

# VOLUNTEERS...

*Connecting people to people and people to place*

A Children's Champions Research Project –  
Analysis of how disability support groups evolve to provide services effectively  
to children 0-5yrs and families in the Cairns South area.

**Research by Kathleen LeMarquand**



Presented by



FNQ Volunteers Inc. (FNQVI) is proud to present this Research Paper on an analysis of how disability support groups evolve to provide services effectively to children 0-5yrs and families in the Cairns South communities and neighbourhoods from Woree to Gordonvale and Yarrabah.

FNQ Volunteers Inc. is the lead agency for volunteering in Far North Queensland and a community partner with the Cairns South Communities for Children, an Australian Government initiative.

In working with and speaking to members of these communities, FNQVI was made aware of the need to identify how support groups, in this case disability support groups evolve, progress, function or cease. Why are some support groups successful, why do some groups struggle? How can support groups be assisted in the early stages of their development and sustained?

FNQVI trusts that this Paper raises the awareness of the important role and functions of disability support groups and encourages service providers, government and non-government to strengthen their connections with volunteer support groups.

### **Acknowledgements**

FNQ Volunteers Inc. wishes to thank all those who have supported and endorsed this Research Paper. Particular thanks go to those support groups and service providers who participated in this project. Congratulations also to Kathleen LeMarquand for her involvement as a Volunteer Children's Champion and her dedication and commitment in bringing this publication to life.

With special thanks to Mission Australia - the Facilitating Partner for the Cairns South Communities for Children - initiative of the Australian Government, who provided the framework, support and funding assistance for this publication.

FNQ Volunteer Inc. also wishes to acknowledge the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs for its ongoing support through the Volunteer Management Programme. With this support, since 1999, FNQ Volunteers Inc. has operated and continues to deliver its services to the Volunteer sector in Far North Queensland communities.

**Ellen Barnes**

**Chief Executive Officer**

### Philosophy of Volunteering

*"Promoting citizen participation through activities and advocacy that lead to a more democratic, caring, dynamic and cohesive society in the context of our changing world"*

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**Through the  
Children's Champions Activity**

**In collaboration with  
Cairns South Communities for Children Initiative  
And Dept of Families, Housing, Community Services and Indigenous Affairs  
'Stronger Families and Communities Strategy'**

**Presents**

**A Children's Champions Research Project**

**'Analysis of how disability support groups evolve to provide services  
effectively to children 0-5yrs and families in the Cairns South area'.**

## INTRODUCTION

This resource is the result from research conducted by the Children's Champions Activity managed by FNQ Volunteers Inc. The Children's Champion Activity is a volunteer community engagement model funded through the Cairns South Communities for Children initiative. The Children's Champions are volunteers that utilise their knowledge and skills to facilitate community participation in the Cairns South area to develop 'Child Friendly Communities'. Activities facilitated by the Children's Champions addressed issues and concepts as illustrated in the 'Community Interdependence Model' developed by Vicki Johnson, Service Managers of the Townsville West Communities for Children (see illustration). Children's Champions provide a link between community and the Cairns South Communities for Children Community Partners and Facilitating Partner Mission Australia.

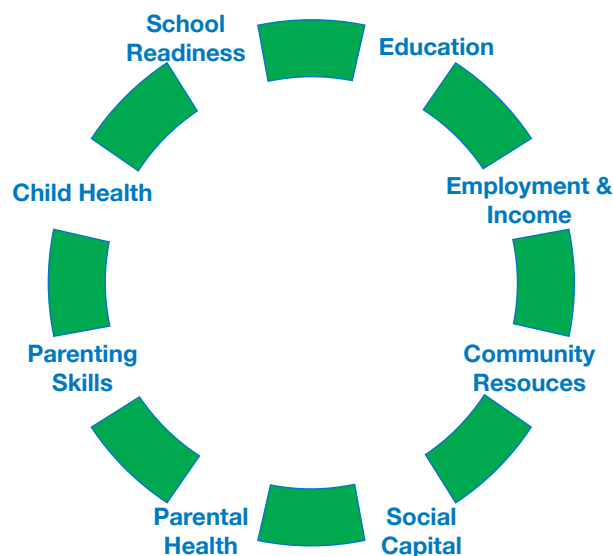
The Cairns South Communities for Children initiative is funded by Dept of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). The Communities for Children initiative is part of a national strategy to build 'Stronger Families and Communities' through implementing locally managed projects that develop local solutions for local need. Communities for Children initiative focus on developing universal early intervention strategies for children 0-5yrs and their families.

The Cairns South Communities for Children initiative includes communities south of Woree to Waugh's Pocket (between Mirriwinni and Innisfail), across to Yarrabah and includes Goldsborough Valley.

# COMMUNITY INTERDEPENDENCE MODEL

As developed by  
**Townsville West Communities for Children Community Strategic Plan**  
**Vicki Johnson, Project Manager, Communities for Children Townsville West**

The model spans prenatal to the transition to school, universally incorporates principles of open communication and diversity and seeks to identify what may be the connections between the factors which impact on the health, wellbeing and development of young children. This cycle is illustrated below and also reflects all C4C Priority Areas:



Using this model the CCC sought to develop strategies that were both immediate – able to meet needs in the early years service system, - and long term – able to build a sustainable system. The strategies are grounded in theoretical and practical evidence, primarily informed by the National Agenda for Early Childhood and recognise that intervening in the early years reduces the risk factors and improves a child’s developmental and health outcomes.

Collectively, these strategies reflect a coordinated approach to addressing issues in service delivery for children 0-5 years and their families in Townsville West. The Activities which sit underneath the strategies not only address the need for information and accessible services, but also the crucial role the environment and social capital plays in the development of young children.

All of the Activities promote a more child-friendly community and advocate partnerships between service sectors. The Strategies and Activities also acknowledge that community development programs that build on the existing strengths of the community and families and incorporate elements of ownership are more likely to achieve sustainable long-term outcomes.

Sustainability is addressed in the Plan for those Activities that will not be finalised at the end of 3 years, through building the capacity of the community to continue the Activities as is the case with supported playgroups becoming parent-led; by establishing partnerships with local businesses or attracting corporate sponsorship; or as a result of integrating Activities within existing local or state government programs which would be facilitated by the provision of evidence through the evaluation process, which would indicate how the Activities were producing successful outcomes.

(Used with permission from Townsville West Communities for Children Community Strategic Plan)



# AUTHORS BIOGRAPHY

## **Kathleen LeMarquand BSc Grad Dip. Genetic Counselling**

As an accredited Genetic Counsellor with the Human Genetic Society of Australasia and a member of the Australian Society of Genetic Counsellors, my previous positions have included, a Genetic Counsellor in The Children's Hospital at Westmead, Sydney's Children Hospital at Randwick, Royal North Shore Hospital, Royal Prince Alfred Hospital and IVF Australia.

As well as working as a Genetic Counsellor, I enjoy community work and have been involved with many Genetic Support groups in Sydney as a volunteer educator. I also enjoy my time as a parent helper at my children's schools and sporting groups. During my time in Cairns I found the time to become more involved with local communities. I introduced myself to FNQ Volunteers Inc. who encouraged and supported me as a 'Children's Champion' volunteer, which I have found very rewarding. Volunteering is something I will always find the time for, because belonging to a community and helping others, is a wonderful feeling.



## FNQ Volunteers Inc. (FNQVI)

**Cairns South Communities for Children Community Partner.**

**Phone: 4041 7400**

**[www.fnqvolunteers.org](http://www.fnqvolunteers.org)**

**Mission statement:**

***'Develop and strengthen volunteering for the benefit of the individual and the community'.***

Established in 1999 in response to community needs, FNQVI refers volunteers into positions within other not-for-profit community throughout the Far North Queensland region. The aims of the organisation is to support volunteers and community organisations by assisting with the development of the required infrastructure, skills and capacity needed to achieve sustainable quality 'volunteering' for the benefit of the whole community. FNQ Volunteers Inc. delivers a range of services to support the involvement of volunteers in contributing to building the economic and social capital of the region.

FNQ Volunteers Inc. (FNQVI) Children's Champions Activity commenced in November 2006 in the Cairns South communities, from Woree to Babinda including Yarrabah. As part of the C4C initiative they have introduced the Volunteer Children's Champions model to the Cairns South community. Children's Champions are volunteers who care about very young children and their families in the local community.

The role of Volunteer Children's Champions is to promote the Communities for Children initiative and activities to families and children in the Cairns South Corridor.



# PROJECT AIM

This project aims to research how disability support groups develop to provide services successfully to children 0-5yrs and their families in the Cairns South area. The research will explore the strengths and barriers faced by existing disability support groups when engaging with their target population. Through this research, FNQVI intends to learn how to best assist sustainability of community disability support groups through the group development process.

# HOW THE PROJECT EVOLVED

The idea for this study evolved from community education sessions facilitated by me, Kathleen LeMarquand as a Volunteer Children's Champion. During the sessions, parents in the Cairns South area spoke of their frustrating experiences searching for a medical explanation for their child's condition. Often, after obtaining a diagnosis, that is life shattering to their family, parents are sent away feeling isolated. Parents attending community education sessions spoke about their lonely, grief stricken time after the initial diagnosis and how they would have liked some support to help understand what the diagnosis means for them, their family and friends, and to know they are not alone.

With a background in Genetic Counselling, I have previously observed the benefits of support groups in the community. Meeting with others that have similar conditions can provide access to more relevant and meaningful information and more empathetic support. Self support groups provide an ideal situation for community members to care for each other, as the strength of self help groups is the power that comes from people involved in their own health issues. Self support groups often begin as several individuals in small groups and expand into larger groups involved in voluntary community support and education. Whilst there are many different support groups in existence in South Cairns, it appears there are also many people feeling very alone, with struggling families, who don't know how to access appropriate support.

# RESEARCH METHODOLOGY

The research area was Cairns South which is defined as south of Woree to Waugh's Pocket Rd including Yarrabah and Goldsborough. All the disability support groups that are supporting the Cairns South communities were included in the research. The target group were children 0-5yrs with a disability and their families.

The research was conducted through:

- Making connections with as many of the existing support groups in the South Cairns area by phone, email and in person where possible
- Examination of existing literature – pamphlets, newsletters and promotional material
- Attendance at scheduled meetings, conferences and private meetings
- Making connections with disability service providers in Cairns South area to establish the referral process to support groups
- Obtaining relevant information on support groups including:
  - Disability
  - Number of participants
  - When the group was formed
  - Structure of the group
  - Activities undertaken by the group
  - Communication styles
  - Amount of community support
  - Access



# WHAT IS A DISABILITY?

Each person's experience of disability is different. Experiences are influenced by what happens in your life, your access to information, services, opportunities, the environment where you live, and the attitudes of people in your community.

The International Classification of Functioning Disability and Health (ICF) classify 'disability' as 'an umbrella term for any or all of the components: impairment, activity limitation and participation restriction, as influenced by environmental factors'.

There are many different types of disability. A disability can be caused by a genetic condition, an illness or an accident, and includes:

- Intellectual disability
- Sensory disability
- Neurological impairment
- Dual disability (one of the above and a psychiatric disability)
- Any combination of these
- Physical disability
- Acquired brain injury
- Disabilities that are unrelated to ageing

# WHAT IS A DISABILITY SUPPORT GROUP?

Support groups, also referred to as self-help groups, are voluntary small group structures for mutual aid and the accomplishment of a special purpose (Zastrow, 2003). In a support group, members provide each other with various types of nonprofessional, nonmaterial help for a particular shared burdensome characteristic. The help may take the form of providing relevant information, relating personal experiences, listening to others' experiences, providing sympathetic understanding and establishing social networks.

A support group may also provide ancillary support, such as serving as a voice for the public or engaging in advocacy.

A support group is fully organised and managed by its members, usually volunteers. A disability support group is a group that comes together because of the common issue of having a disability or caring for someone with a disability.





**RESEARCH FINDINGS-  
EXISTING DISABILITY  
SUPPORT GROUPS**



## Cairns Autism Spectrum Disorder (ASD) Support Group

**[www.casg.org.au/indexOld.htm](http://www.casg.org.au/indexOld.htm)**

**Phone: 0488 578 735**

Cairns ASD support group has an informative website that explains how they can be a support to families with children affected by Autism or Asperger's Syndrome. Services include:

- Access to information, support networks and events for all members.
- A sympathetic environment where issues can be shared and aired without fear of criticism.
- A forum for visiting professionals of the group's choice to aid awareness and provide education and financial support to the group.
- A positive meeting point for carers and family members, to exchange information and useful ideas, to promote friendships, understanding and acceptance.

The Cairns ASD group began with a single parent searching for social and community support. She set up a playgroup with other parents of ASD children and the group has now grown to include 80 members. A membership fee of \$15 now applies to cover the group's resources. They have successfully progressed from a small self-help group to a very supportive and educational service for all the community. They are becoming a strong voice in the Cairns South community and have contributed to greatly improved services for children with ASD.

The ASD group advertise their services on pamphlets in community centres, health centres, child care services and schools and are well known by the disability service providers who refer directly to them. They do not believe they are reaching everyone who has a child with ASD and will continue to expand their presence in the community as they understand the importance of early intervention and the need for families to be supported. The parent leaders are working in a voluntary capacity and do get very busy and 'burn out', especially if they are working and caring for a child with special needs. The committee members change regularly to maintain relevance to new mothers and to obtain fresh enthusiasm. The ASD support group are now looking at the use of volunteers for fundraising activities and possible child care during meetings.

## Cairns Blind & Visually Impaired Support Group

**Phone: 4041 5545**

This is a professionally organised group that meet on the first Tuesday each month. It is not specifically for Cairns South communities and it includes families of children of all ages. Families are referred by health professionals to Vision Australia who then refer to local groups. The support group believes that "Most families are happy with the support they receive from this support group".

## Carer's Queensland Support Groups

### **Edmonton Carers**

**Phone: 4031 0163**

A state wide not for profit organisation that creates support networks and support group meetings for all the carers in the community. They organise special events, fund raising activities, organise guest speakers and help carers access the appropriate service providers.

The Cairns South Carers group are located at Edmonton and meet on the first Thursday of each month at Hambledon House. The group does not concentrate on any particular age group, or disability type, and has a carer oriented program that includes carers of young children, elderly, disabled, adolescents and their friends and neighbours. They prefer carers to come without their dependents to allow for a more open and honest discussion of their concerns. Carer's QLD advertise widely with pamphlets and all of the disability service providers are aware of their existence and refer to their support groups regularly.

## Cerebral Palsy League

**Phone: 4799 9600 (Townsville)**

There is not a structured Cerebral Palsy support group in Cairns. However there are several families in Cairns who have formed friendships after meeting other families with children that have cerebral palsy. They have met through attending disability services. The Townsville Cerebral Palsy League is responsible for the Far North region and will support any groups wanting to start up and they have a good support network in Townsville. Many families have called the Townsville group searching for a Cairns local support group and find it disappointing not to have their own.

## Cystic Fibrosis (CF) Support Group

**Phone: 4041 5219 or 1800 670990**

The CF group in Cairns receive excellent support from the Cystic Fibrosis Association who offers formalised meetings, education and excellent resources. They provide a permanent family support worker in Cairns who helps organise fund raising activities, mother's respite, sibling camps and accommodation in Brisbane for treatment visits. In Cairns there are approximately 40 affected members and their families at present. They are referred through the hospital system via the paediatricians and from the Genetic Counsellor at Cairns Base hospital. The group meet on the fourth Saturday every two months at various locations. The group would like to have more volunteers to help with fund raising activities.

Separate to the CF Association there is a smaller parent support group that meet more regularly and casually in each others homes and local cafes. The group is coordinated by an active parent who sees the need for more social relaxed gatherings. The less formal gatherings, she believes, allow more open and honest discussions about looking after a child with CF. The support group includes families from the greater area of Cairns, not just Cairns South, due to the relatively rare nature of the disability.



## Deaf Services QLD

**Phone: Voice Line 4031 6315 or Fax line 4031 1383**

Deaf Services QLD has a family support officer in Cairns who attends to all families referred to them from the medical system. They do not have a family support group organised for new parents and are not aware of any in the Cairns area. The family support worker was very keen on the idea but did not know how to go about organising a group or groups in different areas. She knew of many families affected by hearing loss in the Cairns South community and believed they would benefit from a local support group.

## Down Syndrome Support Group

**Phone: 4039 1725**

Down Syndrome Association of QLD is the overseeing body and they offer resources and information to all affected families in Queensland. An active parent has been running the Down Syndrome support group in Cairns for several years now, and is about to hand over the reigns to a parent of a younger child. The group was set up for new mothers feeling lost and confused after having a child with a disability they knew very little about. The group meet casually for morning teas at each others homes and various other locations. Many close friendships have formed from the groups. The parents are usually active in the group while their children are 0-5yrs or before school. After those early years they are ready to move on and make new associations with school parents. There are other Down Syndrome groups more concerned with adolescents, adults and a carer's parent group.

The support group recruits directly from the maternity hospitals and provides information packs to new parents of a child with Down Syndrome. They obtain contact details of the new families and personally contact them to invite them to the support group meetings. Most new parents are keen to meet others going through the same thing however it can take several phone calls to some who are a little apprehensive. The group is very active at including everyone and is growing successfully. The support group is not confined to the Cairns South area.

## Duchenne Muscular Dystrophy (DMD)

**Phone: 4057 5731**

**[www.parentproject.org.au](http://www.parentproject.org.au)**

The support for DMD families is generally via the internet on a website named Parent Project Australia. A mother in Cairns is the president of Parent Project and she has a son with DMD now in his 20's. She administers the beach wheelchair for lending to DMD families, is the webmaster, president and grant writer amongst other things for this group. They have a regular scheduled chat on the forum webpage on Sundays. Most of the DMD members use the link to DMD support from the parent project webpage for practical and emotional support or they use Duchenne Community in the USA website which is like Facebook: <http://community.parentprojectmd.org/>

A few of the families help each other out with driving the children as a specialist van is required, they do some local fundraising and the president's son has spoken at schools to help inform others about DMD and catering for disabled students. A quote from the president "I guess most of our support comes from epals, whether that is because we can be ourselves and not ourselves (as our neighbours know us) if we choose...." Whilst anonymity is good sometimes, there is certainly some interest in having a local support group for social interaction as well as the current online network.

A woman with dark hair, wearing a red top, is leaning over a table, assisting two young boys with a craft project. The boy on the left is wearing a white t-shirt and holding a wooden stick. The boy on the right is wearing a green t-shirt and is focused on a task. On the table, there are various colorful wooden blocks and a blue plastic container filled with more blocks. The background shows a window with greenery outside and a yellow wall.

# DISABILITY SERVICE PROVIDERS

## **The Association of Genetic Support of Australasia Inc. (AGSA)**

**Phone: (02) 9211 1462**

**[www.agsa-geneticsupport.org.au/home](http://www.agsa-geneticsupport.org.au/home)**

The Association of Genetic Support of Australasia facilitates support for those affected directly or indirectly by genetic conditions throughout Australasia. They ensure there is always someone to talk to and will provide relevant contacts to make the journey a little easier. AGSA have a contact register with over 500 genetic contacts and details of support groups, and are meeting new people every week who are starting their own new connections.

AGSA help families set up their own local groups and through a project they are currently running, 'Filling the Void' they aim to support people living in isolation who are caring for someone with a genetic condition. This includes support through telegroup counselling, face to face counselling, seminars and workshops.

## **ARC Disability Services Inc. – Accommodating, Responsive, Creative.**

**Phone: 4046 3600**

**[www.arcinc.org.au](http://www.arcinc.org.au)**

Support Services for people who have disabilities, and for their families.

They provide:

- The ARC Respite House
- The ARC Flexi Respite Service
- The ARC Resource Centre
- The ARC Emergency Support Service
- The ARC Post School Services Program
- The ARC Family Support Program

Families are referred to ARC by Disability Services QLD, Community Health, schools, self referral and other health and disability service providers. They advertise using pamphlets and word of mouth. They are an excellent service provider and are the only respite centre in Cairns. ARC refer their families to support groups that they are aware of and have an extensive list of groups and service providers. They do not initiate groups however it is something they could consider if they had enough staff or volunteers to organise it.

## Community Health Centre Edmonton

**Phone: 4045 9900**

The community health centres provide a range of clinics for assessment, education and support for parents and caregivers of children aged 0-12 years. This includes:

- Short consultation in child health clinics. Consultation includes: sleep and settling, behaviour management, postnatal support, breastfeeding management and support, development, injury prevention, immunisation and nutrition.
- Extended consultation at the Infant Feeding Support Program for infants under 6 months with feeding issues.
- 'Triple P' Positive Parenting Program including seminars, groups and individual sessions
- Hearing assessment and hearing referral clinic for children and young people 4-18yrs
- Health surveillance and screening (hearing and vision assessment, growth and development assessments).

Services are provided by a multidisciplinary team. Referral to the clinic is either self referral or by medical practitioner. The Community Health Centre refers families who have children with disabilities to

ARC, Disability Services QLD and counsellors. Local support groups are not referred to unless specifically asked for and the Health Centre was not aware of most of the support groups in the area. Edmonton Community Health Centre has in the past tried grouping new mothers in the 0 to 12 month period including some families that had children with disabilities. Due to reduced staff numbers, time constraints and costs this service is not currently occurring.

The community health centre recognises the need for a dedicated early childhood nurse to provide regular home visits to new mothers. This would help identify those families with special needs and they could be encouraged to join a support group.

There is a current project, funded by Cairns South Communities for Children, looking at this service.

## Disability Services QLD (DSQ)

**Phone: 4046 7200**

**[www.disability.qld.gov.au](http://www.disability.qld.gov.au)**

Disability Services Queensland helps people with a disability and their families to access the support and services they need as they move through the different stages of their life. Disability Services Queensland's Family and Early Childhood Services supports families with a child aged up to six years who has, or is at risk of, a significant developmental delay. With the support and information provided through the service, families are able to strengthen their knowledge, skills and resources, giving them a better opportunity to help promote their child's developmental learning and inclusion in the local community.

DSQ refers to any known support groups and encourage families to participate in support groups. In 2007 they trialed a playgroup for six special needs children and their families. This was a great success and they would like to try it again. Families are not always referred to DSQ until they are school age which is unfortunate and families can not use more than one disability service provider at any time. This confuses parents as to what is the best option for their child and trying out various services is difficult as the referral process is very lengthy.

## Early Childhood Development Unit (ECDU)

**Phone: 4042 8129**

Children from birth to six years who have, or are suspected of having significant educational needs may access a variety of programs/services through the Early Childhood Development Unit. Parramatta State School is the primary unit and there is also ECDU at Isabella Sate School servicing the Cairns South area.

Early intervention programs for special needs children is their primary focus. Families are referred to the ECDU via GP's, self referral, daycare centres and community health centres. The referral process is very lengthy as they put a profile together of the child before deciding placements. There are limited places available due to staff shortages and funding.

ECDU is a great place for parents to meet other parents as the children often have group therapy and the parents can have a coffee and chat during that time. The staff have noticed that many friendships have been formed this way. Isabella Sate School ECDU ran a parent/grand parent support group last year which was very successful. The school premises are wonderful and the special education area is well suited to all disabilities. The support group is no longer running due to constraints from school regulations, lack of support staff and parental commitment.

## General Practice Cairns

**Phone: 4080 1500**

General Practice Cairns covers all the General Practitioner (GP) doctors in the Cairns area. A survey was sent to all the GPs in the Cairns South area asking them what disability support groups they knew were in the area and what service providers they referred families with children that have disabilities to. Unfortunately there were no replies and the referral process from GPs, to disability support groups and services, cannot be commented on.



## Genetic Health QLD (GHQ)

**Phone: Cairns Genetic Counsellor 4050 6247**

**Brisbane: 36361686**

All of Queensland Health's clinical genetics services are provided by Genetic Health Queensland (GHQ).

GHQ's clinical team includes consultant clinical geneticists, registrars and genetic counsellors. They provide diagnostic, counselling, support and educational services to individuals and families who have or are at risk of having a genetic or inherited condition. It also provides health promotion in relation to hereditary disorders, professional and community education and outreach services delivered by local genetic counsellors and visiting consultant clinical geneticists.

Medical practitioners may refer people to GHQ. Other health professionals may refer to the service for certain conditions and should contact the service.

People who might be referred to GHQ include those who have:

A personal or family history of known or suspected genetic conditions such as: muscular dystrophy, Down syndrome, haemophilia, cystic

- fibrosis, albinism, growth disorders, fragile X syndrome, learning difficulties, metabolic disorders
- A personal or family history of birth defects such as cleft lip and palate, club foot, congenital heart disease and spina bifida
- An increased risk of genetic conditions because of their ethnic background (eg Greek and Indian people have an increased risk for beta thalassaemia, Jewish people for Tay-Sachs disease, and Europeans for cystic fibrosis)
- Consanguinity (husband and wife, or partners, are related eg first cousins)
- The woman is 35 years or over and pregnant or considering pregnancy
- An increased risk result from screening tests during pregnancy
- Exposure to drugs, alcohol, chemicals, infection or radiation during pregnancy
- A history of infertility, multiple miscarriages, stillbirths or early infant deaths where personal or family history or tests have indicated a possible underlying genetic cause
- A personal or family history of intellectual disability, slow development and/or seizures
- A personal or family history of hearing or visual impairment
- A strong personal or family history of cancer.

The Cairns Genetic Counsellor is located at Cairns Base Hospital and a Geneticist visits regularly for scheduled clinics. She refers to all the relevant support groups and has regular contact with many of the Cairns South families. Unfortunately many families do not get referred to or even know of the existence of the Cairns Genetic Counsellor.



## **Hambledon House – South Cairns Family Support Centre**

**Phone: 4045 0222**

*“Supporting individuals, families and community groups living in the southern suburbs of Cairns and Yarrabah community”.*

Hambledon House has an extensive array of pamphlets and written material on many of the services in the Cairns South area. There is a dedicated Family Support Officer who visits families in need and develops community programs. She does not currently see any families with children that have disabilities and she does not know of any support groups for these families in her area. As she is new in the position she is still learning about the Cairns South local community and their needs, and will look at disability support groups in the future.

Hambledon House offers its premises as a suitable place for disability support group meetings with all the appropriate facilities. It is \$15.50 for the room hire and can be booked on a regular basis or a one off situation. There are already many different support groups using this facility including the Carers Support Group. It is a great place for disability support groups to meet and should be better utilised.

## **Inclusion Support Agency Far North QLD (ISAFNQ)**

**Phone: 4032 1713**

ISAFNQ assist child care services to include children with additional needs in child care. Inclusion Support Facilitators assist child care services to build their skill base and capacity to include children with additional needs; they do not assist parents or children directly.

The target groups for inclusion support are:

- Children from culturally and linguistically diverse (CALD) backgrounds, including refugee children
- Children with ongoing high support needs, including children with a disability
- Aboriginal and Torres Strait Islander children

## **Parent Support Education QLD District Office**

**Phone: 0428 452 398**

Parent Support Education is primarily for school aged children and their families and they will help parents access early childhood and special needs programmes. All students with a disability are supported in state schools. A wide range of support services to assist with information, programs and processes about students with disabilities is available through contacting schools and the Parent Support Officer.

The Parent Support Officer is also involved with many support groups in Cairns, particularly the Carers QLD groups. A strong advocate for disability support groups and the Support Officer highlights the need for the involvement of volunteers to look after young children while parents socialise without interruption.

## Playgroup FNQ Regional Office

**Phone: 4033 6966 or 4033 6566**

**[www.playgroupaustralia.com.au](http://www.playgroupaustralia.com.au)**

A playgroup is a group of mums, dads, grandparents and caregivers who meet together each week with their babies, toddlers and preschoolers for interaction and fun.

Playgroup Queensland caters for families with children with Autism Spectrum Disorder engaging families in PlayConnect playgroup. Playgroup Queensland also has “My Time” which caters for families with a child with a disability using peer support networks. The Playgroup Association does have the facilities for children with disabilities and would accommodate them in any community model playgroup. Playgroup Queensland market to all families inclusive of diversity.

## Self Help QLD (SHQ)

**Phone: (07) 3344 6919**

**[www.selfhelpqld.org.au](http://www.selfhelpqld.org.au)**

*“Supporting people to find their own solutions to improve well being”.*

Self Help Queensland Inc is a not for profit community organisation comprising a network of self help and support groups in Queensland. The groups include participants with a broad range of health conditions and well-being issues such as genetic conditions, chronic illness, mental health, disability, grief and loss, sexual health and many more.

SHQ provides:

- Referrals to self help and support groups for health conditions and well being issues
- Information relating to the Self Help Sector
- Free Quarterly Newsletters by post or email
- Free use of meeting room, kitchen and office equipment for groups
- Letters of support for groups seeking funding
- Assistance in promoting groups
- Information, networking and practical advice for starting new groups
- Publication – “Self Help Queensland Directory of Self Help and Support Groups” 2006/07 Inaugural Edition hard copy for sale

SHQ is an excellent organisation that is under utilised as it is relatively unknown in Cairns.



## Wuchopperen Indigenous Health Service

**Phone: 4080 1002**

**[www.wuchopperen.com](http://www.wuchopperen.com)**

*“Our purpose is to improve Aboriginal and Torres Strait Islander health outcomes through excellence in service delivery.”*

The Wuchopperen Indigenous Health Service does not have a specific disability support program. For the families who have children with disabilities they are offered counselling services, home help services and are referred to Disability Services QLD. There is not an indigenous specific disability support service in the Cairns South area. The indigenous children with disabilities are cared for by their extended families and are offered external services if they would like them. The Social and Emotional Well Being Worker interviewed was unaware of any support groups in the Cairns South area. They are interested to learn about setting up support groups and have had enquiries about disability support groups for adults.

## Yarrabah Community

**Shire Council Phone: 4056 9120**

**[www.indiginet.com.au/yarrabah](http://www.indiginet.com.au/yarrabah)**

*“The Women’s Resource Centre helps women in trouble, families with transport to and from hospitals, shopping, disabilities, catering for functions, counselling and any other family needs.”*

There are no known disability support groups within the Yarrabah community and disability is an area that needs further exploration within indigenous groups. Unfortunately due to time constraints and more pressing community issues at present we were unable to access the Yarrabah community and cannot comment on their involvement with disability support groups.



# DISCUSSION

Parents of young children with a disability are at significant risk of isolation and are often socially disconnected from family and friends due to the intensity of their caring role. Carers make a significant contribution to the community in providing care to their relatives, they experience higher rates of physical, mental or emotional health problems and their social networks are often severely limited (Edwards, Higgins & Zmijewski, 2007). Disability Support Groups give parents the chance to socialise and share ideas with others who understand the rewards and challenges of the caring role. The role of community and government services and not for profit organisations is to encourage the evolution of disability support groups to provide services effectively to children 0-5yrs and their families.

Disability support groups are usually formed by people who have come together for mutual assistance in satisfying a common need such as a child with a disability, and hope to bring about desired social/personal change (Zastrow, 2003). Many of the parents, usually mothers, spoke about their needs not being met through existing disability/community services and joining a support group help filled the void and provided much needed emotional support. Having experienced the pain and life changing consequences of having a child with a disability, support group members are often highly motivated and dedicated to finding ways to help themselves and others in similar situations. This was an observed characteristic of many of the successful group members.

Another understood benefit of support groups is that the participants benefit from the 'helper therapy principle' where the helper gains psychological rewards by helping others (Zastrow, p 126, 2003). This principle was discussed with several groups and members believed by helping others it enabled them to put their own problems into perspective. When people help each other in support groups they tend to feel empowered, as they are able to control important aspects of their lives. Building social networks and empowering communities has been shown to contribute to stronger communities and promote positive social outcomes (Gauntlett, Hugman, Kenyon et al, 2000). Empowerment increases motivation, energy, personal growth, and an ability to help that goes beyond helping oneself or receiving help. The success of many support groups is contributed by the emphasis on empowerment.

The importance of face to face social interactions were discussed and most agreed it was important. Parents of children with very rare conditions were satisfied with online support services for information and discussions however still felt isolated in their local community. For many parents group membership provides benefits which go beyond the support for their condition. These benefits include friendship and emotional support, raised self esteem and improved communication skills. Some of the general characteristics of a successful disability support group are listed below.

## CHARACTERISTICS OF A SUCCESSFUL DISABILITY SUPPORT GROUP FOR CHILDREN 0-5YRS AND THEIR FAMILIES.

- Managed and maintained by members with a common interest (child with a disability)
- Have little or no professional supervision but supported by a health service or professional
- Successful referral process for introducing new members – face to face encouragement from health services
- Provide information, advocacy and support for their own group and wider community on disabilities
- Engage in community activities
- An emphasis on empowerment
- Offer sibling support

For continued existence, groups must deal with the challenges of encouraging new leaders, attracting new members, obtaining funds or assistance to support their activities, and meeting the changing needs of members. Important organisational characteristics associated with longevity are committed and effective leadership, community connections that help provide needed funds or practical assistance, and the willingness of group members to change activities to meet changing needs (King, Stewart, King et al, 2000). A great example of a group managing its members' needs and funding very well, is the ASD support group. They grew from a few families to over 80 members and are now very involved in educating the community about their disorder and advocating for change in child care centres and schools.

Another important aspect of disability support groups is to be non-competitive with other support groups and disability services and to maintain a cooperative orientation. Working with disability service providers, GPs and other community services is necessary to have a successful referral system to disability support groups. The groups need to make themselves known to these organisations and be proactive in encouraging new membership. Family Support workers in Cairns South should encourage parents of young children with disabilities to make use of groups such as AGSA, Self-Help QLD and FNQ Volunteers Inc. to help set up new local disability support groups or refresh old ones. The Community Health service, Wuchopperen Indigenous Health, Yarrabah Community and other disability service providers require educating on the types of organisations that are available in assisting support group set up. As one of the parents said "There are some good services available, but they could be better advertised and coordinated".

There have been some disability groups in Cairns that began with all the right intentions and had most of the characteristics previously listed, however over time they collapsed. Some of the factors that create barriers to support group set up or result in subsequent failure are listed below.

## FACTORS THAT CONTRIBUTE TO UNSUCCESSFUL DISABILITY SUPPORT GROUPS:

- Parents of newly diagnosed child with a disability are not ready to socialise with others – different stages of grief
- Lack of child care during support group meetings
- Many families are single parents looking after more than 1 child and are too busy or both parents working
- Transport to meetings can be an issue
- Poor referral process and lack of awareness of group existence
- Pamphlets & written material not as encouraging as face to face consultations
- Groups can become too big and lose personal touch
- Professionals become too involved and take over
- Liability laws - hiring facilities
- High staff turnover in service providers – reduced local knowledge

The barriers to the success of disability support groups can be dealt with to improve on the number of disability support groups in the Cairns South area. All of the disability service providers for the area have agreed that many families would love to attend support groups if it was organised for them. The initial grouping of families can come from community providers and hopefully through some strong individuals the support groups will grow and succeed. For many people, finding out that they are 'not the only ones' is a major turning point in their grief process and having common ground and a common language helps parents feel normal again. They discover groups can have a stronger voice than an individual, which helps them express their needs, be heard and get things done (Self-Help QLD, 2006). Highlighting all the benefits of support groups to individual families through face to face consultations is believed to be the best way to ensure their participation.



# CONCLUSION

It is very clear, from meeting and discussing over the phone with many disability support groups and disability service providers, that the benefits of support groups to the local community are plentiful. They improve community wellbeing, (the physical, mental and social wellbeing of people), they help break down social stigmas through community education and they help create lasting friendships.

Understanding the characteristics that make disability support groups successful and effective service providers will hopefully encourage existing groups, to reflect on their current effectiveness and role in the community. Disability service providers should also gain valuable knowledge of what support groups exist, how to improve their referral system and what organisations are available to help set up new support groups.

Through community consultation the need for more disability support groups, for children 0-5yrs and families in the Cairns South area, has been highlighted. The establishment of new disability support groups will hopefully be actively encouraged as an outcome of this research.



# FUTURE INVOLVEMENT FOR FNQ VOLUNTEERS INC.

FNQ Volunteers Inc. through the Children's Champions Activity supports the involvement of volunteers to develop 'Child Friendly Communities'. FNQ Volunteers Inc. is committed to build and sustain the Children's Champions model to effectively engage with community.

FNQ Volunteers Inc. is able to facilitate the involvement of volunteers with Service Providers in the Disability Sector. Through membership FNQ Volunteers Inc. is resourced to provide the following services:

- Volunteer referral
- Advocacy
- Community development
- Network information
- Training – volunteers and volunteer managers

Volunteer Support Groups are encouraged to access these services directly to assist in the development of their group. FNQ Volunteers Inc. provides capacity building programs for Support Groups including:

- Advocacy
- Accessing community resources
- Communicating effectively
- Marketing

## Contact Details

FNQ Volunteers Inc.

Suite 10, Virginia House, 68 Abbott St Cairns 4870

Tel: 07 4041 7400 Email: [info@fnqvolunteers.org](mailto:info@fnqvolunteers.org)

# ACKNOWLEDGEMENTS

This project would not have been possible without my partnership with FNQ Volunteers Inc. I would like to thank all the staff at FNQ Volunteers for their support and particular thanks go to Ellen Barnes and Tracey Dickinson for their continual support and encouragement.

Special thanks to all the wonderful individuals I spoke to from the disability support groups mentioned in this document; without your generosity and assistance this project would not have evolved. Your contribution to the Cairns South community is commendable.

Thank you to all the disability service providers, community organisations, Indigenous support services and health workers for their precious time to meet with me and discuss my research project. Your input was invaluable.

I also wish to acknowledge the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs for its financial support as part of the 'Stronger Families and Communities Strategy'.

# APOLOGIES

I am sorry to any support groups, community groups or service providers who have not been included in this research. Your omission is only because I did not know of your existence or I was unable to get in touch with you within the short time frame of this project. FNQ Volunteers Inc. would love to hear from you and include you in any future updates and CommunityConnect Directories.

Kathleen LeMarquand

Researcher

# APPENDIX 1

## Survey sent to General Practice Cairns

[www.gpcairns.org.au](http://www.gpcairns.org.au)

### PROJECT

Analysis of how disabilities Support Groups evolve to provide services effectively to children 0-5yrs and families in the Cairns South area.

Researcher: Kathleen LeMarquand BSc Grad Dip Genetic Counselling in partnership with FNQ Volunteers Inc. Funded by Dept of Families, Housing, Community Services and Indigenous Affairs "Stronger Families and Community Strategy"

This project is not conducted in conjunction with any University as I am doing it in a partly voluntary capacity and in partnership with FNQ Volunteers Inc. as an accredited Genetic Counsellor with the Human Genetic Society of Australasia I am working under the Genetic Code of Ethics.

There will be complete depersonalisation of information, and information provided by individuals will be collectively described under their organisation name or profession. General Practitioners will be referred to as GP's and no names will be used and are not required in the questionnaire. The names of support groups can be named under a location such as "Edmonton Support Group" or as the type of disorder/disability such as "Down Syndrome Support Group".

### QUESTIONS

1. Are you aware of any disability support groups in your area? If so which ones.
2. Do you refer families that have a child or children with disabilities to support groups?
3. What other disability service providers do you refer these families to?

It would be great to receive some responses as it would help us determine how best to assist sustainability of community disability support groups.

Thank you for your support

Kind regards,

Kathleen LeMarquand

# APPENDIX 2

## QUESTIONNAIRE USED FOR INTERVIEWING SUPPORT GROUPS.

Tell me about your support group.

When, where and how often do you meet?

How many members do you have?

When and how was the group formed?

What age are the children who have the disability?

How do you advertise your group? How did your members find out about your group?

What activities do you do as a group?

What community support do you receive? Would you like more community support? Are you aware of groups like FNQ Volunteers Inc. and Self Help QLD?

Can I meet with your group to discuss this further?

## QUESTIONNAIRE USED FOR INTERVIEWING DISABILITY SERVICE PROVIDERS.

What services do you offer families with children aged 0 to 5yrs that have disabilities?

Are you aware of any disability support groups in your area? If so which ones.

Do you refer families that have a child or children with disabilities to support groups?

What other disability service providers do you refer these families to?

Have you thought about organising support groups for parents of children with disabilities?

Are you aware of groups like FNQ Volunteers Inc. and Self Help QLD who can help support you, using volunteers?

How are families referred to you?

Do you see a need for more disability support groups?

Can I meet with you to discuss this further?

# REFERENCES

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# USEFUL WEBSITES

**FNQ Volunteers Inc.:** Information on volunteering [www.fnqvolunteers.org](http://www.fnqvolunteers.org)

**Mission Australia:** [www.missionaustralia.com.au](http://www.missionaustralia.com.au)

**NAPCAN:** Offers free wellbeing and prevention tools and resources for professionals, families, carers and children [www.napcan.org.au](http://www.napcan.org.au)

**Raising Children Network:** Information on parenting, community resources and downloadable resources [www.raisingchildren.net.au](http://www.raisingchildren.net.au)





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Artwork by Impress Art Graphic Designs, 07 4056 5688