Hearing from the experts: Parents’ knowledge of what works

Altogether Autism Conference
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Acknowledgement

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• Autism NZ
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 at 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
  
  o Flexibility?
  o Feasibility?
  o 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.
Hearing from the experts – Parents' knowledge of what works for their children

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