

Hearing from the experts: Parents' knowledge of what works

Altogether Autism Conference

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Acknowledgement

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Backdrop

- Why the survey:

International Literature; NZ context

- What the survey involved
 - Phase 1 -Survey Monkey e-Questionnaire -3 different settings
 - Phase 2 – Focus Groups – 13 families across NZ
 - Phase 3 – Case studies – 5 families across NZ

3 key questions

What were the interventions accessed;

What was effective and useful;

What would be more useful and effective

Who, where & what

Number of participants

Location of participants

Ethnicity of participants

Nature of Employment

Age range/Gender of Child/Children

Levels of severity

Educational settings

Purpose of interventions/programmes

What would be more useful & effective- home and after school for children

- Behaviour interventions
- Communication support
- Daily living skills support
- Sensory therapies
- Social skills programme
- Holiday programmes/Leisure activities
- Advocacy

What would be more effective and useful for wider family support

- For parents and caregivers
 - ✧ Support groups
 - ✧ Education and Training
 - ✧ Respite, Carer relief
 - ✧ Information and Advice
 - ✧ Counselling
- For siblings
 - ✧ Self esteem building courses
 - ✧ Help to **Understand** their siblings problems and how best to deal with them (*when the information comes from a parent - it can seem like playing favourites between the children*).
 - ✧ Sibling camps
 - ✧ Youth groups (*more often*)
 - ✧ Counselling as and when needed
- Other

In summary – Most useful and effective home
and out of school for all

- Education and Training
- Extended family support
- Carer relief/Respite
- Counselling and Therapy
- Information and Advice

What would be useful and effective- Educational settings

- Education and Training
- Clear communication
- Individualised programme
- Therapies
- Support groups
- Safe school environment

Key issues

- **Availability**

Large cities vs smaller ones; Finite period of intervention;; Lack of consistency; Capacity and Capability in Education/Health sector, Information/Advice

- **Accessibility**

Location, Advocacy; Funding; Cultural appropriateness; Respite, Recreation.

- **Affordability**

Funding – ‘The money helps but it isn't everything’. SES

Ways forward

- **Flexibility?**
- **Feasibility?**
- **What else?**

Summing it up through parents' voice

Educate ALL teachers - they need to have to do a paper on autism, the ones already teaching need to do a educational course

Educate the doctors - ???? I don't know how best to do this.

Educate police - FANZ is an excellent course

Educate the public - Adverts / Educate the kids at school.

Oh and for families, take the stigma away from the word Autism (via the above education), so early intervention which I feel is so very very critical can be accessed.