

Optimising Care for Children with VCFS & their Families:

a study into healthcare, education
& support service needs

Aim of Research

- Identify the needs of children with VCFS & their families in relation to healthcare, education & support services.
- Provide a model that integrates the healthcare, education & support services needs.

**The needs of children
with VCFS
& their families**

Health Services

- Awareness
- Access
- Availability
- Coordination

Awareness

- The need for information
 - Your child's condition, diagnosis & treatment
 - Available services
 - Likely growth & development
 - How to monitor your child
 - How to play, talk & educate your child
 - How to handle behaviour

Access

- Financial needs
 - Covering costs of specialists
 - Treatments
 - Time off work/child care for other siblings
- Geographical needs
 - Location
 - Distance services

Availability

- Specialists/Allied health professionals
 - That have experience
 - That are in a suitable location
 - In a reasonable timeframe

Coordination

- Communication between:
 - Doctors
 - Education
 - Support services

Education

- Again it's about:
 - Awareness
 - Access
 - Availability
 - Coordination

Services

- Disability services
- Centrelink
- Respite services
- Child care services

For the parents

- Researcher – you source information
- Care provider – nurse, social worker, doctor, and the list goes on...
- Treatment provider- dispenser of drugs, specialised treatments and psychological interventions
- Monitor – recognise new symptoms, ensure old symptoms are not getting worse
- Coordinator, advocate, personal representative for your child.....etc, etc, etc....the list goes on.....

Parents also have needs

- Family support & counselling
- Partnership

**How do we meet the
needs of children with
VCFS & their parents?
Some possible models**

VCFS Clinic

- A clinic that has integrated team of specialist doctors, allied health care professionals, education specialists, support services experts.
- A one stop shop!!!

Care Coordinator

- A person is allocated the responsibility to look after the needs of your child and you. Putting you in touch with medical professionals, allied health services, education specialists and support services.
- This person negotiates the best care for you and your child.

Parent as Care Coordinator

- The parent is provided with a pack of information e.g- medical records, information about diagnosis, treatment and interventions. The parent carry's that information with them, that information then forms the basis of access to health, education and support services.

Where to from here!!!

- First step, we need to identify needs of children with VCFS and their families in the Australian context .
- Step two, we want know the stresses of parenting a child with VCFS, as well as how you cope and what social support you have.
- Step three, we are going to examine models of care overseas to see what they are doing.
- Step four, we are going to get all of that information together and present it to you, and see what model of care best suits you. We will also invite some healthcare professionals, education and government representatives to have a look too.
- Step five, from the feedback we going to put together a model for the delivery of care for children with VCFS.

So if you are interested....

- In talking to me about your experiences with services or filling out some questionnaires., please contact me.
- The information you provide will be valuable in providing better care for your children.

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