Department of Communities, Child Safety and Disability Services

My child has Fragile X syndrome

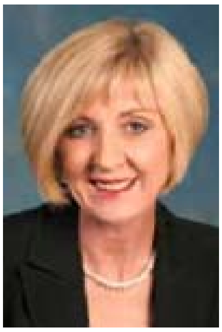
Information for Queensland families of young children

Photo by xxxxxxxxx

A Parent Connect resource

Queensland Government

Message from the Minister



Having a child with Fragile X syndrome raises many questions — from wanting to understand what Fragile X means for your child and your family, to how you can support your child's inclusion in family and community life.

My child has Fragile X syndrome is a guide that helps answer these questions. It includes practical information for families about accessing services and supports, as well as kindergarten programs and starting school.

Fragile X is a genetic condition, and although every child is different and will require different levels of support, accessing services during the early years is critical for families.

This early intervention means children with Fragile X can be supported to achieve important developmental milestones.

Supporting families with young children is a priority for the Queensland Government. We are committed to improving direct services to families by delivering initiatives such as Parent Connect, and by increasing the number of speech and language pathologists for all children with a disability in Queensland schools.

As we deliver these new priorities for Queensland, I look forward to enabling a better future for Queensland families of children with disability.

I would like to thank the Fragile X Syndrome Association of Australia for contributing to this guide and for their ongoing support for children with Fragile X and their families.

The Honourable Tracy Davis MP
Minister for Communities, Child Safety
and Disability Services

Contents

1. About Fragile X syndrome

This guide is intended to answer some of the questions you may have about Fragile X syndrome and the supports and services available to you and your family in your child's early years.

Fragile X syndrome is the most common cause of inherited intellectual disability.

Fragile X syndrome is caused by a change in the FMR1 gene located on the bottom of the X chromosome. A diagnosis of Fragile X syndrome is made when specialist DNA testing identifies the FMR1 gene as damaged (fragile). Both males and females can carry the Fragile X gene.

What are the early signs of Fragile X syndrome?

Fragile X can affect individuals in a range of ways and to varying degrees. Some children with Fragile X may only have mild learning difficulties while others will experience significant intellectual disability and behavioural difficulties.

A number of characteristic physical features may be present in children with Fragile X syndrome; others will not become apparent until adulthood. Common physical features, most predominant in males, can include:

- a larger than average head size (macrocephaly)
- chest which appears hollow
- long face or prominent chin
- prominent ears
- especially soft and smooth skin
- puffy eyelids
- a single palmar crease
- a high arched palate.

Tips for parents

Children with Fragile X syndrome often develop very good long-term memories.

Approximately 50 per cent of people with Fragile X have some of these characteristic features which vary in degree from person to person.

Babies with Fragile X often have delayed motor milestones and low muscle tone. Delayed language development and limited speech before three years of age is also common in children with Fragile X, however, generally by school age most children will have achieved satisfactory verbal communication.

Almost all children with Fragile X syndrome have trouble self-regulating their behaviour. Some behaviours are similar to autism and are most common in males. These include avoiding touch, difficulty in making eye contact, hand flapping, and biting or chewing of the child's own hands and clothing.

Anxiety, shyness, poor concentration, sleep disturbance, tantrums, late toilet training, fixation on certain subjects and difficulties with change in routine are other possible behavioural symptoms.

Despite behavioural challenges, children with Fragile X will often develop pleasant personalities and a good sense of humour.

Although there is currently no cure for Fragile X syndrome, early intervention combined with therapies, medications and targeted teaching methods can assist children with a diagnosis of Fragile X to develop to their full potential.

How common is Fragile X syndrome?

Approximately one in 260 females and one in 800 males are Fragile X carriers.

It is generally estimated that one child per week is born in Australia that is fully affected and 20 are born who are carriers.

Males are generally more severely affected than females. Fragile X syndrome occurs in all countries and across all socioeconomic groups.

Find out more

Fragile X Association of Australia
1300 FX INFO (1300 394 636)
www.fragilex.org.au
Email: support@fragilex.org.au

2. Diagnosis

The early years of your child’s life are critical to their future development so if you are concerned that your child may have Fragile X syndrome it is important to seek a formal diagnosis as soon as possible. An early diagnosis will assist you to access supports and services that can be tailored to best support your child’s needs and to maximise their strengths and development potential.

Diagnosis will assist you to better understand what your child may be experiencing and enable you to explore and identify suitable therapies and supports. Services will also provide information and support for you about how to support your child’s development at home.

Importantly, even if your child’s initial assessment is developmental delay, this will often be sufficient for your child to access early intervention services. Early intervention services are critical to getting the best possible outcome for your child.

Who provides a diagnosis of Fragile X syndrome in Queensland?

In Queensland, a geneticist or paediatrician can arrange for your child to be tested for Fragile X syndrome. Your GP can provide a referral to either of these specialists. A blood test called DNA Studies for Fragile X syndrome is used to diagnose the syndrome.

Cytogenetic blood testing may also be carried out to check for any other genetic disorders. Test results may not be available for several weeks.

Prenatal testing is also available for female carriers of Fragile X syndrome. These tests, chorionic villus sampling (CVS) and pre-implantation genetic diagnosis (PGD) can be conducted early in a pregnancy, however, the results of testing may take several weeks to be confirmed.

Families living in rural and remote areas can access a visiting Department of Health paediatrician. Talk to your GP about getting a referral.

After diagnosis

It is normal to feel worried about your child’s future when you receive the diagnosis of Fragile X syndrome but it is also important to understand there is a lot that can be done to support your child to grow and develop to their full potential.

Sometimes parents feel overwhelmed and experience feelings of disbelief, sorrow, anger and guilt. It is important to recognise that this is normal and that you will need support to get through this difficult time. You may get this support from family and friends and you can also contact the Fragile X Association of Australia. In Queensland, the Fragile X Association of Australia provides telephone and email support. You may also like to talk to your GP for advice on supports in your local area.

Tips for parents

Children with Fragile X often experience developmental delay in the areas of speech, crawling, sitting, walking and toilet training.

Parent Connect

The Department of Communities, Child Safety and Disability Services' Parent Connect initiative supports parents of newborns and children newly diagnosed with disability. It is an early response service providing information and linking families to family support networks, community services and funding to access specialist services.

Child health services in the community

Staffed by nurses and allied health professionals, free child health services are available at community clinics. Home visiting may also be provided. Child health checks are recommended at one, two, four, six and 12 months of age. Information is available on child health, parenting, child development, immunisation and nutrition. Families can be linked to local services and parent groups. For further information refer to your baby's Red Book.

Carers Queensland

Carers Queensland provides carers with information, education, training, advocacy, counselling and other support services that may assist them in their caring role. The organisation also raises awareness about the valuable role and contributions of carers.

Financial support

If you live in a rural or remote area and need to travel to attend specialist medical appointments, you may be eligible for the Patient Travel Subsidy Scheme. Ask your GP for further information.

Should your child's support needs mean that you are unable to enter paid employment, you may be eligible for Carer Payment. Centrelink can provide more information regarding your eligibility as well as information on supplementary payments such as Carer Allowance and Child Disability Assistance Payment.

Find out more

Parent Connect is provided by the following organisations:

Cairns – The Benevolent Society
4045 0003
www.benevolent.org.au

Townsville – The Cootharinga Society of North Queensland
4759 2008
www.cootharinga.org.au

Rockhampton – The Cootharinga Society of North Queensland in partnership with The Umbrella Network
4928 6550
www.theumbrellanetwork.org

Sunshine Coast – Sunshine Coast Children's Therapy Centre
5441 4937
www.scctc.org.au

Brisbane North – Mission Australia
3828 9311

Brisbane South – Mission Australia
3713 2602

Ipswich – Mission Australia
3713 2602
www.missionaustralia.com.au

Gold Coast – The Benevolent Society
5644 9400
www.benevolent.org.au

Child health services in the community
13 HEALTH (13 43 25 84)
www.health.qld.gov.au

Carers Queensland
3900 8100
1800 242 636 (Advisory Service)
www.carersqld.asn.au

Patient Travel Subsidy Scheme
www.health.qld.gov.au

Centrelink
132 468
www.humanservics.org.au

Disability Information Service
13 QGOV
www.communities.qld.gov.au

3. Early intervention services

Early intervention services are important for all children with disability to help develop skills in play, communication, social relationships and functional behaviours. Services can also assist in increasing children's independence and ability to adapt to new environments. Early intervention helps children with Fragile X syndrome develop the skills needed to participate in child care and kindergarten and improves their readiness for school.

Supports provided by early intervention services for children with disability aged from birth to school-entry age and their families, include:

- information and planning
- advice on your child's developmental needs
- multidisciplinary therapy to support your child's development and help them reach developmental milestones
- referrals to other specialist services and mainstream services
- coordination of services for children with complex needs
- support with transitioning to a kindergarten program and school
- counselling and linking families with other families and support groups.

Tips for parents

Children with Fragile X syndrome tend to learn visually, so try to use photos and pictures to assist your child's understanding.

Tips for parents

Children with Fragile X syndrome can often be hypersensitive to stimuli. Ask your therapist about calming techniques such as massage and other activities which may assist your child.

How will my child benefit from early intervention?

Early intervention is most effective and provides the best possible outcomes for your child when provided as early as possible after diagnosis.

Services should be tailored to the individual needs of your child and family. It is important for you as a parent to have a good rapport with your child's specialists and feel able to ask lots of questions about their therapy and progress.

Early childhood intervention services can assist you and your family to develop knowledge and skills and provide support to meet the needs of your child, optimise your child's development and increase their ability to participate in family and community life.

All services recognise the importance of working in partnership with families.

Ideally services will be provided in a flexible way that meets the needs of as many families as possible.

Successful early intervention services may involve professionals working directly with your child as well as teaching you strategies to support your child to develop their potential.

Early intervention for children with Fragile X syndrome may include speech and language therapy, occupational therapy and physiotherapy, genetic counselling and support for parents, and teaching parents how to support their child's development at home.

The type of early childhood intervention services required by your child will be influenced by the types of issues they experience and other factors such as their age. Your early intervention service provider will work with you to develop a plan tailored to your child's needs.

Where can I access early intervention supports?

Both the Australian Government and Queensland Government fund early intervention services for children with disabilities, including Fragile X syndrome. This section details the main services available.

Better Start

Children with Fragile X syndrome under six years of age are eligible for supports and services through the Australian Government's Better Start for Children with a Disability initiative.

Through Better Start children can be registered to access early intervention funding of up to $12,000 (up to a maximum of $6000 in any one financial year). Families have up until their child's seventh birthday to use this funding.

Better Start funding can be used to pay for early intervention services provided by a range of early intervention professionals including speech and language pathologists, audiologists, occupational specialists, physiotherapists, psychologists and orthoptists.

Up to $2100 (35 per cent) per year of a child's early intervention funding can be used to purchase resources. Resources must either be recommended by a Better Start service provider, be directly linked to an early intervention service or be for the delivery of interventions in the family home.

Families living in regional or remote areas may be eligible for an additional one-off payment of $2000. This payment is to assist with additional expenses associated with accessing services.

Early intervention service

The Department of Communities, Child Safety and Disability Services provides early intervention services to children who have, or are at risk of, developmental delay. This includes children with Fragile X syndrome.

These services can support your child in their play and independence, as well as develop their communication skills, and gross and fine motor movements.

The department also provides information for families on a range of topics and will support you to connect with other services and supports (e.g. playgroups, childcare and parent support groups).

Children are prioritised for services according to their level of need and availability of places.

Local Area Coordinators

Disability Services has Local Area Coordinators to link children with disability and their families in regional, rural and remote areas with supports and services relating to their individual needs and interests, including accessing visiting specialists to obtain a diagnosis.

Tips for parents

Speech and language development is often affected by a number of factors for children with Fragile X syndrome including low muscle tone. Speech specialists and occupational specialists can both be beneficial to your child's speech development.

Early childhood development programs and services

The Department of Education, Training and Employment provides multidisciplinary therapy and early intervention services to children from birth to prior-to-Prep age with a suspected or diagnosed disability and significant educational needs. Children with Fragile X syndrome who have developmental delay, intellectual or physical disability can access these services.

Early childhood development programs and services generally consist of two phases. Phase one involves assisting children from birth to 3.5 years through specialists attending playgroup sessions with parents. Phase two involves assisting children aged 3.5 to five years through centre-based programs. As children move through phase two, the transition to Prep becomes a significant focus. Specialist multidisciplinary outreach support may also be provided in the child's home or educational setting during both phases one and two.

Child development services

The Department of Health provides early intervention services to children with a moderate to severe developmental delay or disability aged up to nine years, including children with Fragile X syndrome.

Priority is given to children not eligible to receive services from other Queensland Government agencies. Services include providing advice on your child's developmental needs and therapy services that encourage your child's development. Parent education and information sessions are also provided.

Other service providers

While there are early intervention services available for children with disability, some families may want to seek support from a range of providers.

Your GP, paediatrician or child health nurse should be able to refer you to a range of specialists.

Links to websites that may help you locate professionals such as physiotherapists, speech and language pathologists, occupational specialists and psychologists are provided in this guide.

Find out more

Better Start
Call Carers Queensland
1800 242 636
www.betterstart.net.au

Early intervention services
Disability Services service centres
13 QGOV
www.communities.qld.gov.au

Early childhood development programs and services
Contact your local education regional offices
www.education.qld.gov.au

Child Development Services
13 HEALTH (13 43 25 84)
www.health.qld.gov.au

Local Area Coordinators
13 QGOV
www.communities.qld.gov.au

Mater Children's Hospital Paediatric Complex Care Service

Children with complex health and disability needs may be eligible for this service. The Paediatric Complex Care

Service assists children and their families to access appropriate services and supports in both hospital and community settings. Services provided include:

- a phone contact service (care line)
- regional support for families who live outside the Brisbane area
- hospital support including regular visits and advocacy
- links to community services and supports
- information and training
- equipment support
- referrals.

Support for parents

It is not unusual for parents of children with a disability to feel overwhelmed from time to time, especially during times of change, such as when your child starts early intervention services, child care or kindergarten.

Having a network of support, including formal supports such as early intervention services, and informal supports such as other parents of children with Fragile X syndrome and your family and friends, can be a big help.

Raising Children Network website

Is an Australian Government initiative that provides a web-based source of information about parenting and child development activities for children, including children with disability.

The Umbrella Network

Is based in Rockhampton and is a network of support and information for families who have a child with disability, including intellectual disability.

Triple P — Positive Parenting Program

Triple P — Positive Parenting Program can help many families who have a child with special support needs to creatively problem solve and develop flexible and supportive family routines and strategies to support their child's learning and development.

Stepping Stones — Triple P Positive Parenting for parents of children with a disability can help parents address their children's behaviour and emotional problems (e.g. going to sleep, mealtimes, choosing what clothes to wear, dressing, toileting, going shopping and going to the doctors).

Stepping Stones can be accessed in different ways through information seminars, individual sessions on specific issues, group sessions, online options and tip-sheets and workbooks for parents.

Other parents

Parents often find the best support they have comes from other parents of children with Fragile X syndrome Other parents understand the joys and challenges of raising a child with Fragile X syndrome and can share advice and information about local services.

Find out more

Mater Children's Hospital Paediatric Complex Care Unit
3163 1876
Email: complex_care@mater.org.au

The Umbrella Network
0408 500 287 - Rockhampton

4723 4278 – Townsville
www.theumbrellanetwork.org

Raising Children Network
Australian parenting website
www.raisingchildren.net.au

Triple P — Positive Parenting Program
3236 1212
www.triplep-steppingstones.net
www.triplep-parenting.net

Playgroups

Play is an integral part of all children's development, including children with a disability. Through play, a child learns, builds confidence and develops a range of skills in readiness for childcare, kindergarten and school.

Playgroups nurture children with play based learning experiences during key times of growth and development in their early years.

Playgroups offer a wonderful opportunity for young children to come together and play in a safe, relaxed and welcoming environment. Playgroups are low cost and inclusive and all children under school age are welcome.

Playgroups also help families by providing social support for parents. It provides an environment where parents can discuss and share parenting experiences and get information on how to address parenting issues.

There are a range of playgroups available, including community playgroups, supported playgroups, PlayConnect and Playgroup Plus Program.

MyTime groups

Provide local support for mums, dads, grandparents and anyone caring for a young child under school age with disability or a chronic medical condition.

MyTime gives parents the chance to socialise and share ideas with others who understand the rewards and intensity of the caring role. Parents can meet with people in similar circumstances to have fun, hear from others and find out about available community support. Research-based parenting information is also available at group meetings.

Each group has a play helper who can lead children in activities such as singing, drawing, and playing with toys, blocks or sand so parents can spend time focusing on catching up with others.

Baby Bridges

Baby Bridges is a playgroup program for children with disability from birth to five years. Parents and carers hear up-to-date information from carers and specialists while their child attends a playgroup taken by professional occupational, music or speech specialists.

Find out more

Search for services or specialists in your local area through the websites of professional associations:

Playgroup Queensland
1800 171 882
www.playgroupqld.com.au

MyTime groups
1800 171 882
www.mytime.net.au

Baby Bridges
Contact the Horizon Foundation
1800 843 008
www.babybridges.com.au

The Australian Physiotherapy Association
www.physiotherapy.asn.au

Speech Pathology Australia
www.speechpathology.australia.org.au

Occupational Therapy Australia
www.otqld.org.au

Australian Psychological Society
www.psychology.org.au

4. Early childhood education and care

What are early childhood education and care services?

Early childhood education and care services include child care and kindergarten services. Children can attend approved child care services from birth and all children are eligible to attend a kindergarten program in the year before they commence school (Prep). The Queensland Government provides funding to approved kindergarten programs delivered in long day care or kindergarten services.

The early years of any child's life have a significant impact on their future health, development, learning and wellbeing. It is generally accepted that children who participate in early childhood education are likely to have better academic performance, better behaviour, and stay in education for longer. This includes children with Fragile X syndrome.

Participating in a quality early childhood education and care program will provide children with Fragile X syndrome opportunities to develop their social, communication, sensory, memory and motor skills from an early age.

How will my child benefit from child care?

Child care provides all children an early opportunity to relate to peers and other adults. This is no different for children with Fragile X syndrome.

It can also be an opportunity for you to receive input from qualified early childhood professionals and try new approaches to supporting the development of your child.

Child care can also provide you with opportunities to return to work, study or to have time with other members of your family.

What supports are available for my child to attend child care?

The Australian Government supports children with disability who attend child care through the Inclusion and Professional Support Program. This support may be available to:

- subsidise the cost of additional educators or carers
- provide access to specialist equipment to assist inclusion
- provide professional development and resources for educators.

How will my child benefit from a kindergarten program?

All children benefit from participating in an approved quality early education program, including children with Fragile X syndrome.

Participation in a kindergarten program can help your child develop skills in communication, social interaction and positive behaviours. It can also assist your child to follow routines, as well as provide exposure to early literacy and numeracy concepts.

Participation in a kindergarten program will give your child a greater chance of successfully transitioning into Prep and then into mainstream schooling.

Kindergarten programs offer play-based learning in a fun and nurturing environment.

All children benefit from these early learning experiences and develop abilities including:

- being involved and learning to interact with other children
- developing a desire to learn and ways of learning
- understanding and managing their feelings
- learning about themselves, developing their identity, confidence and independence, and
- communication skills.

How will my child be supported in a kindergarten program?

Teachers in kindergarten services and long day care services can access support to assist children with disability to participate in their programs.

Children with disability, including children with Fragile X syndrome, can receive additional support to participate in a kindergarten program. Kindergarten services can apply under the Disability Support Funding Program, Department of Education, Training and Employment, to receive additional funding to support your child's participation in their kindergarten program.

Additional support may include:

- equipment and play resources
- training and professional development for kindergarten teachers
- extra teacher aide time to support the child's inclusion in the kindergarten program.

Kindergarten programs in long day care services may be eligible for the Australian Government's Inclusion and Professional Support Program, which provides professional development and other assistance to child care services supporting children with additional needs.

Kindergarten teachers can modify the kindergarten program to support the inclusion of your child. The wider kindergarten community can also be provided with information about Fragile X syndrome to encourage inclusion of your child and your family in the service.

Tips for parents

Children with Fragile X are excellent imitators so ask for your child to be paired with a good role model at kindergarten and school.

How do I plan my child's transition into a kindergarten program?

Starting in a kindergarten program involves significant transition for children with Fragile X syndrome and their families.

Your child will most likely need a period of preparation before they start in a kindergarten program as well as support to settle in and ongoing support to ensure their needs are being met and they are achieving educational goals.

Successful transition planning requires a team approach with your family and the kindergarten teacher. Planning should commence six to 12 months before your child starts in the service.

Transition planning for your child to start their kindergarten program involves a range of activities including enrolment, working with the kindergarten teacher to plan a suitable program for your child and help to identify the additional supports needed, such as training and educational and play equipment.

Other activities involved in transition planning for your child include visiting the kindergarten to become more familiar with the environment and routines, and gradually adjusting routines at home to be similar to those they will experience in the program.

Tips for parents

Link your therapist or early intervention provider with your child's kindergarten teacher to help plan your child's program. This will help identify the supports your child will need, such as any aids and play equipment being used by your child.

.

Find out more

Early childhood education and care services

Early years centres provide education, family support and health services for children 0–8 years.
www.dete.qld.gov.au
or phone 13 QGOV

Disability Support Funding Program, Early Childhood Education and Care Services and Kindergarten Services
www.dete.qld.gov.au

Inclusion and Professional Support Program
(Australian Government)
www.mychild.gov.au

5. Starting school

Starting school is an important time for children and families. The transition to school may present challenges for your child, as well as for the rest of your family and good planning is critical. It is important to commence planning for the transition to school at least 12 months before your child is due to start.

Where can I enrol my child?

All children are able to enrol at their local state school. It is best to talk to the principal of the school about the type and level of support available for your child before completing enrolment forms. You may also be asked to attend an interview with a staff member as part of the process.

Choosing a school for your child is an important decision, so it may also be useful to talk to other parents who have children at the school you are considering.

Is my child ready for Prep?

Prep is offered in all state schools as a full five-day-per-week program. To be eligible for Prep a child must turn five by 30 June in the year they start Prep. With the introduction of the Australian Curriculum, full-time attendance in Prep gives children, including children with Fragile X syndrome, the foundation they need for successful learning in Year 1 and beyond.

If you are concerned that your child is not ready to start Prep at that time, you can choose to start your child a year later when they reach compulsory school age (six years and six months).

You should discuss the specific needs of your child with the principal of the school you plan to enrol your child in. The principal will help you determine the impact of delaying your child's entry into Prep.

Parents of compulsory school-age children have a legal obligation to ensure that their children are enrolled in school and attend every day of their educational program. Enrolment and full-time attendance at Prep fulfils this obligation.

Tips for parents

Children with Fragile X syndrome often have difficulty communicating what is upsetting them. Make sure your child's teacher is aware of situations and stimuli which affect your child.

How can I prepare my child for school?

Beginning school is a big step for all children and their families. Children develop at different rates and in different ways. It is important to show your child you believe they are ready for school and not show if you are worried.

We recommend you contact your local school in the year before you enrol your child to discuss your child's individual needs. This will give the school time for planning to ensure your child has a successful and positive start to schooling.

If you are concerned about your child's readiness for school, discuss this with the school of your choice and your early intervention service provider.

If your child has been receiving services from an early childhood intervention service or a kindergarten program, staff from these services can provide information to the school about your child's strengths and needs, which will assist with the transition process.

There are a number of things you can do to help prepare your child for the transition to school. This should include visiting the new school several times before starting school, initially during quiet times of the day (possibly before or after school hours) and later at busier times so your child becomes familiar with the school environment.

How will my child be supported to learn at school?

The Australian Curriculum Foundation Year has been developed to give children in Prep the important foundational learning they will need for successful progression to Year 1.

The Australian Curriculum starts in Queensland in the 2012 school year. It aims to provide a high-quality curriculum for all, while understanding the diverse and complex nature of students with disability. It is shaped by the proposition that each student can learn and the needs of every student are important.

The principal is responsible for ensuring that all students with disability are provided with appropriate adjustments to enable them to access the curriculum.

When required, students with disability can be supported through appropriate adjustments made by teachers and schools in relation to:

- what a student learns
- how the student learns and instructional processes
- how the student demonstrates what they have learned
- the environment in which the student learns.

Tips for parents

Many children with Fragile X syndrome enjoy using computers. Talk to your child's teachers about using a computer to assist your child's learning. You can also explore a range of educational software for use at home.

Student Support Services

Students with disability are likely to require additional educational support so they are able to access and participate at school alongside their same-age peers.

These students can be supported through the full array of student support services allocated to regions and schools. This may include assistive technology, alternative format material, specialised equipment, special provisions for assessment, and access to specialist teachers, speech and language pathologists, physiotherapists, occupational therapists and guidance officers.

Collaboration with parents is an important part of the process of identifying and responding to the individual needs of students with disability.

For specific information regarding what your child will be learning at your chosen school and the types of equipment and support available, you should contact the principal.

Equipment at school

Education Queensland has an equipment loans service for students with disability who attend state schools. Schools can borrow specialised equipment and assistive technology from a regionally managed loans service to trial with students with disability. This helps schools to identify and make decisions about appropriate resources to support students' educational programs. The equipment remains the property of the Department of Education, Training and Employment.

Non-government schools

Catholic Education's Education Adjustment Program supports students who have disability in Catholic schools by identifying the educational adjustments required by a school to meet the learning and teaching needs of your child. Other non-government schools may have specialist services for children with disabilities related to Fragile X syndrome — check with the principal of the school you are considering.

Find out more

Local schools

- **Education for children with disability: a guide for parents**
- **School Transport Assistance Program for Students with Disability**
- **Support for children with disability at school**

www.education.qld.gov.au

Delayed entry to Prep
www.dete.qld.gov.au

Australian curriculum
www.australiancurriculum.edu.au

Tips for teachers

Children with Fragile X syndrome are prone to hyperarousal and anxiety. For tips on positive interactions and communication styles to help minimise this behaviour see the article *Top 10 things a teacher should know about Fragile X Syndrome* (December 2012, Laurie Yankowitz, Ed.D.) at: www.fragilex.org

6. Aids, equipment and assistive technology

If your child's disability affects their functioning across a range of areas, you may need to access assistive technology, specialised equipment or other aids to assist them in their daily living, communicating, learning, therapy and play. Professionals involved in your child's health, education and therapy will be able to give you advice regarding the most appropriate aids, equipment and assistive technology to consider.

This section details some services that may assist you to access support in this area.

Department of Health — Medical Aids Subsidy Scheme

The Medical Aids Subsidy Scheme (MASS) provides access to subsidy funding for the provision of MASS endorsed aids and equipment to eligible Queensland residents, including children with disability.

The range of MASS aids and equipment is aimed at assisting people to live at home and include aids for mobility, communication, continence and daily living.

Aids and equipment are subsidy funded either on a permanent loan basis, private ownership or through the purchase of consumables.

Department of Communities, Child Safety and Disability Services

Assistance can be provided to purchase aids, equipment and assistive technology for eligible children if the item is related to the disability and encourages independence and community participation. To access assistance, a prescription from your child's therapist is required.

The Community Aids Equipment and Assistive Technologies Initiative

The Community Aids Equipment and Assistive Technologies Initiative subsidises aids and equipment for eligible clients. Categories for aids and assistive technologies include community mobility, communication support, active participation and postural support.

LifeTec

LifeTec Queensland provides information, consultation, and education on assistive technology which aims to help improve quality of life and increase independent living skills. LifeTec has offices in Brisbane and Townsville and has a mobile outreach team that offers services across the state.

All Abilities Playgrounds

All Abilities Playgrounds are located across Queensland and are specifically designed to enable children with and without disability to enjoy fun and challenging play together, side-by-side. There are 17 playgrounds located across the state.

There is also an All Abilities ePlayground which offers free online fun and games for children of all abilities.

Department of Education, Training and Employment

Education Queensland has an equipment loans service for students with disability. This service provides specialised equipment for students with disability if it supports their educational program. The equipment remains the property of the school when a student leaves.

Noah's Ark Toy Library

Noah's Ark Educational Resources and Toy Library has a wide range of toys and equipment, some of which are designed and adapted for children with disabilities or special needs.

To borrow from the Noah's Ark Educational Resources and Toy Library, you will need to be a member of Noah's Ark.

Membership is open to:

- families with a child with a diagnosed disability
- schools supporting a child or children with diagnosed disability
- community organisations supporting a child or children with diagnosed disability
- children's Services supporting a child or children with diagnosed disability
- professionals (e.g. teachers, therapists) supporting a child or children with diagnosed disability.

Find out more

Medical Aids Subsidy Scheme
www.health.qld.gov.au

Disability Services service centres
13 QGOV
www.communities.qld.gov.au

Common Aids Equipment and Assistive Technologies Initiative
www.qld.gov.au/disability

Education Queensland
www.education.qld.gov.au

All abilities playgrounds
www.communities.qld.gov.au

Noah's Ark Toy Library
3391 2166
www.noahsark.net.au

For further information contact the Department of Communities, Child Safety and Disability Services:

Telephone: 13 QGOV (13 74 68)
Telephone Typewriter (TTY): 133 677
Email: disabilityinfo@disability.qld.gov.au
Web: www.communities.qld.gov.au

If you are deaf, or have a hearing impairment or speech impairment, contact us through the National Relay Service:

- TTY users phone 133 677
- Speak and Listen users phone 1800 555 727 then ask for 13 QGOV (13 74 68)
- Internet relay users connect to the NRS (www.relayservice.com.au) and then ask for 13 QGOV (13 74 68)

Other languages and formats:

If you need the assistance of an interpreter, please contact the Translating and Interpreting Service, TIS National, on 13 14 50 and ask to be connected to the Disability Information Service.

This document is available in alternative formats (including large print) on request. If you would like a copy in another format, please contact Disability Information Service on 13 QGOV (13 74 68) or email disabilityinfo@disability.qld.gov.au

* Calls from mobile phones are charged at applicable rates.

Queenslanders now have access to disability related information at one easy online location. Visit www.qld.gov.au/disability to find out about government supports and services for people with disability, their families and carers. The website includes links to information about support groups and counselling, education and where to access help.

Department of Communities, Child Safety and Disability Services
GPO Box 806
Brisbane Q 4001

Images: Fragile X Association of Australia

All images in this document are for illustrative purposes only

Information current as at March 2014