

FRAGILE X ASSOCIATION OF AUSTRALIA LIBRARY LISTING

The Association has an extensive collection of books, videos, CDs and DVDs and we are adding to them all the time. The printed booklets *Explaining Fragile X Syndrome* are available free of charge to members to distribute to family, friends and the community. *Books which have a bibliography have an asterisk after the publishing details.

BOOKS

| TITLE | AUTHOR | PUBLISHER | DEPOSIT |
|---|---|---|-----------|
| Boys with Fragile X Syndrome | O'Connor, R | The National Fragile X Foundation, 1995 | A\$15 |
| From the Fragile X Awareness Series for Children, this book is intended to help children and families understand and explain the different features many boys with Fragile X Syndrome display. A colourful story book, it is an ideal way to help siblings and classmates discuss and understand Fragile X. | | | |
| The Broken Toy | Marilyn Morgan | Authorhouse, 2005 | A\$15 |
| This short book tells the story of a mother's fight to gain the best for her son with fx. Dan was born in 1977 and the book takes us through the various stages of his life and an honest picture at the end of a young man who has achieved much despite his deficits. | | | |
| Children with Fragile X Syndrome: A Parent's Guide | Weber, J.D. | Woodbine House, 2000* | A\$40 |
| Written by leading practitioners and parents for families, teachers and other professionals working with children with fragile X syndrome. Up-to-date information helps families adjust and understand their child's strengths and weaknesses. It includes some useful chapters on parental emotions, family life, diagnosis, genetics, education | | | |
| Curriculum Guide for Individuals with Fragile X Syndrome | Braden, Marcia L | Revised Edition | A\$40 |
| This unbound curriculum guide was developed to assist parents, school staff and clinicians in creating an appropriate educational blueprint for individuals with fragile X. It includes a developmental progression of skills, teaching strategies and behavioural programming. | | | |
| Disability Discrimination Legal Centre, NSW | | | no charge |
| We have informative material published by the NSW Disability Discrimination Legal Centre Inc. about the legal rights of persons with disabilities in NSW. Included is a format for making a written complaint about disability discrimination under either the Commonwealth Disability Discrimination Act or the NSW Anti-Discrimination Act. | | | |
| Educating Boys with Fragile X Syndrome: A Guide for Parents and Professionals | Spiridigliozzi, G.A., Lachiewicz, A.M., MacMurdo, C.S., Vizoso, A.D., O'Donnell, C.M., McConkie-Rosell, A., Burgess, D.B., Child Development Unit | Duke University Medical Centre, 1994* | \$A15 |
| This excellent booklet provides information and ideas to parents, educators and therapists who work with boys with fragile X syndrome. It is of great value in the initial development of an appropriate education programme for these children. | | | |
| Educating Children with Fragile X Syndrome | ed. Denise Dew-Hughes | Routledge Falmer, 2004 | A\$45 |
| While the focus is on education, a wider perspective is presented to support the main theme. The contributors, who are drawn from the most prominent experts on the syndrome, tackle education and related issues and suggest strategies from a practical standpoint. | | | |
| Educational Files Volumes 1 & 2 | The National Fragile X Foundation, USA | | A\$40 |
| These files are prepared by the National Fragile X Foundation (USA) through the collaborative efforts of numerous physicians, researchers, clinicians and parents, all with first hand involvement in fragile X syndrome. | | | |
| Fragile : Handle with Care: Understanding Fragile X Syndrome | Braden, Marcia L | 1996 | A\$40 |
| This is an exceptional book written by a master in the field of special education and behavioural psychology. | | | |
| Fragile : Handle with Care: More about Fragile X Syndrome - Adolescents & Adults | Braden, Marcia L | Spectra Publishing Co Inc, 2000 | A\$40 |
| An updated version of Handle with Care | | | |
| Fragile X Fragile Hope: Finding Joy in Parenting a Child with Special Needs | Griffin, Elizabeth | Emerald Books, 2005 | A\$30 |
| This is a new publication by Elizabeth Griffin, who has a son with fragile X and autism. Many negative aspects of the journey from diagnosis to acceptance, such as chronic stress, sleep deprivation and the hurtful lack of awareness exhibited by relatives and friends, are discussed. Towards the end of the book the mood lightens – the final chapter is 'When did life get to be so good?' | | | |
| Fragile X Syndrome: Diagnosis, Treatment & Research | Hagerman, R.J & Hagerman P.J, 3rd Edition | John Hopkins Press, 2002* | A\$80 |
| This superb book is a must for the professional with any interest in fragile X syndrome. Topics covered in the first part of the book include epidemiology and the associated cytogenetic and molecular findings, present research regarding protein studies and neuropsychology of the fragile X syndrome. The second part covers treatment and management strategies including genetic counselling, medical follow up, psychopharmacology, psychotherapy, education, occupational therapy, speech and language therapy and protein and gene therapy. Highly recommended. | | | |

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| Fragile X Syndrome: A Guide for Teachers | Saunders, Suzanne | David Fulton Publishers, London , rev.ed 2001* | A\$40 |
| This English book, by a lecturer in Special Education at Oxford, gives a comprehensive coverage of issues which arise when children with Fragile X syndrome go to school. Optimum classroom conditions and teaching strategies are discussed, as well as social and behavioural development. | | | |
| Fragile X Syndrome: A Handbook for Families and Professionals | Finucane, B., McConkie-Rosell, A., & Cronister, A | Elwin Inc., 1993 | A\$5 |
| This revised edition includes all of the newest molecular information including diagnostic DNA testing and is an ideal first guide for families, counsellors, educators, carers and all those wishing to learn about fragile X syndrome. | | | |
| An Introduction to Sensory Integration | Arkwright, N. | The Psychological Corporation, 1998 | A\$10 |
| A thorough examination of sensory integration, including discussion of the central nervous system, the vestibular system, the proprioceptive system and the tactile system. A clear explanation of how occupational therapy with a sensory integration approach can help your child. | | | |
| Issues and Strategies for Educating Children with Fragile X Syndrome - A Monograph | Wilson, P., Stackhouse, T., O'Connor, R., Scharfenaker, S. and Hagerman, R. | Spectra Publishing Co Inc, 1994* | A\$40 |
| This 98 page educational monograph discusses specific medical issues, occupational therapy, speech and language therapy recommendations and strategies for a regular classroom situation. Accompanying video is available. | | | |
| Justice for People with Disabilities: Legal and Institutional Issues | Hauritz, M., Sampford, C., Blencowe, S. | The Federation Press, 1998* | A\$33 |
| The emphasis in this book is on legal rights, services to people with disabilities and on the social values which govern such relationships. Issues include affirmative action, the limits within which the law can promote the rights of people with disabilities, accessibility and disability advocacy. Relatively technical and legalistic. | | | |
| Lessons from my Child | Cindy Dowling, Neil Nicoll and Bernadette Thomas | | A\$30 |
| The book comprises emotional snapshots written by parents of children with various disabilities. The stories reflect the many stages parents move through as they come to terms with their children's disability. There is great honesty in the parents' descriptions of parenting a child with special needs and encouragement for families with | | | |
| Love is in the Air | Sue Williams | ABC Books, 2009 | A\$20 |
| This book is about Merry Makers, a dance company for people with intellectual and physical disabilities. It is a warm, inspiring book and has chapters on 2 men with Fragile X syndrome. | | | |
| A Medication Guide for Fragile X Syndrome | Tranfaglia, M.R. | FRAXA Research Foundation, 1997 | A\$30 |
| This wonderful guide by the founder of the FRAXA Research Foundation is intended to serve as background to help parents, carers and others to communicate with physicians regarding medication. The medications are only to be used under the supervision of a qualified physician and almost all are available only by prescription. | | | |
| My eXtra Special Brother: How to love, understand, and celebrate your sibling with special needs | Heyman, Carly | Lightning Source, 2003 | A\$15 |
| A sister's words on life with a Fragile X brother. Warm and uplifting. | | | |
| One of the kids | Strove, Wendy | The Disability Council of NSW, | A\$15 |
| This handbook is for the parents of children with disability and is designed to help these parents to identify and achieve their dreams for their child, especially the dream of including their child in an ordinary school. | | | |
| The Out-of-Sync Child: Recognising and Coping with Sensory Integration Dysfunction | Kranowitz, C.S. | Skylight Press, 1998* | A\$30 |
| An accessible, clearly written guide to Sensory Integration Dysfunction which provides detailed, practical help for children with this problem. Covers areas such as over or under-sensitivity to touch, smell, sound, sight and movement, unusually high or low activity levels and problems with motor coordination. | | | |
| 1. Planning for the Future 2. Special Disability Trusts: Getting things sorted. | Australian Government - Dept of Families, Community Services & | Commonwealth of Australia, 2007 | \$5 |
| Both these publications are an excellent source of information for families of people with disabilities. You can get your own copies of these books through the Intellectual Disability Rights Service, Level 1, 128 Chalmers St, Surry Hills, NSW 2010, Tel: 02 9318 0144 | | | |
| Professional Collaboration with Parents of Children with Disabilities | Kranowitz, C.S. | Skylight Press, 1998* | A\$55 |
| Directed at professionals who deal with children with disability, the thesis of this book is professional accountability to children and their parents. The vision is that when professionals collaborate with parents, they feel confident in the professionals' skills and the relationship between them will bring all the benefits of a collaborative one and none of the disadvantages of a dependent one. Although rather technical, recommended reading for parents as well as professionals. | | | |

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| Promises, Promises | Clear, M | The Federation Press, 2000* | A\$39 |
| A discussion of the modern commitment of Australian governments and communities to the principle of equal participation in society of people with disabilities. Have promises been fulfilled and how effective have structural changes been? | | | |
| One Day at a Time: Children with a disability - family experiences | Davies, Sue | Kurrajong Early Intervention Service, 2001 | A\$15 |
| Relates the experiences of parents of children with a range of disabilities who are receiving assistance from the Kurrajong Early Intervention Service, Wagga Wagga, NSW. In 1998 parents told their own stories on different aspects of raising a child with a disability. In the revised version, parents update their original stories and give us an indication of how the children have progressed. Many histories concern autism and cerebral palsy. There is <i>one story of a family with Fragile X.</i> | | | |
| Siblings | Strohm, Kate | Wakefield Press, 2002 | A\$28 |
| Siblings of children with special needs write their own stories. As well as the discussion of emotional issues, there are short sections on respite care, planning for the future, guardianship and estate planning. This is a valuable book which contains many insights and is not afraid to tackle sensitive issues. | | | |
| Through the Maze -Information and support for aparents of children with a disability in NSW | ACD NSW | 2010 edition | \$10 |
| A handbook to help you 'through the maze', to identify and access the services most helpful for your child and family, irrespective of the nature of your child's disability. This handbook is available free to members of ACD NSW see www.acdnsw.org.au . | | | |
| Using AAC to develop emotions and problem solving skills | Bloom, Ylana and Bhargava, Dolly | Bloom & Bhargava, 2004 | |
| A manual based on a social-cognitive approach designed to guide individuals with communication difficulties and/or additional disabilities. The purpose of this manual is to provide the communication partner with the necessary tools to guide the individual towards gaining better self-control over their emotions and improving their problem solving skills. | | | |
| Vocational and Educational Training (VET) syllabuses. | NSW Board of Studies, 1999 | | A\$12 |
| The syllabuses are: Business Services(Administration), Construction, Information Technology, Metals and Engineering, Primary Industries, Retail Operations, Tourism and Hospitality. There is an accompanying Cdrom, Stage 6 Sperial Programme of Study: Life Skills Courses and Suppoort materials, which may be borrowed for \$30 | | | |
| When I'm Gone: An introduction to wills and estate planning for parents of people with an intellectual disability. | Booth, Stephen | Intellectual Disability Rights Service Inc., 1999 | \$8.50 |
| This short book includes chapters on making a will, choosing executors and trustees and ideas about how to divide up your property. Members who would like to purchase their own copy can contact the Intellectual Disability Rights Service, Level 1, 128 Chalmers St, Surry Hills, NSW 2010, Tel: 02 9318 0144 | | | |
| What's Wrong with Timmy? | Shriver, Maria | Little Brown, 2001 | A\$30 |
| Siblings of children with special needs write their own stories. As well as the discussion of emotional issues, there are short sections on respite care, planning for the future, guardianship and estate planning. This is a valuable book which contains many insights and is not afraid to tackle sensitive issues. | | | |
| X Stories - The Personal Side of Fragile X Syndrome | Ed. By Charles Luckman & Paul Piper | Flying Trout Press, 2006 | A\$30 |
| A book of stories from people who have been touched by fragile X who tell in their own words how it has transformed their lives. Stories about family life before and right after diagnosis and stories that span generations, as fragile x carriers and fully affected individuals move into adolescence, adulthood and old age. There are contributions from our own Association Members Nicola Jones and Leonie Star. <i>Highly recommended for the newly diagnosed family.</i> | | | |
| PAMPHLETS | | | |
| TITLE | | PUBLISHER | |
| Enduring Guardianship in NSW: your way to plan ahead | | Office of the Public Guardian, Attorney General's Dept of NSW, rev. 2003 | |
| This booklet outlines the reasons and how to appoint an enduring guardianship | | | |
| Facts about Fragile X Syndrome | | National Institute of Child Health and Human Development (USA) | |
| A brief but useful introduction to Fragile X Syndrome | | | |
| Processes involved in Transitioning a Child with Fragile X Syndrome from an early childhood setting into a maintream class at | | Kerr, J. and Star, N., 1999 | |
| A detailed and practical guide to transitioning a child into a mainstream class in Australia. Written by an experienced special needs primary teacher and an experienced mother. Includes material on cognitive, behavioural/emotional and social issues, speech and language, physical and sensory issues, and how best to get your message across to the school. | | | |

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| VIDEOS | | | |
| TITLE | AUTHOR | PUBLISHER | DEPOSIT |
| Fragile X Syndrome: the commonest inherited form of learning disability | The Fragile X Society, UK | 1998 | A\$40 |
| This 20 minute documentary uses fly-on -the-wall footage to illustrate the wide-ranging effects of Fragile X Syndrome and shows the characteristic behaviours that provide clues for diagnosis. | | | |
| Educational Intervention | | | A\$20 |
| This very short video illustrates a strategy for improving reading and for encouraging a student to face the teacher. | | | |
| Educational Issues and Strategies for Children with Fragile X Syndrome | Hagerman, R.J | National Fragile X Foundation, USA | A\$40 |
| This video accompanies the monograph <i>Issues and Strategies for Educating Children with Fragile X Syndrome</i> . Randi Hagerman and other specialists present tactics for educating children with Fragile X. The video, which includes molecular information and medication therapies, follows one child through a multidisciplinary evaluation. It then follows three children in kindergarten, fifth grade and secondary school through a typical day. | | | |
| Fragile X Conference Video | International Fragile X Alliance | Nov-97 | A\$35 |
| Featuring leading experts from the USA. Randi Hagerman, Louise Gane, Jennifer Hills and Bill Sobesky present an overview of treatment and mangement strategies, counselling and vocational issues. | | | |
| It's a Long Road | The Carers Association of Western Australia | | A\$30 |
| The stories of four families with children with disabilities are told with honesty and courage. Included are comments by counsellors and practical helping strategies. | | | |
| Processes involved in Transitioning a Child with Fragile X Syndrome into a Mainstream Class at School | The Fragile X Association of Australia | 1999 | A\$15 |
| This is a video of a meeting held at Stanmore Public School, Sydney on 22nd November 1999. It films a lengthy discussion among parents, primary school teachers, special needs teachers and teaching aides on the transition of children with Fragile X into mainstream schools. It is set in an Australian educational setting with Australian participants. | | | |
| Social Skills Training Model #2 | Braden, Marcia L | Oct-00 | A\$20 |
| Children are filmed in an informal setting in Marcia Braden's house. They are shown conversing while relaxing and interactign with each other during play. | | | |
| CDs AND DVDs | | | |
| TITLE | AUTHOR | DEPOSIT | |
| Fragile X Syndrome: Clinical and Molecular Aspects | A/Professor Sylvia Metcalfe & Dr Jonathan Cohen | A\$30 | |
| Aimed at health students, both undergraduates and postgraduates, this publication covers the clinical features of Fragile X Syndrome together with a valuable introduction to the genetics. It is a valuable way of informing family, friends and teachers about Fragile X. Available for purchase from the Fragile X Alliance. | | | |
| Fragile X Syndrome Lecture Series by Marcia Braden | Braden, Marcia L | A\$80 | |
| These comprehensive, multimedia presentations provide an apoportunity to gain from a wealth of knowledge and firsthand experiences. Discs include Educational Intervention, Behavioural Issues, Sexuality, Developing an Effective Education Plan and Issues for Adolescents. | | | |
| Fragile X Syndrome: A module of Medical Genetics | A/Prof Sylvia Metcalfe & Dr Jonathan Cohen | \$40 | |
| This multimedia program is designed to introduce the user to genetic concepts of fragile X syndrome. Topics include clinical features, molecular causes, patterns of inheritance, genetic & pathology testing, and genetic counselling. Learning is supported by use of images, animations, videos, interactive drag and drop excercises & multiple choice questions with feedback. | | | |
| Living with Fragile X | Kathy Elder and Greg Mishey | \$40 | |
| An excellent DVD which explains what Fragile X is and how it is passed, exposes the day to day challenges | | | |
| And now for some light relief: | | | |
| TITLE | AUTHOR | PUBLISHER | DEPOSIT |
| Do you want to know a secret? | Clark, Mary Jane | St Martin's Paperbacks, 1998 | A\$15 |
| This is a thriller, written by a mother of a son with Fragile X. The action revolves around a TV anchorwoman and the death of her male colleague who had a Fragile X son. | | | |
| The Curious Incident of the Dog in the Night -time. | Haddon, Mark | Random House, 2003 | A\$15 |
| This a beautifully written and plausible detective story. The central character is a boy whose intellectual disability | | | |