

Mental Health and Developmental Disabilities in Children

A Research Report Prepared For Child and Youth Mental Health British Columbia Ministry of Children and Family Development

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Preamble

The Children's Health Policy Centre (CHPC) in the Faculty of Health Sciences at Simon Fraser University prepared this report at the request of the British Columbia (BC) Ministry of Children and Family Development (MCFD). Our goal was to summarize the best currently available research evidence in order to inform policy and practice for treating mental disorders in children with developmental disabilities. This report is one in a series of reports prepared in support of MCFD's *Child and Youth Mental Health Plan for Bristish Columbia*.¹ Our reports are intended as a resource for policy-makers, practitioners, families and community members. The complete series of reports produced for MCFD is available on our website at www.childhealthpolicy.sfu.ca.

About the Children's Health Policy Centre

Located in the Faculty of Health Sciences at Simon Fraser University, we are a research group dedicated to integrating research and policy to improve children's health. We particularly focus on children's social and emotional development, or *children's mental health*, as one of the most important investments society can make. We conduct research on the policy process and research relevant for informing policy-making: addressing determinants of health; preventing problems where possible; promoting effective treatments and services; and monitoring our collective progress towards improving the lives of all children. In turn, partnerships with policy-makers inform our research. We also provide education on health policy, children's mental health and population health. Our work supports and complements the vision of the Faculty of Health Sciences to integrate research and policy for public and population health locally, nationally and globally.

Executive Summary

Developmental disabilities are conditions affecting a range of social and cognitive functions including communications, learning, and interpreting and responding to social cues. Specific examples include pervasive developmental disorders (including autism and Asperger's disorder), mental retardation and fetal alcohol syndrome. Approximately 30 per cent of children with developmental disabilities also suffer from co-occurring mental disorders⁵. Mental disorders are characterized by significant disturbances in behaviours, mood or thought processes with associated distress and impairment. All types of mental disorders, including mood, anxiety and psychotic disorders, can occur in children with developmental disabilities. Moreover, children with developmental disabilities have an increased vulnerability to mental health problems relative to typically developed children.

This report focused on treating mental disorders in children with developmental disabilities. We identified the best available research evidence published in systematic reviews over the past 10 years. To be included, reviews had to meet a high standard well accepted in the scientific community involving an explicit focus on developmental disabilities in children, a description of the search strategy and a list of criteria used to select original studies for detailed review. Since most systematic reviews focused on treatments for the underlying developmental disabilities rather than on co-existing mental disorders, a review of a relevant practice parameter is included to ensure a more comprehensive summary of treatments.

Findings

- Twelve reviews met criteria; however, most focused on treating underlying developmental
 disabilities rather than co-existing mental disorders. None addressed children with
 fetal alcohol syndrome. Psychosocial interventions, including parent-mediated, peermediated and behavioural interventions, resulted in some improvements in language
 and cognitive and behavioural functioning. Additionally, the medication naltrexone
 significantly reduced self-injurious behaviours among children with mental retardation.
- The selected practice parameter recommended the use of research-supported treatments for mental disorders in children with developmental disabilities, with modifications to address cognitive and communication deficits. Assessing medication risks and benefits and conducting frequent medication reviews were also stressed as important safety mechanisms.

Recommendations

- New research is needed focusing on developmental disabilities and co-existing mental disorders. The research is especially limited regarding children with fetal alcohol syndrome. Accordingly, new research in this area is vital.
- Where children have developmental disabilities and co-existing mental disorders, treatment interventions should be modelled after the principles and key elements of approaches supported by research evidence for specific mental disorders. Additionally, practice parameters offer useful guidelines by reflecting collaborative expertise.
 For example, cognitive-behavioural approaches recommended for treating anxiety and depression can be modified and combined with psychosocial interventions for developmental disabilities. New interventions should also be evaluated.
- For children with pervasive developmental disorders, the research evidence supports using a
 number of psychosocial interventions to address the core symptoms of these disorders. Most
 are based on behavioural principles and include specific behavioural techniques. Parent- and
 peer-mediated early interventions, along with intensive behavioural interventions, appear
 to improve functioning in areas such as cognitive development and social interactions.
- For children with mental retardation, the research evidence supports using psychosocial interventions to address multiple domains of functioning. Behavioural interventions can improve abilities in areas including social, leisure and daily living skills. School- and community-based interventions can improve self-determination skills including goal-directed and self-regulated behaviours. Additionally, the medication naltrexone appears to reduce self-injurious behaviours for children where psychosocial interventions alone are not enough. It is essential to carefully monitor any children being treated with medications.

1. Introduction

1.1 What are Developmental Disabilities?

Developmental disabilities are conditions affecting a range of social and cognitive functions including communication, learning, judgment and interpreting and responding to social cues.² For the most part, developmental disabilities are present at birth. Pervasive developmental disorders (PDDs) are one type of developmental disability. The *Diagnostic and Statistical Manual (DSM)* of the American Psychiatric Association (APA)³ characterizes PDDs as severe and pervasive impairments in social and communication skills that occur with stereotyped behaviours and activities. Autism and Asperger's disorder are specific PDD diagnoses. Additionally, mental retardation (MR) is described in the *DSM* as significantly below–average intellectual and adaptive functioning. Finally, fetal alcohol syndrome (FAS), caused by prenatal exposure to alcohol, is characterized by intellectual, attention and impulse control deficits. Estimated prevalence rates for developmental disabilities range from 0.3% for PDDs⁴ to 1% for mental retardation.³ Developmental disabilities are distinguished from mental disorders by being typically more stable over time rather than relapsing or remitting.²

1.2 What are Mental Disorders?

Mental disorders are significant disturbances in behaviours, mood or thought processes associated with distress and impairment. Children with developmental disabilities are more vulnerable to mental health problems than typically developed children.⁵ An estimated 30 per cent of all individuals with a developmental disability have a co-existing mental disorder.⁶ Even higher rates are reported for co-occurring behavioural difficulties such as self-injury. All types of mental disorders, including mood, anxiety and psychotic disorders, can occur in children with developmental disabilities.⁶

A mental disorder co-existing with a developmental disability can significantly impact the education, living situations and interpersonal relationships of children. Given the severe impairment caused by mental disorders in children with developmental disabilities, the associated social costs are high. Consequently, identifying effective treatments for mental disorders in children with developmental disabilities is essential to reduce symptoms and impairment early in life.

Children's mental health is determined by multiple biological and social factors interacting over time as a child develops. Although it is not known why children with developmental disabilities are more vulnerable to mental disorders, a number of risk factors have been identified. Children with developmental disabilities experience negative social conditions including rejection and stigmatization contributing to excessive stress, a known risk factor for mental health problems.⁷ Additionally, children with developmental disabilities often have limited coping skills, an identified protective factor regarding the effects of stress on mental health.⁷ Finally, many developmental disabilities are caused by genetic syndromes. Such syndromes are often associated with a characteristic behavioural repertoire known as a behavioural phenotype. Behavioural phenotypes may contribute to the increased rate of mental disorders among children with developmental difficulties.⁷

1.3 Purpose of this report

This report was requested by MCFD in order to inform policies and programs for treating mental disorders in children with developmental disabilities. This report is one in a series of reports prepared by the Children's Health Policy Centre in support of MCFD's *Child and Youth Mental Health Plan for British Columbia*.¹ Our reports are intended as a resource for policy-makers, practitioners, families and community members. The complete series of reports produced for MCFD is available on our website at www.childhealthpolicy.sfu.ca.

2. Methods

Using Medline, PsycINFO, and the Cochrane Database of Systematic Reviews, we searched for systematic reviews published in English from January 1994 to August 2005 on treating mental disorders in children with developmental disabilities aged 0–18 years. Reviews were included that examined efficacy (can this intervention work in ideal settings?) and, if possible, effectiveness (does this intervention work in usual settings?). The search terms were developmental disabilities, learning disabilities, mental retardation, pervasive developmental disorder, fetal alcohol syndrome, autism, or behavioral phenotypes combined with treatment, intervention, management or concurrent disorders. Reviews focusing solely on physical disabilities were excluded. All abstracts identified through these searches were assessed and relevant reviews were retrieved. Using the criteria listed in Table 1 below, each review was then evaluated by two assessors. Due to the limited number of relevant systematic reviews, those containing one study that met the criteria for original studies were also included. Disagreements about which articles to include were resolved by consensus among two or more authors.

TABLE 1. Criteria for Evaluating Research Articles*

Basic Criteria

- · Articles published in English about children aged 0-18 years
- · Articles on topics relevant to children's mental health

Systematic Reviews

- · Clear statement of relevant topic
- · Clear description of the methods including sources for identifying literature reviewed
- · Clear statement of criteria used for selecting articles for detailed review
- · At least two studies reviewed met criteria (below) for assessing original studies

Original Studies

- · Clear descriptions of participant characteristics, study settings and interventions
- · Random allocation of participants to intervention and comparison groups
- · Maximum drop-out rates of 20% post-test
- · Follow-up of six months after post-test
- · For treatment studies, diagnostic "gold" standards used
- · For medication studies, double-blind placebo-controlled procedures used
- · Both statistical and clinical significance assessed and reported at post test

*Adapted from Evidence-Based Mental Health (2006).8

None of the reviews that met criteria focused specifically on treating co-existing mental disorders in children with developmental disabilities. Therefore, the goal of providing high-quality research evidence on this topic was achieved by including a practice parameter, identified by scanning relevant interdisciplinary journals. The selected parameter was chosen for inclusion based on its focus on current research and promising interventions for children with developmental disabilities and co-existing mental disorders.

3. Findings

3.1 Summary

A total of 66 reviews were retrieved. Of these, 12 met our inclusion criteria. Findings are summarized in Table 2. Six reviews included only randomized controlled trials (RCTs). The other six included RCTs plus a variety of other methodologies, such as case studies, single subject and multiple baseline experiments. Where possible, only findings from the RCTs are presented due to concerns about biases introduced when other methods are employed. Seven reviews focused on children under 18 years, whereas five included results from adult studies as well. Where possible, only data from the child studies are presented.

In all cases, findings are only reported on behaviour or other measures directly related to mental health outcomes. Most reviews reported on children who were diagnosed with autism or another PDD.⁹⁻¹⁷ Two reviews focused on children with Two reviews focused on children with MR;¹⁹⁻²⁰ none focused on FAS. One review included individuals with a range of developmental delays including MR and specific learning disabilities.¹⁸ Most reviews focused on treating the underlying development disabilities. No reviews specifically assessed treating co-existing mental disorders in children with developmental disabilities.

TABLE 2. Treating Mental Disorders in Children with Developmental Disabilities

Author(s)	Scope	Studies Included	Main Findings
Nye & Brice (2005) ⁹	Population: Children with autism aged 3-8 years Inclusion criteria: Studies on combined vitamin B6, magnesium treatments published 1861-2002	2 RCTs (2 of 2 studies)	Combined vitamin B6, magnesium treatments were ineffective in changing behavioural outcomes
Millward, Ferriter, Calver, & Connell– Jones (2005) ¹⁰	Population: Children with autism aged 4-10 years Inclusion criteria: Studies on gluten and/or casein-free diets published 1966-2003	1 RCT (1 of 1 study)	Gluten and casein-free diets reduced "autistic traits"; authors advised caution in recommending such diets based on one RCT
Williams, Wray, & Wheeler (2005) ¹¹	Population: Children under age 18 years with PDDs, excluding Rett's syndrome Inclusion Criteria: Studies on intravenous secretin published 1998–2005	14 RCTs (14 of 14 studies)	Single and multiple doses of intravenous secretin were ineffective as a treatment for autism

TABLE 2. Treating Mental Disorders in Children with Developmental Disabilities (Cont.)

Author(s)	Scope	Studies Included	Main Findings
Sturmey (2005) ¹²	Population: Children with autism & other PDDs; age unspecified Inclusion Criteria: Studies on secretin; search dates unspecified	15 RCTs (15 of 15 studies)	Secretin was ineffective as a treatment for PDDs; some studies reported marginally positive effects
Diggle, McConachie, & Randie (2005) ¹³	Population: Children with autism, Asperger's syndrome, other PDDs aged 1-6 years Inclusion Criteria: Studies on parent-mediated early intervention programs published 1861-2002	2 RCTs (2 of 2 studies)	Parent-mediated early intervention programs, involving behavioural methods such as functional analysis, significantly improved language development and measured intelligence
Sinha, Silove, Wheller, & Williams (2005) ¹⁴	Population: Children, adults with autism spectrum disorders aged 3-39 years* Inclusion Criteria: Studies on auditory integration therapy (AIT) published 1887-2003	6 RCTs (6 of 6 studies)	 AIT improved behavioural and auditory problems based on 3 RCTs; authors advised caution due to validity concerns with outcome measures used in 2 of these same 3 RCTs
Pfeiffer, Norton, Nelson, & Shott (1995) ¹⁵	Population: Children, adults with autism, age unspecified* Inclusion Criteria: Studies on megavitamin treatments published 1975-1994	7 RCTs (7 of 13 studies)	Megavitamin treatments improved behavioural outcomes; authors noted numerous methodological problems in the research reviewed and advised caution in interpretation
McConnell (2002) ¹⁶	Population: Children with autism aged 9 years & under Inclusion Criteria: Interventions on social functioning published through October 2001	1 RCT (1 of 55 studies)	Peer-mediated and comprehensive interventions improved quality of social interactions
Roberts, Mazzucchelli, Taylor, & Reid (2003) ¹⁷	Population: Children with general developmental delays aged 6 years & under Inclusion Criteria: Psychosocial interventions for children with developmental disabilities, behavioural problems, published 1980-2001	2 RCTs (2 of 48 studies)	Intensive behavioural interventions improved cognitive, language, academic functioning for children with a PDD

^{*} Reported findings include data from child studies exclusively

TABLE 2. Treating Mental Disorders in Children with Developmental Disabilities (Cont.)

Author(s)	Scope	Studies Included	Main Findings
Algozzine, Browder, Karvonen, Test, & Wood (2001) ¹⁸	Population: Children & adults with various developmental disabilities aged 3 years or older (57% aged 21 or younger)* Inclusion Criteria: Studies on "self-determination" interventions published 1972-2000	5 RCTs (5 of 51 studies)	School and community-based interventions moderately improved self-determination (e.g., goal-directed, self-regulated autonomous behaviour) for children with mental retardation and other disabilities [†]
Symons, Thompson & Rodriguez (2004) ¹⁹	Population: Children & adults with MR, 35% with concurrent autism aged 7-67 years* Inclusion Criteria: Studies on naltrexone for the treatment of self-injurious behaviour published 1983-2003	RCTs not specified (27 studies)	Naltrexone was effective for decreasing self-injurious behaviours, with significant improvements most likely for males [†]
Scotti, Ujcich, Weigle, Holland, & Kirk (1996) ²⁰	Population: Children & adults with MR or autism aged 2-69 years (60% aged 21 or younger)* Inclusion Criteria: Studies on behavioural and medication interventions designed to reduce behavioural problems, published 1988-1992	RCTs not specified (179 studies; 84% involving single- subject data)	Most studies reported at least one positive collateral behavioural outcome such as increased skill or positive behaviour [†]

^{*} Reported findings include data from child studies exclusively † Includes findings from non-RCT studies

3.2. Practice Parameter Findings

One practice parameter was retrieved which provided recommendations for treating children with developmental disabilities and co-existing mental disorders. The practice parameter focused on MR and is summarized in Table 3 below. Additionally, brief reports on well-researched treatments for anxiety disorders, conduct disorder, depression, eating disorders and obsessive-compulsive disorder are available at www.childhealthpolicy.sfu.ca. In many cases, these treatments can be adapted for children with development disabilities, with modifications to address cognitive and communication deficits.

TABLE 3: Recommended Practices for Children with Mental Retardation & Co-Existing Mental Disorders

General Principles

- Children with MR are at increased risk for co-existing mental disorders, including PDDs and attention-deficit/ hyperactivity disorder (ADHD) as well as tic, mood, anxiety, psychotic and eating disorders.
- An overall treatment program needs coordination and continuity of all interventions, including communication between service providers.
- Clinicians and caregivers must agree on distinct treatment goals.
- Treatment should occur in the least restrictive environment.
- Treatment follow-up is necessary, including an intervention effectiveness assessment.

Psychosocial Interventions

- Group, individual and family psychotherapy focusing on concrete goals may have benefits.
- Treatment principles are consistent with those for individuals without MR; techniques should be modified based on developmental level and cognitive and communication skills.
- Concrete therapeutic goals with an overall aim to achieve maximally feasible quality of life should be established.
- Families may need support in understanding their child's condition along with concrete advice and assistance in obtaining additional resources and supports.

Pharmacotherapy

- If needed, medication should be integrated into a comprehensive treatment plan and prescribed only for specific mental disorders.
- Adequate information, including possible risks and benefits, should be collected prior to medication prescription.
- There is considerable abuse potential in "as needed" prescriptions; caution is warranted.
- Periodic trials reducing and discontinuing doses are recommended to assess ongoing need.

Alternative Interventions

• Dietary treatments, such as vitamin supplements and dietary restrictions, are not supported by current research evidence.

Adapted from Szymanski & King (1999)²¹

4. Discussion

We found limited high-quality research evidence on treating mental disorders in children with developmental difficulties. Although 12 research reviews met our inclusion criteria, most focused on treating PDDs and MR rather than co-existing mental disorders. None addressed FAS. Most forms of treatment were found ineffective or had limited or methodologically problematic research to support their use (e.g., dietary restrictions, vitamins, secretin and AIT).

Additional methodological limitations existed in the reviews on children with developmental difficulties. First, some reviews provided insufficient information to accurately establish how many RCTs were available to support each intervention. Second, some reviews included few studies and many studies had small sample sizes. Third, some reviews using adult and child samples did not separate findings by age group when reporting on the studies. Considering age groups separately is important because differences in developmental levels can affect outcomes. Fourth, some reviews provided limited information regarding the content of the intervention. Finally, most reviews examined studies that assessed efficacy (can this intervention work in ideal settings?), not effectiveness (does this intervention work in usual settings?). None assessed costs.

Research evidence supported the use of some psychosocial interventions to treat the core symptoms of PDDs. Specifically, parent-mediated early interventions significantly improved language and cognitive development. The parent-mediated interventions trained parents in behavioural techniques, such as functional analysis, designed to improve the management of their child's behavioural problems. Similarly, intensive behavioural interventions resulted in improvements in cognitive, language and academic functioning for children with pervasive developmental disorders. Additionally, peer-mediated interventions with autistic children improved social interactions. Peer-mediated interventions provided social skills training to typically developed children in order to improve the social skills in young children with autism. For children with PDDs, comprehensive interventions including social skills training, adult-mediated prompting and reinforcement, and self-monitoring also improved social interactions.

Some psychosocial interventions to address functional abilities in children with MR were supported by the research evidence. Specifically, behavioural interventions improved social, leisure and daily living skills. Additionally, self-determination interventions positively impacted skills such as planning and goal-setting among children with MR. Self-determination interventions typically involved teaching the aforementioned skill sets in classroom settings. Regarding medication, naltrexone reduced self-injurious behaviours among children with MR. Naltrexone, an oral narcotic antagonist, significantly reduced self-injurious behaviours in most children at dosages ranging from 0.5 mg/kg to 2.0 mg/kg. The reviewed practice parameter, focusing on treating concurrent mental disorder in children with MR, stressed the use of coordinated, research-supported treatments, with modifications to address cognitive deficits.

5. Recommendations

- New research is needed focusing on developmental disabilities and co-existing mental disorders. The research is especially limited regarding children with fetal alcohol syndrome. Accordingly, new research in this area is vital.
- Where children have developmental disabilities and co-existing mental disorders, treatment interventions should be modelled after the principles and key elements of approaches supported by research evidence for specific mental disorders. Additionally, practice parameters offer useful guidelines by reflecting collaborative expertise.
 For example, cognitive-behavioural approaches recommended for treating anxiety and depression can be modified and combined with psychosocial interventions for developmental disabilities. New interventions should also be evaluated.
- For children with pervasive developmental disorders, the research evidence supports using a number of psychosocial interventions to address the core symptoms of these disorders. Most are based on behavioural principles and include specific behavioural techniques. Parent- and peer-mediated early interventions, along with intensive behavioural interventions, appear to improve functioning in areas such as cognitive development and social interactions.
- For children with mental retardation, the research evidence supports using psychosocial interventions to address multiple domains of functioning. Behavioural interventions can improve abilities in areas including social, leisure and daily living skills. School- and community-based interventions can improve self-determination skills including goal-directed and self-regulated behaviours. Additionally, the medication naltrexone appears to reduce self-injurious behaviours for children where psychosocial interventions alone are not enough. It is essential to carefully monitor any children being treated with medications.

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