



A PRACTICAL APPROACH



FOR COMPLEX NEURODEVELOPMENTAL DISORDERS (CND)
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March 2023 edition

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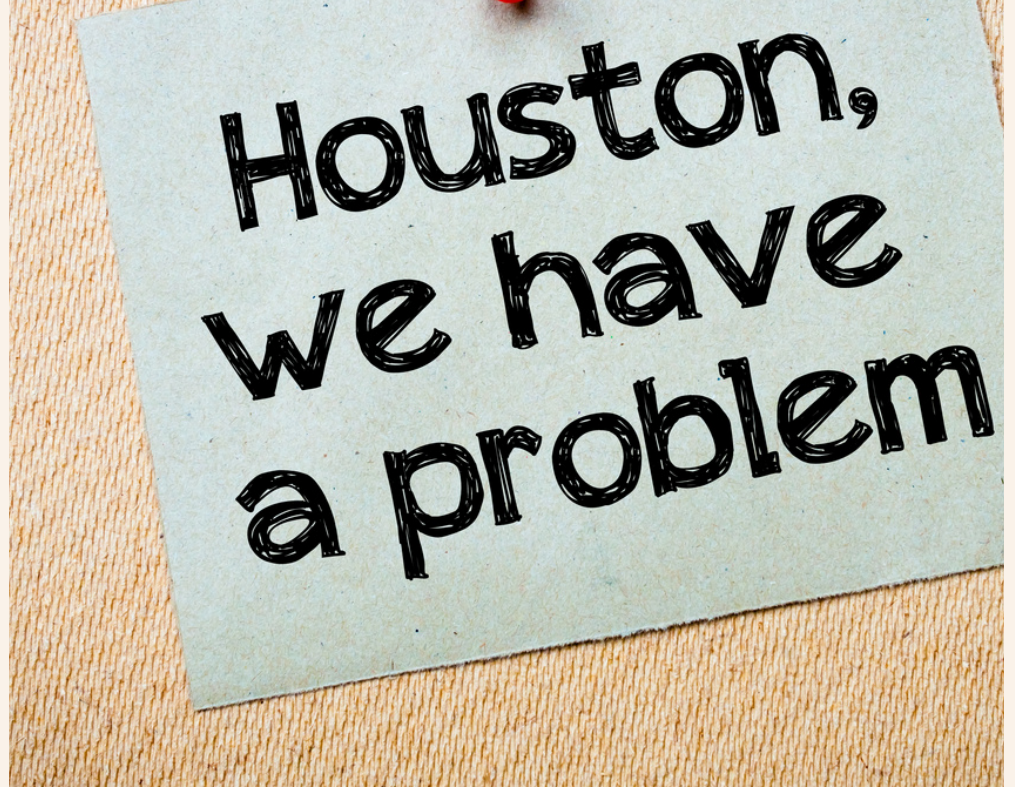
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TABLE OF CONTENTS

- 01. Accept that there is a problem
- 01. Check in with yourself
- 02. Get organized
- 03. Get a Diagnostic Assessment
- 04. Identify and list strengths
- 05. Gather supports and take a break
- 06. Get to know the school system
- 07. Assess and prioritize issues/concerns
- 08. Find treatment options
- 09. Plan for the future
- 10. About the authors
- 12. Resources

ACCEPT
THAT
THERE ARE
CHALLENGES
THAT NEED TO
BE BETTER
UNDERSTOOD.



- When the problem is not improving with usual and recommended strategies it is necessary to explore why and to approach things differently.
- The end goals are the same - it may require a different route to get the the same place.
- If the usual strategies were going to work, there would not be a problem. Typical parenting strategies work. If they don't we need to dig deeper to understand why. We can't assume that this is a result of poor parenting or 'difficult' kids.

CHECK IN WITH YOURSELF

Are you.....

- well rested?
- in good physical health, mental health, emotional health?
- able to devote time to address the problem areas?

Is there agreement with other family members and health care providers that there is a problem?

LATEST UPDATES

GET ORGANIZED

Keep a folder - electronic records are very helpful, and maybe also a binder that you can add to, store and bring with you for reference. To include:

- Child/youth/adult Identification
- Health records - Doctors, psychiatrist, medication past and present
- Reports and assessments - psychology, speech and language, occupational therapy, physiotherapy
- Education - report cards and Individual educational plan, IPRC - identification/implications and associated documentation
- Resources - Financial
 - assistance for children with severe disabilities
 - disability tax credit (T2201)
 - Special Services at home
 - Easter Seals - diapers
 - Access 2
 - Via Rail
- Meetings/correspondence - children's mental health, wait lists, Children's Aid Society, etc.

GET A DIAGNOSTIC ASSESSMENT



- People who receive an assessment do better, with or without a diagnosis.
- The testing provides clarity and the recommendations provide a pathway to helpful and relevant supports.
- Comprehensive assessment of learning and behavioural strengths and weaknesses is essential.

COGNITIVE ASSESSMENT



- The clear understanding of strengths and areas of challenge is necessary in order to plan and implement helpful mental health, developmental and behavioural approaches.
- Overall IQ is not predictive of day-to-day functioning.
- Keep this in mind when you see/hear 'refusal to complete', 'became non-compliant'.

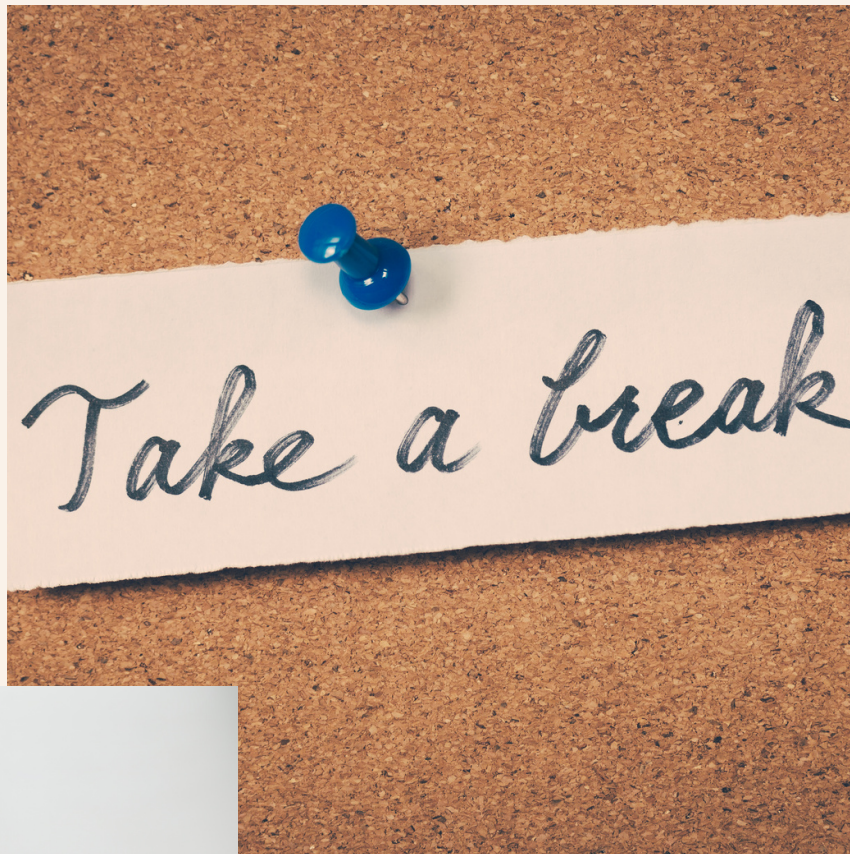
STRENGTHS IDENTIFICATION



Find them... anything... list them and refer to them often. People who struggle daily, need to be reminded of what they offer and teach us in a positive way.

- Communication - vocabulary
- Desire to do well, and eager to please
- Tries hard, resilient
- Creative, musical, artistic
- Physical activity and sports
- Forgiving and able to begin each day as a 'new day'
- Gets along well with adults or younger children
- Appreciates helping and taking care of others
- Kind, compassionate, tolerant

GATHER
SUPPORTS
AND TAKE
CARE OF YOU!



Take a break from all the learning and testing, and advocating..
Just be... and challenge our expectations.

Reach out to;

- family
- friends
- community
- financial resources
- family care and respite opportunities

GET TO KNOW THE SCHOOL SYSTEM: IDENTIFICATION AND INDIVIDUAL EDUCATIONAL PLAN (IEP)



- Have clear documentation of your child's specialized needs within the school system.
- Many complex neurodevelopmental disorders are not designated reason for identification in many jurisdictions but this is changing.
- Advocacy for the CND to be understood, rather than focussing on 'behaviour' - The behaviour designation implies 'control' and family issues, and takes away from the brain based condition that presents some medical barriers.
- Children with hidden disabilities often appear more capable than they are. Leading to a "A Cloak of Competence".

IEP - A FORMAL DESCRIPTION OF EDUCATION DELIVERY THAT WILL BE DIFFERENT FROM GENERAL CURRICULUM

Accommodated: academic expectations are the same as the other children.

Modified: Academic expectations are different from the other children.



ASSESS AND PRIORITIZE AREAS OF CHALLENGE...



Safety Concerns:

- Physical aggression
- Emotional safety
- Destruction
- Sleep
- School attendance
- Vulnerability and high risk behaviours
- Family preservation

Behaviour is Communication:

- What is driving the behaviour? ie. anxiety? impulsivity?
- What are people trying to tell us? ie. emotional dysregulation - what's underneath?
- What is the purpose of the behaviour?
- Which sets of behaviours are causing the most difficulty?
- Sometimes we need to start with the more 'doable' adjustments to experience small 'wins' that lead to hope and inspiration.

WHERE TO START?

Begin with the skill that is usually acquired earliest in typical development i.e self regulation.

Find a support person or group to help with new and hopeful strategies.



Find positive ways to include recreation and leisure in to day-to-day activities and routines. Participation should not depend on 'good' behaviour. These activities are so helpful in terms of:

- Lifelong healthy lifestyle habits and expectations
- Successful social opportunities
- Personal growth and a place to enjoy and 'shine'
- Opportunity to develop strengths and to build self-esteem

Sometimes team sports can be too demanding, other times they can be really motivating. The likes/dislikes of each of us are different so we need to be creative and open to building on new interests and skills. Keeping it simple can be a great place to start. ie. biking, swimming, skating.

PLAN FOR THE FUTURE



Complex Neurodevelopmental disorders are lifelong conditions therefore neuro-behavioural deficits may continue across the lifespan. They will need to be supported and skills will continue to develop over time.

SPECIAL CONSIDERATIONS AND RESOURCES :

- Ongoing challenges leave people with CNDs at higher risk for mental health problems.
- Educational and Vocational support and programming can be helpful and is often required.
- Finding a case manager/therapist who is CND and trauma informed can be helpful to have as a support and resource to assist with transitions and applications etc.
- Developmental Services Ontario and Ontario Disability Support Program can be applied for months before turning 18.
- Disability Tax Credit
- Disability Savings Account

ABOUT THE AUTHORS



DR. CLARE MITCHELL
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Dr. Clare Mitchell is a Developmental Paediatrician in London, Ontario. Her clinical focus is assessment of children and adolescents with developmental delays and/or mental health problems, especially those with complex neurodevelopmental disorders such as Fetal Alcohol Spectrum Disorder, Tourette Syndrome, and Autism Spectrum Disorders. Dr. Mitchell is grateful for the opportunity to work with such a skilled, dedicated and compassionate group of professionals.

Dr. Mitchell is part of the London Region FASD and the Waterloo FASD Diagnostic Clinics and has been an active member of the FASD Community of Practice in London Ontario. Dr. Mitchell has provided educational sessions about FASD in a wide range of venues including parent groups, youth justice, mental health professionals, clinicians and national conferences. Dr. Mitchell is an Associate Professor at the Schulich School of Medicine and Dentistry, Western University. Dr. Mitchell is Head of the Division of Developmental Pediatrics. She has completed a term as Associate Program Director of the Paediatric Residency Training Program and Interim Curriculum Committee Chair. She was the Chair of the Paediatric Undergraduate Education committee for many years.

Nationally, Dr. Mitchell completed a term as President of the Developmental Section of the Canadian Paediatric Society. Dr. Mitchell is the Medical Director of Canada-Guyana Outreach. This interdisciplinary team conducts annual medical missions to Guyana, with a focus on developing Paediatric and developmental resources in remote Guyanese communities.

ABOUT THE AUTHORS



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Angela has over 25 years of experience supporting individuals and families in a variety of settings. She is currently a Social Worker in private practice providing education, advocacy, assessment and direct support for individuals and families experiencing complex issues including the impact of PAE/FASD. Angela was the first Coordinator of the London Region Fetal Alcohol Spectrum Disorder Diagnostic Clinic, and helped to develop the Community of Practice and the Family and Caregiver Support group that continues to actively support families. Angela has coordinated provincial projects as a part of the Ontario's FASD Initiative, including the Family and Caregiver Support Group Project, the FASD Provincial Website, and the FASD Service Provider Training Project. Angela has provided educational opportunities re: FASD in a variety of support groups, professional development sessions, and in local, provincial and national conferences. Angela is also an active member of the FASD ONE Diagnostic Action Group and involves herself in many different projects aimed at building a more inclusive service delivery system.





www.canchild.ca

Information about diagnoses, with strategies and tools for complex neurodevelopmental disorders (see KIT)

www.empoweringparents.com

Resources and strategies for parents

www.smilingmind.com.au

Mindfulness for all ages

www.livesinthebalance.org

Dr. Ross Green and the Collaborative Problem Solving Approach

www.fasdontario.ca

Links to resources for FASD

www.autismontario.com

Links to resources for Autism Spectrum Disorders

www.tourette.ca

Links to resources for Tourette Syndrome and associated disorders

www.caddra.ca

Information about ADHD

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A CND informed team of therapists and community engagement and wellness support workers