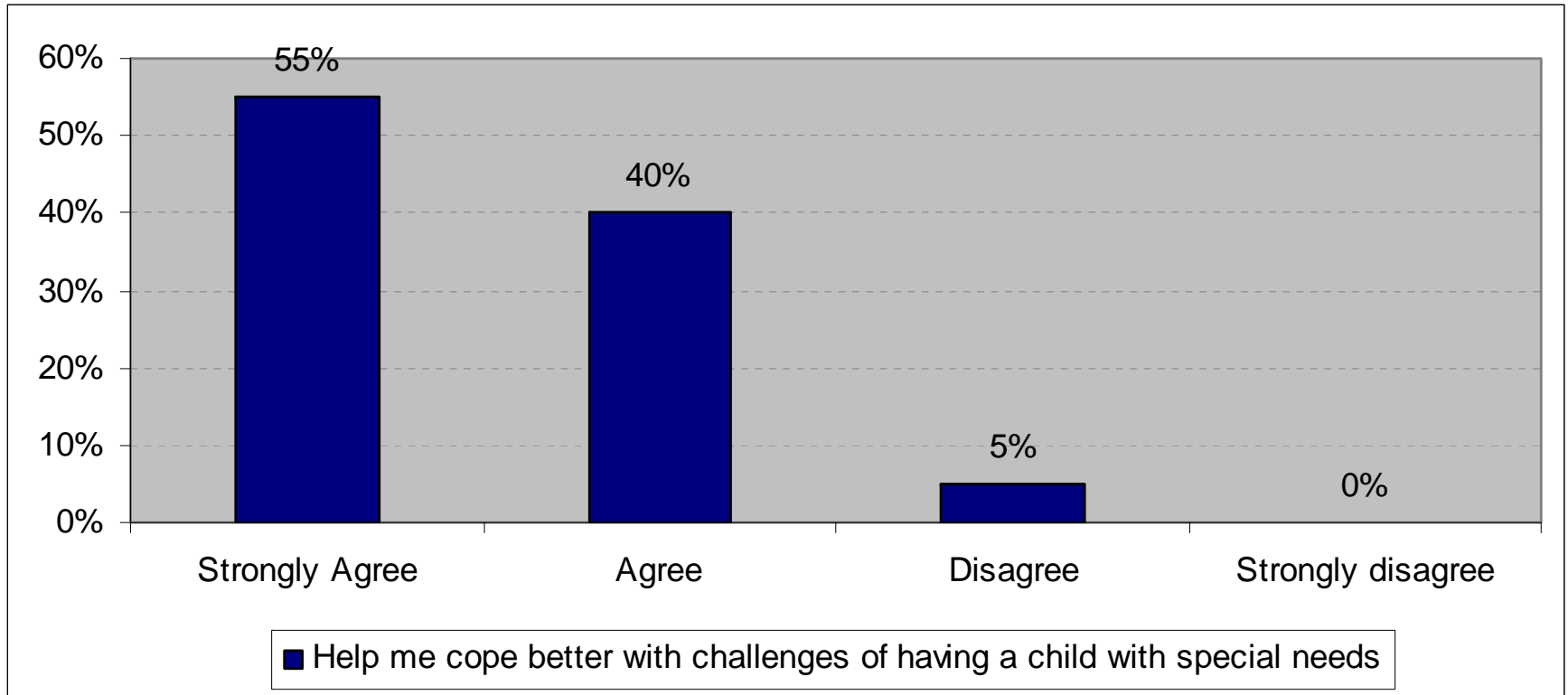


# Build resilience





# Build resilience



# Build resilience

- Strengthen their relationships
  - *Winston: It's a pretty good team building exercise to get everybody cooperating a little bit more. Because they're normally fighting & that. (14 year old, Camp 2)*



# Build resilience

- Renewed confidence in parenting
  - *Katie: And it's just nice to hear from specialists in their field to hear that you're doing a good job. Because we don't get to see many specialists, yeah it's just really, reassuring to know that you are doing the right thing. (Camp 2)*





# Build resilience

- Children able to meet others in a similar situation
  - *Don: It's good for them to realize they are not the only kids with disabled siblings. I think it's good for them to come here and know that all these other siblings have sisters or cousins or relations with RETTS Syndrome. (Camp 2)*



# Build resilience

- Relax, have a break and “recharge the batteries”
  - *Isabelle: Yeah and probably the nicest time I had was Wednesday afternoon, everybody had gone out and there was just two other parents and the two girls on the floor... Just having a level of peacefulness to talk and have a cup of tea. That's just a real gift really. (Camp 3)*



# Students gain experience

- 50 students trained
- 15 students at last camp (average 2-3 days each)
- Students from occupational therapy, speech pathology, teaching, nursing, social work



# Students gain experience

- *I've got a few clients at the moment, at my placement and they'll come in with parents and say, 'oh sorry, we're just so busy, we didn't get time to do the homework [set by an allied health professional]'. Before I was at the camp I would just think, oh they don't care much or they're just a bit lazy, but you can really see why people just don't get the homework done. When you see people's lifestyle and you forget what it was like when you were a kid, especially when things were a little bit tougher or you can't understand them or whatever.*



# Students gain experience

- *Beth: I think it's a reality check, that it is the whole deal - like the text book thing, they come out and they don't get the whole family thing. The family's been dealing with it from birth and maybe we know what we're talking about. The text books won't say that, but it's like, oh, no, we've been there, done that, we've found this. Even though it's in no text book, this is what works for us. So I think, yeah maybe they might pick up on that a bit. (Camp 3)*

# Shameless plug

- 80% strongly agreed the camps allowed their family to access health services (mainly dental) they would otherwise not have been able to access
- 90% strongly agreed the camps were a very worthwhile experience for them
- 95% strongly agreed they would recommend the camps to other families

# Further Info

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