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The interRAI Child/Youth Mental Health – Developmental Disability (ChYMH-DD) Instrument

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Abstract:

This article provides a brief overview of mental health issues of children and youth with intellectual developmental disorder (IDD). It then describes a new assessment instrument, *the interRAI Child and Youth Mental Health – Developmental Disabilities (ChYMH-DD)*, recently developed through a partnership between the Child and Parent Resource Institute (CPRI) in London, Ontario and interRAI, an international consortium of expert researchers and clinicians that are committed to improve the quality of life of vulnerable persons through a seamless comprehensive assessment system. The ChYMH-DD is a comprehensive functional assessment intended for children and youth who have comorbid mental health concern(s) and developmental disability/disabilities.

Background:

Prevalence and risk factors of dual diagnosis

The World Health Organization estimates the prevalence of IDD at approximately 1 to 3 per cent of the population[1]. Defining prevalence for dual diagnosis (individuals with a mental health problem and diagnosed developmental disability) is difficult, as reported rates of mental health problems vary widely from 15 to 50 per cent of those with IDD[2]. A study by the Office of National Statistics in Great Britain found that children and youth with IDD are six-times more likely than the general population to have one or more diagnosed psychiatric disorders[3] (e.g., attention-deficit hyperactivity disorder, depressive disorders, conduct disorders). The same study also indicated that children and youth with IDD are more likely to experience a range of additional social and environmental risk factors, such as adverse life events (e.g., abuse, serious accidents), lower socioeconomic status, single parenting, family dysfunction, parental distress, as well as experience fewer quality relationships with peers and friends[3].

Challenges associated with dual diagnosis

Considered a lifelong condition, the presence of IDD can be extraordinarily challenging for children, youth and their families. As a child or youth ages, transition points pose numerous challenges. Information on specific services may be lacking thereby limiting easy access and appropriate triaging, resulting in longer wait lists. Additionally, the necessary services may not exist locally resulting in complications accessing appropriate services. Eligibility for programs and services may change or programs and services may shift their focus[4]. Moreover, new assessments may be required when funding sources change. The complexity of navigating the service system increases significantly when mental health issues are also present; consequently, transitions have been described as a time of stress and confusion[5] and act as barriers to needed intervention and support.

Compounding the challenges for children, youth and their families is a dearth of appropriate assessment tools for this unique population. Many assessments tend to have a narrow focus which may omit areas of need that could be captured through comprehensive assessment. Furthermore, there is inconsistent use of assessment instruments across organizations, with many using assesments that have not undergone systematic psychometric evaluation. Consequently, clients may be triaged based on multiple forms without well- established reliability and validity[6]. To complicate issues further, the primary difficulty when assessing children and youth with a dual diagnosis is the variability inherent in physical, emotional, and intellectual development[7]. For example, abilities/disabilities can vary with environmental context and behaviours can be misunderstood[8]. These issues contribute to frustration when attempting to access appropriate services.

Moving towards a better understanding of needs

For the best possible outcomes, early identification while promoting a needs-based, life span approach is of utmost importance to support optimal outcomes at all stages. A comprehensive evaluation of the psychiatric, social, environmental, and medical needs and strengths can provide a better understanding of the child/youth to improve outcomes and incorporate best practice across the life trajectory.

The interRAI Child and Youth Mental Health – Developmental Disability (ChYMH-DD) is a new instrument designed to meet the needs of these unique children and youth. The instrument is intended for use with children and youth with IDD and mental health issues.

About interRAI:

interRAI is an international organization committed to improving care for vulnerable populations across the lifespan through the creation of a suite of assessment instruments that support multiple applications. interRAI assessments are designed to be integrated, comprehensive, and evaluate needs in various settings[9] including home care, long-term care, mental health agencies, correctional facilities, rehabilitation, and assisted living. Although the instruments are designed with a particular population in mind (e.g., mental health), compatible items and the use of common language ensure the assessments measure similar constructs, regardless of setting. This method of instrument construction has been demonstrated to produce valid and reliable assessments around the world[10-14]. Moreover, this approach enhances communication between health settings and contributes to a continuity of care for the individual as they receive services across sectors[15]. There are a number of instruments in the interRAI family of instruments that promotes a lifespan approach to assessment and treatment for those with IDD:

- **Home-Care Pediatrics** (HC-Peds; a 0-3 years version and a 4-20 years version)
- **Child and Youth Mental Health-Developmental Disabilities** (ChYMH-DD; a 0-3 years version and a 4-20 years version)
- **interRAI Intellectual Disability** (interRAI-ID; for individuals 21 years of age or older)
- **interRAI Home Care** (interRAI-HC; for elderly populations, or adults seeking supportive services in the home)

The remainder of this bulletin will focus on the ChYMH-DD, although more information about other instruments in the suite can be found at http://www.interrai.org.

Overview of the ChYMH-DD:

The ChYMH-DD collects health information for a child/youth (age 4-20 years) with developmental disabilities and mental health concerns in both inpatient and outpatient settings. Like all interRAI assessments, items on the ChYMH-DD are coded using observations that take place over a specified time frame and focus on observable behaviours. A small number of powerful questions are used to collect meaningful information within each domain:

- Identification Information
- Substance Use or Excessive Behaviour
- Strengths and Resilience
- Communication
- Family and Social Relations
- Medications
- Education and Employment
- Environmental Assessment
- Intake and Initial History
- Harm to Self or Others
- Cognition and Executive Function
- Hearing and Vision
- Psychosocial Well-Being
- Prevention, Service Utilization, Treatments
- Diagnostic and Other Health Information
- Mental State Indicators
- Behaviour
- Health Conditions
- Independence in Daily Activities
- Service Termination
- Stress and Trauma
- Nutritional Status
- Assessment Information
- Discharge *(for inpatient services)*

All possible sources of information are reviewed before coding the instrument, such as interviews with the child/youth and family, medical records, and reports from other service providers. When the child or youth has a communication or cognitive impairment, there is an increased reliance on information from caregiver(s), staff, and teachers. A detailed manual accompanies the instrument that outlines the definition, intent, and coding rules for each item. The result is a valid, reliable, and comprehensive[13] assessment that outlines individual strengths and needs with an emphasis on functioning while providing data and valuable information for multiple applications.

Applications of the ChYMH-DD:

(1) Collaborative Action Plans (CAPs)

Embedded in the ChYMH-DD is a set of evidence informed treatment guidelines called Collaborative Action Plans (CAPs). Triggered from items in the ChYMH-DD, CAPs are intended to assist direct care staff and care teams focus their efforts in areas of most imminent need, allowing for the prioritization of services and expanding the approach to care beyond the treatment of only symptoms[16]. CAP documents include five sections: (1) *Problem Statement*, which outlines how the issue may affect the child's/youth's life (2) *Goals of Care*, which discuss what the guidelines are attempting to achieve (3) *Triggers*, which delineates who should have the care plan developed (4) *Clinical Guidelines* which discuss appropriate evidence-based approaches to the problem, and (5) *Additional Resources* which direct the reader to research literature about the area of need.

CAP guidelines are created from extensive literature review, expert opinion, and an international committee of experts who ensure the guidelines are applicable around the world. The guidelines represent "best practice" for treatment of mental health and developmental disabilities. CAP guidelines are not intended to be prescriptive in nature; rather, they support needs-based care planning while recognizing different areas of expertise across service providers. ChYMH-DD CAPs include:

- Social Relations
- Support Systems for Discharge
- Mobility
- Strengths
- Dental
- Parenting
- Communication
- Transitions
- Education
- Injurious Behaviour
- Traumatic Life Events
- Parental Strengths
- Caregiver Distress
- Life Skills
- Play and Leisure
- Continence
- Eating Behaviour
- Family Functioning

(2) Outcome Measurement

The ChYMH-DD includes multiple scales comprised of individual items to capture the complexity of areas of need. The scales provide a detailed account of a child's/youth's clinical status in major domains. Scale scores are calculated from items with varied response options and use algorithms based on pathways with different risk levels to obtain measures of status or functioning[17]. Higher scores reflect increased severity of symptoms or frequency of problems related to functioning.

Scales assist with describing a child's or youth's current level of functioning, and support care planning based on needs. Furthermore, a child or youth's progress and response to intervention can be evaluated at multiple assessment points, with areas of improvement and deterioration[17] calculated and clearly presented in the outcome report.

When assessments have been completed with many clients, aggregate data from subscales can support program planning (i.e., to ensure programs reflect needs of those admitted), referrals (i.e., areas of need may be better served by specialized services), and appropriate triage (i.e., through identification of those with urgent needs). As the database of assessment information grows across multiple organizations, benchmarking against others becomes possible and provides information for continuous improvement[17].

(3) Resource Allocation

Many service sectors use funding models based on standardized rates per client rather than on the basis of complexity of needs, leaving some agencies underfunded (i.e., those that serve resource-intensive clients)[9,17]. interRAI assessments include a *Case-Mix* application, which categorize children and youth into groups with similar resource requirements to determine resource needs. Using a Case-Mix approach, funders and system planners can ensure resource allocations are driven by client needs[9], rather than numbers, facilitating better client care.

(4) Quality Indicators

Quality Indicators (QIs) reflect quality of care at the agency level, without the need for additional data collection9. interRAI QIs focus on a range of issues important to a child or youth's quality of life and delivery of care. Current QIs used in interRAI assessments include prevalence indicators (e.g., client safety, medication oversight) and improvement in symptoms (e.g., communication). Used in conjunction with Case-Mix systems, interRAI QIs adjust for the variation within clinical populations to enable fair comparisons across agencies and regions.

Impact

Stakeholders across the IDD service delivery system have diverse needs. With the use of this integrated assessment suite, a number of these needs can be addressed to improve the service delivery process. At the client level, burden is decreased for children, youth and their families as transitions are eased between sectors and services through enhanced integration and coordination. In addition, expedited referrals and delivery of appropriate services based on needs are possible with a valid, comprehensive functional assessment. Additionally, outcome measures are available to gauge client success over time thereby providing efficient, effective, evidence-based care.

At the agency level, information from the assessment supports the specific needs of the children and youth, and corresponding best practices from CAPs can link intervention to existing evidence, supporting clinical capacity building, knowledge transfer and mobilization. These evidence informed protocols promote clinical skill development while meeting individual needs of the client[17]. Furthermore, the information gathered from assessments allows agencies to evaluate and report service outcomes that assist with quality improvement initiatives and service planning. Activities such as personnel planning and resource allocation are also supported with the Case-Mix system.

Finally, the ChYMH-DD can provide comprehensive, standardized data across large catchment areas, allowing for the identification of needs across the system, and providing justification for expenditures. The ChYMH-DD can also provide data for applied research as the database of clinical profiles grows. Opportunities exist to study relationships between variables related to mental health and IDD and examine rare diseases and disorders cross-culturally.

Although the development of the ChYMH-DD has only been recently developed, its potential as a clinical and research tool is being recognized around the world. For example, implementation is now underway in parts of the United States (e.g., Arkansas, New York). The ChYMH-DD and the family of related interRAI instruments address the fragmented service system for those with IDD to support proper triaging and more effective use of scarce resources. It assists with waitlist reduction and individualized care as well improved communication and information sharing, which contributes to continuity of care across service sectors[15]. The applications for resource allocation and quality improvement provide valid and reliable information for service providers and agencies to improve service delivery. Using this comprehensive and coordinated approach, the interRAI assessment system and its range of applications has great potential to improve the lives of those with IDD, from birth to old age.

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WINNER OF THE **2013 Dr. G.T. Swart Essay Award** in Intellectual/Developmental Disabilities is: **Horace Cheng**, Year 3 medical student, Schulich School of Medicine & Dentistry, Western University, London, Ontario.

The following two short stories are his submissions.

First story: **Breaking Good News**

"Sorry, your child does not have fetal alcohol syndrome."

Breaking bad news is one of the finer skills within the realm of the art of medicine. Its importance in the patient-physician relationship is well recognized by physicians and medical educators. In fact, the proper techniques of delivering bad news were emphasized time and again throughout our undergraduate medical school curriculum. My preceptor was empathetic to the child and the foster parents as well as doing his best to provide the best environment to communicate the news. I nodded in agreement with that statement which made sense, but yet something wasn't quite right.

"Well, I mean it's a good thing that your child does not have fetal alcohol syndrome. But I understand why you might be disappointed."

Shouldn't one rejoice with such news? Why was the family sitting across from us so dejected? How did we end up in this twilight zone of medicine?

Ronald was a 9 year old boy with a long history of childhood psychiatric issues. He had been a long time patient of the community paediatrician I was working with for my paediatrics clerkship rotation. Ronald was in the clinic for his routine 4-month follow-up. His list of active issues reminded me of the table of contents of a psychiatry textbook; attention-deficit / hyperactive disorder (ADHD), oppositional defiant disorder (ODD), learning disorder, mild developmental delay, anxiety disorder NOS, mood disorder NOS. I felt a bit overwhelmed with such a huge problem list, but thankfully Ronald's foster parents were able to briefly and patiently explain to the issues he had been struggling with. School has never been easy for Ronald, who could not keep up with his peers academically. His mild delay in development compounded by his learning disability meant that he often did not understand what was happening in school. As a result he would often fidget in his seat and disrupt other students in the class. It was no surprise that such disruptive behaviours did not endear him to his teacher and classmates. He was often ridiculed by his classmates for being "slow" and he felt isolated. Though there were several causes to his anxiety, the hostile school setting stood out as being the most salient feature for Ronald. Ronald vocalized that he "hated school" and he associated the learning environment with frustrations and emotional pain. His foster parents reported that his mood was often quite labile during school days, but improved significantly over the holidays. Ronald's school had recently spoken to his foster parents about a formal assessment of his suspected history of fetal alcohol syndrome (FAS). It was thought that a diagnosis of FAS might secure more funding and support resources for the child's education.

As I presented the case to the consulting physician I was conscious of the fact that the history was by no means complete even though I had spent the better part of an hour on the history-taking. At the end of the case presentation my preceptor asked me ‘what would I do’? I shrugged my shoulders and shared my thoughts with my preceptor: That Ronald's multiple psychiatric issues were linked deeply to his being placed in an environment that was beyond his ability to cope with. And that without additional support Ronald will simply wither away in his school setting, and that he would not be able to achieve what is expected of him while sustaining additional emotional and psychological harm. To my surprise my preceptor shrugged back and shared with me that this is often the most frustrating aspect of his job: A Catch-22 situation where the patient needed to be so much worse before he could qualify for special support which might provide the patient a chance to get better. Using the clinical scenario as a teaching platform, he walked me through the latest guideline for making a diagnosis of Fetal Alcohol Spectrum Disorder (FASD). After spending some time reviewing Ronald's case history, we shared the same opinion that this new issue of FAS was a red herring that the patient's family had latched onto in their desperation. With that dose of hard reality we walked back to the examination room to wrap up the interview with the family.

The consulting pediatrician was able to evaluate the symptoms Ronald was having and adjust the medications and their dosages to address these immediate issues. Eventually, the elephant in the room emerged with the foster mother's request for a referral to a FAS assessment by a geneticist. My preceptor explained the guideline for diagnosis of (FASD) with the family and that there were insufficient indications for a referral for the multi-disciplinary workup that was required. I could sense the frustration of everyone in the room as an impasse developed over this issue. Finally after some additional discussions we ended up in the paradoxical situation of having to break a medically good news story which was perceived to be bad by the patient's family.

This had been a difficult clinical scenario for me as a learner due to the complexity of the issues and the helplessness of everyone involved. However, it served as a valuable lesson in how governmental decisions can play a central role in the care of vulnerable patient populations. This was also the first time I had tried stepping in the shoes of a child who really struggled in an educational system that I personally had few difficulties with during my own childhood. With the help of imagination, I could almost relate to the sense of frustration, helplessness, and terror that this child faced on a daily basis by reflecting on some my clerkship experiences. Lastly, this encounter reinforced the idea that nothing was quite as straightforward in real clinical situations as compared to lectures and standardized patient simulations. And that sometimes it is more difficult to break good news than to deliver a bad diagnosis.

Second story: **Pyrrhic Victory**

"I'm so sad, so sad today...I want to give up."

"What do you mean by giving up, John?"

"I want to give up on my life." (put head in his two hands, tremor)

This happened on the last day of my two weeks in-patient psychiatry rotation at Victoria Hospital. John was a patient well known on the ward for his numerous admissions in the past. He was in his late 50s and has suffered from mild intellectual disability, panic disorder, and chronic schizophrenia for most of his life. Despite such challenges John remained a pleasant patient who was generally upbeat about life. His gentle, cooperative, and undemanding nature was well known on the ward. My daily round and individual interviews with John could be summarized as short and pleasant. The team had been waiting for his transfer to Regional Mental Health Care - London for the past few days. His treatment plan had been the same for the past few weeks without any issues arising. The array of SSRIs, anxiolytics, and dopaminergic agents seemed to be working well in modifying his behavior and overall affect.

I had saved this interview as my last one in a hectic day, thinking that it would be as uneventful as the interviews of prior days. However, something was different about John this day and I sensed a change from the ‘usual John’ from the moment I entered his room. Instead of greeting me with his usual warm smile, John was gazing out the window into the distance with a stoic expression. His thoughts were focused inward on something serious and grim. It was my job as a clerk to figure out what had transpired and what was on his mind.

"I want to do something with my life. I used to be a janitor, I knew how to clean and mop. I want to work," John stated.

John continued, "I am sad that nobody cares about me, and my family hasn't come to visit me for a long time. I need more support. I want to have someone to talk to, someone to go out on a walk with, someone to talk about my life with."

Sitting across from this man with palpable distress in his voice and profound sadness in his eyes, I felt empty. I could clearly see the image of my stunned self, reflected in John's clear eyes as he looked straight at me. And through these crystal globes I saw myself in him, figuratively speaking. At that moment I stopped seeing John as a patient, but rather transported myself into his frame of mind. Was he being unreasonable? Were these not the very same things that you and I want for our lives? Would I not feel the same intense melancholy on reflecting on a life crippled by mental illness? The difference between John and I was that he was braver and wiser of the two in declaring and demanding out loud what it means to exist. This unexpected epiphany caused me to reflect on what it means to live. The silence lasted for a few more seconds -- a part of me urged me to attend to the issue at hand and push these existential thoughts to the back of my mind.

"John, would you be ok if we adjust some of your medications? They should make you feel better ..."

He nodded, but I felt that we both knew that was the easy way out ... an evasive maneuver to avoid confronting the heart of the issue. How can a life spent institutionalized in psychiatric facilities and group homes away from family, a life deprived of self-determination and fulfillment from one's own labour, a life perceived as lost and wasted ... how can that be made right with a few medications? If there was any victory in modern pharmacotherapy over mental illness on that day, it was a pyrrhic victory devoid of any real meaning.

I was profoundly troubled as I parted ways with John after the interview. I stopped by the coffee shop and bought him a coffee and a donut. Though the unexpected treat brought him a temporary joy, I had no doubt in my mind that this action was really for me to soothe my heavy conscience.

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