Emotion Regulation in Children and Adolescents with Intellectual Disabilities

by Mary Girgis

Thesis submitted in fulfilment of the requirements for
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Doctor of Philosophy

under the supervision of

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Certificate of Original Authorship

I, Mary Girgis declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Graduate School of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution. This research is supported by the Australian Government Research Training Program.

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Statement of Thesis Format

This body of work is a thesis by compilation comprised of 5 papers (4 publications and 1 manuscript under review). Additionally, introduction and discussion chapters are included, as well as, linking texts that establish continuity and coherence between chapters. APA 7th formatting is used throughout the thesis.

List of Original Publications and Manuscripts

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3. Girgis, M., Paparo, J., Roberts, L., & Kneebone, I. (2024). How Do Children with Intellectual Disabilities Regulate Their Emotions? The Views of Teachers. *Journal of Mental Health Research in Intellectual Disabilities*, 1–22. https://doi.org/10.1080/19315864.2024.2308284

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Co-author Contributions

By signing the Statement of Authorship, each author certifies that:

i. The PhD candidate's stated contribution to the publication is accurate (as detailed above)
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iii. The sum of all co-author contributions is less than or equal to the candidate's contribution

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Abbreviations

A-ID	Autistic children and adolescents with a co-occurring intellectual disability
BOC	Behaviours of Concern
DBC-ASA	Developmental Behaviour Checklist-Autism Screening Algorithm (Brereton et al., 2002)
DSM V-TR	Diagnostic Statistical Manual fifth edition text revision
O-ID	Children and adolescents *only* diagnosed with an intellectual disability (i.e., excluding autism)
PM-PROMs	Process model-based patient-reported outcome measures
PROMs	Patient-reported outcome measures

Abstract

Background: Emotion regulation difficulties are commonly experienced by children and adolescents with intellectual disabilities and are often expressed as co-occurring mental illnesses and behaviours of concern. In order to comprehensively understand the emotion regulation experiences of this population, the leading emotion regulation framework should be applied. Currently, the preeminent model is the process model of emotion regulation, which highlights five cyclic opportunities for emotion regulation and dysregulation: situation selection, situation modification, attentional deployment, cognitive change, and response modulation. Although the relevance of the process model has been examined in a broad range of settings and populations, it has yet to be determined in this demographic. Thus, this dissertation aims to determine the applicability of the process model to children and adolescents with intellectual disabilities.

Method: The methodology followed international guidelines used for determining construct relevance. First, a systematic review of process model-based instruments validated for this population was completed. Second, a service provider survey was carried out to assess the real-world usefulness of the process model, and the need for process model instruments. Lastly, qualitative methods (i.e., focus groups and interviews) were used with educators, parents, and children and adolescents, to further evaluate the relevance of the process model.

Results: The systematic review identified 10 measures in use, that aligned with the process model; however, no measure assessed all five emotion regulation domains. The service provider survey ($N = 122$) indicated that all emotion regulation domains were informally assessed when working with this demographic, which supported the real-world relevance of the model, and identified the need for process model-based assessment instruments. Overall, the thematic analysis of the perspectives of children and adolescents with intellectual

disabilities ($N = 17$), their educators ($N = 29$), and their parents ($N = 20$), supported the relevance of the process model. Additionally, the results suggested the parameters of the situation modification domain should be expanded to reflect the emotion regulation experiences of this population.

Conclusion: Overall, the findings indicated the process model largely encompasses the emotion regulation experiences of children and adolescents with intellectual disabilities, however, no suitable measures are currently available. Future research may build on this work and develop quantitative measures encompassing all the domains of the process model.

Chapter 1: Introduction

Children and adolescents with intellectual disabilities are prone to experiencing emotion regulation difficulties, which are often expressed as behaviours of concern or mental illnesses. Almost half of this population are diagnosed with a mental illness, and a fifth are diagnosed with two or more such conditions (Buckley et al., 2020; Munir, 2016). Despite the evident emotion regulation difficulties experienced, the leading emotion regulation framework—the process model of emotion regulation—has not been comprehensively considered within the context of children and adolescents with intellectual disabilities (Cremades et al., 2022; Gross, 1998, 2024; Samson et al., 2022).

This dissertation aims to determine the applicability and relevance of the process model of emotion regulation to children and adolescents with intellectual disabilities. In so doing, it will seek to better understand the emotion regulation and dysregulation experiences of this population. The approach of determining the applicability of the process model, also parallels the initial steps needed to develop process model-based patient-reported outcome measures (PM-PROMs; Mokkink et al., 2018; Swan et al., 2023). In this sense, this body of work intends to lay the foundation for future PM-PROMs; however, the development of a PM-PROM is beyond the scope of this dissertation.

This introductory chapter will summarise the current literature pertaining to the emotion regulation difficulties experienced by children and adolescents with intellectual disabilities, including the theoretical relevance of the process model of emotion regulation, and the challenges of applying the process model to this demographic. The chapter concludes with the proposal of several studies to assess the applicability of the process model of emotion regulation to children and adolescents with intellectual disabilities.

Intellectual Disabilities and Emotion Regulation Difficulties

Between 1% and 3% of children and adolescents are diagnosed with intellectual disabilities. An intellectual disability is defined by the Diagnostic Statistical Manual fifth edition text revision (DSM V-TR) as "…a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains" (American Psychiatric Association, 2022, p. 38). In the context of this definition, the conceptual domain relates to academic skills and understanding of abstract concepts, such as time. While the social domain relates to social communication and language. The practical domain consists of skills of daily living, such as, bathing and grooming. The severity of such difficulties can be classified as either mild, moderate, severe, or profound (American Psychiatric Association, 2022). Intellectual disabilities can arise from various factors, including chromosomal disorders, metabolic disorders, infections, and environmental influences (Shree & Shukla, 2016). Down syndrome is the most common chromosomal cause of intellectual disability, while Fragile X syndrome is the most frequently inherited form, and Fetal Alcohol Spectrum Disorder is the most prevalent type caused by environmental factors. However, 50% of intellectual disabilities have no identified cause (Ilyas et al., 2020).

The prevalence of mental health disorders in typically developing children and adolescents ranges between 8% to 18% (Einfeld et al., 2011), whilst children and adolescents with intellectual disabilities have a significantly higher prevalence of mental illness, ranging between 10% and 60% (Munir, 2016). However, a recent systematic review of mental illnesses found that between 38% and 49% of this demographic was diagnosed with a co-occurring mental health disorder (Buckley et al., 2020). This variation can partly be explained by differing definitions of adolescence. Specifically, the World Health Organization defines adolescence as the transitional period between childhood and adulthood, encompassing the

ages of 10 to 19 (World Health Organization and the United Nations Children's Fund (UNICEF), 2024). However, in contemporary society, the transition into adulthood is typically delayed, as the completion of education, marriage and parenthood, now occurs later in life (Sawyer et al., 2018). In light of these transition delays, Sawyer et al. (2018) argues the upper age limit should be increased to 24 years to more accurately represent this extended developmental period.

With this in mind, emotion dysregulation, when expressed as mental illnesses, presents differently across age groups. For instance, children with intellectual disabilities are more likely to develop conduct, anxiety, and pervasive developmental disorders, than typically developing children (Emerson, 2003). Such children, between the ages of 5 and 10, are at an increased risk of developing hyperactivity, while those between 11-16 years old are more likely to develop mood disorders. Further, 19 to 24 year olds with intellectual disabilities are more likely than their 13-18 year old counterparts to be diagnosed with a mental illness, suggesting emotion regulation difficulties are more likely to occur during this phase of the transition into adulthood (Young-Southward et al., 2017). This pattern diverges from the emotion regulation development trajectory seen in the typically developing population, wherein regulation abilities tend to improve by late adolescence (Riediger, 2024). This is partly due to adolescents at this stage increasingly utilising adaptive cognitive strategies, such as problem-solving (Eschenbeck et al., 2018). In contrast, mid-adolescence (12-15 years old) tends to be associated with greater emotion regulation difficulties, as this period often marks a peak in the use of maladaptive strategies, such as avoidance and rumination (Cracco et al., 2017). Adding to the complexity, emotion regulation typically develops in a non-linear fashion and is subject to individual differences (Riediger, 2024). The differences in emotion regulation development in late adolescence between individuals with intellectual disabilities and their typically developing peers may possibly stem from

variations in skill acquisition and underlying neurobiology. In this context it is important to comprehensively understand these emotion regulation difficulties, in order to support amelioration, particularly as it has been reported that co-occurring mental illnesses are a greater predictor of education restrictions, unemployment, social exclusion, and overall quality of life, than the severity of intellectual disability (Munir, 2016). One opportunity to do this is through the application of the leading emotion regulation framework, the process model of emotion regulation (Cremades et al., 2022; Gross, 2024). The process model primarily describes how regulation impacts emotion generation and is best understood within the context of valuation systems and an emotion generation framework, such as the modal model of emotion (Gross, 2015). Thus, the process model is built on four premises (Gross, 2015, 2024).

- Valuation systems underpin emotion generation and emotion regulation.

- Emotion generation is a type of valuation system (i.e., modal model).

- Emotion regulation is a type of valuation system (i.e., process model).

- Emotion regulation influences the emotion generation process.

Emotion Generation and Emotion Regulation

This section will focus on the four premises noted above, and discuss the relationship between valuation systems, emotion generation, and emotion regulation, as per the conceptualisation of emotion generation offered by the modal model of emotion, and the enhanced understanding of emotion regulation offered by the process model (Gross, 1998, 2014a, 2024).

Valuation Systems

Emotion regulation is governed by valuation systems, which are conscious and unconscious decision-making mechanisms that perceive and evaluate inputs, and then prompt decisions or responses (Gross, 2015). There are numerous types of valuation systems, ranging

from basic reflexes to complex higher order decisions (Rangel et al., 2008). Despite this range, valuation systems arguably share four cyclic elements (Gross, 2015):

- World (W): Internal and external situations

- Perception (P): Perceiving the situation

- Valuation (V): Evaluating the situation within the context of goals, specifically determining any discrepancies between the desired and perceived state

- Action (A): A decision or response to bridge the gap between the desired and perceived state.

Valuation systems are specific to the input type they have evolved to manage, and theoretical frameworks refine the valuation system components to target specific concepts. For instance, the modal model of emotion is a representation of the emotion generation valuation system (Gross, 2015).

Valuation System: Emotion Generation (Modal Model of Emotion)

In order for emotion to be regulated, the emotion generation sequence must first occur (Gross, 2015). The modal model of emotion represents a valuation system responsible for the generation of emotion. The modal model posits that emotion is generated according to a cyclical sequence that maps directly to each component of the valuation system: that is, situation (world), attention (perception), appraisal (valuation), and response (action; Gross, 2015), see Figure 1.1.

Figure 1.1

Mapping of Valuation System Components to Gross's (2015) Modal Model
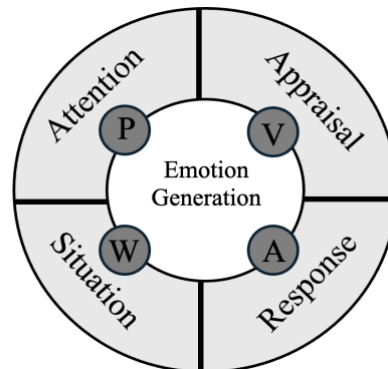
Note. Valuation system components: World (W), Perception (P), Valuation (V), Action (A).

The situation component is the occurrence of either an external or internal (i.e., cognition) event, while the attention component relates to the individual becoming aware of the situation. Next, appraisal is the process of the individual assessing the situation within the context of their goals. Lastly, the response element is the occurrence of an emotional response (i.e., neurobiological, behavioural or experiential changes). The following example illustrates emotion generation according to the modal model: A child's birthday is today (situation); the child becomes aware of the day (attention); the child associates their birthday with a dislike of clowns (appraisal); the child feels fearful (response). Within this context, emotion generation involves a transaction between an individual and situation (Gross, 2014a).

Valuation System: Emotion Regulation (Process Model of Emotion Regulation)

The process model encompasses four stages: identification, selection, implementation, and monitoring (Gross, 2015, 2024). These stages map to the modal model valuation system components (Gross, 2024). Specifically, the situation is the entire emotion generation valuation system described above, with the following stages mapped accordingly: identification (attention), selection (appraisal), and implementation (response).

The Identification Stage. Once an emotion is generated, the emotion regulation valuation system is triggered, starting with the first stage, identification. At this stage, the

individual becomes aware of their emotional position, which triggers the goal to reconcile the gap between their desired and perceived emotional state (Gross, 2015, 2024).

      The Selection Stage. The goal to change the emotional experience initiates the selection stage (Gross, 2015, 2024). This requires the individual to decide at which point in the emotion generation process to intervene (situation, attention, appraisal or response). This translates to five emotion regulation options, (situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2024), see Table 1.1 for definitions and examples.

Table 1.1

Definitions and Examples of the Five Domains of the Process Model of Emotion Regulation as Based on Gross (1998, 2014b)

Domain	Definition	Example
Situation Selection	An individual first becomes aware of an upcoming situation and the associated emotional reaction. This leads them to either initiate or avoid the situation.	A child avoiding bath time by hiding or a child requesting their birthday presents early.
Situation Modification	When a situation has commenced the individual can modify the environment to alter the emotional impact.	Using headphones to help with homework or chores completion.
Attentional Deployment	The ability to shift attentional focus. Redirecting attention can be grouped into three categories. <u>Distraction:</u> the ability to either redirect attention to non-emotional aspects of a situation or away from the situation entirely. <u>Concentration:</u> attention is sustained by the engagement of tasks which occupy finite cognitive abilities.	Distraction: child averting their eye gaze and focusing on a toy rather than their parents arguing. Concentration: when a child is concentrating on a YouTube video.

Domain	Definition	Example
	Rumination: directs attention to emotions and related consequences.	Rumination: when an adolescent worries about hypothetical threats.
Cognitive Change	The individual evaluates whether an event can be managed within the context of their goals.	Reframing is one strategy, wherein an adolescent engages in self talk about being excited instead of anxious when presenting a class speech.
Response Modulation	This domain occurs later in the emotion regulation process and focuses on changing the trajectory of behavioural, experiential, or physiological responses.	When an adolescent is behaving aggressively and then walks around their school to reduce this state.

Note: Reprinted from 'A systematic review of emotion regulation measurement in children and adolescents diagnosed with intellectual disabilities' by M. Girgis, J. Paparo, and I. Kneebone, 2021, *Journal of Intellectual & Developmental Disability*, p. 2. Copyright 2020 by Taylor and Francis Group.

In practice, when an individual becomes aware of a situation and its emotional implications, and has a goal to regulate their emotions, they can either choose to engage with or circumvent the situation (situation selection). If they have chosen to engage, then the individual can modify the physical environment to manage their emotional response (situation modification). Attention can also be shifted to regulate emotions (attentional deployment), and the individual can alter their cognitive understanding of the situation or their goals (cognitive change). Lastly, the individual can manage their emotions by modifying their responses across the experiential, physiological, and behavioural domains (response modulation). The goal to regulate emotion can also be self- or other-focused, previously referred to as intrinsic or extrinsic regulation (Gross, 2024). Self-focused emotion regulation pertains to regulating emotions in oneself, while other-focused emotion regulation concerns regulating the emotions of others. Both these goals can be achieved using social or non-social means: in other words, using the resources of others or an individual's own resources (Gross, 2024). Children typically have a self-focused social goal, which commonly translates to the child regulating their emotions by recruiting parental help (Gross, 2014a, 2024).

The Implementation and Monitoring Stages. Once an emotion generation location is selected, the individual progresses to the implementation stage. This stage involves selecting specific strategies aligned with the five domains of emotion regulation (situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2024). For instance, the following specific strategies could be chosen:

- Situation Selection: The child is aware of the upcoming birthday party, and instead of attending, visits their friend next door.

- Situation Modification: The child wears headphones during the party.

- Attentional Deployment: The child distracts themselves by playing on an iPad.

- Cognitive Change: The child tells themselves everything is going to be okay, as there are no clowns.

- Response Modulation: The child takes deep breaths and goes for a walk when they experience heart palpitations.

These strategies seek to alter specific points in the emotion generation process. The use of emotion regulation strategies creates new situations and progresses the emotion regulation response (Gross, 2015). The identification, selection, and implementation stages are cyclic in nature, and over time the selected strategies may need refinement—a process influenced by the separate monitoring stage, which consists of making choices regarding the continuation or refinement of strategies. Practically, several emotion regulation strategies can be used in rapid progression or simultaneously (Gross, 2024).

Interplay of Emotion Generation and Emotion Regulation Valuation Systems

Emotion regulation can be conceptualised as the interplay of two valuation systems, across two levels, as depicted in Figure 1.2.

Figure 1.2

The Interplay Between the Emotion Generation and Emotion Regulation Valuation Systems,

Based on Gross (2015, 2024)
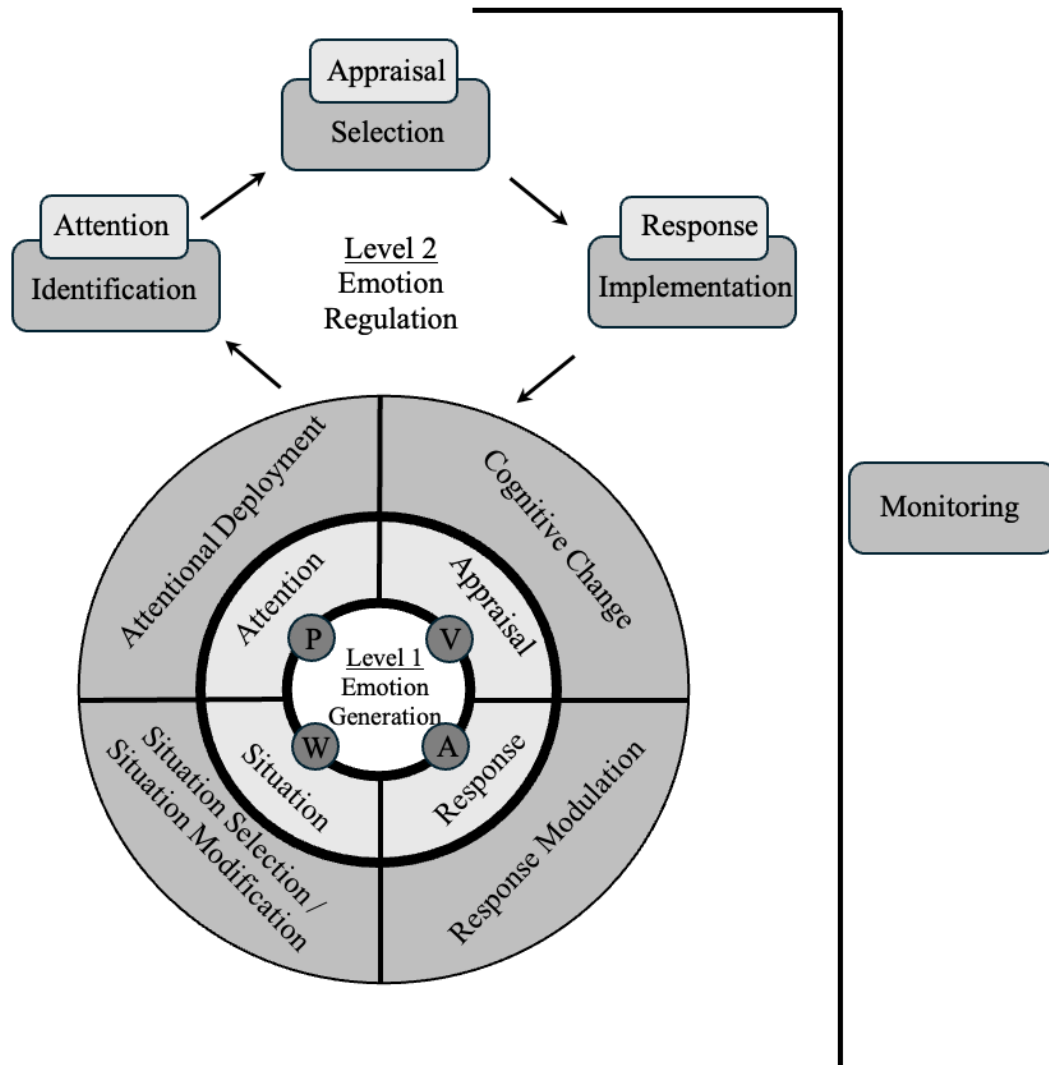
Note. Valuation system components: World (W), Perception (P), Valuation (V), Action (A).

The first level consists of the emotion generation valuation system, that is, the modal

model, which is also depicted in Figure 1.1. The emotion generation level triggers the second

level, the emotion regulation valuation system (i.e., the process model; Gross, 2024). The

emotion regulation phases (i.e., the identification, selection, and implementation stages) map

to the components of the modal model valuation system (i.e., attention, appraisal, and

response). This then influences the emotion generation process. Meanwhile, the monitoring process examines the interaction between these two systems and evaluates the effectiveness of the emotion regulation strategies, which prompts a decision to either continue, change, or stop the regulation strategy, in order to meet the desired emotional goal. This interaction between systems forms a continuous cycle, wherein emotions are perpetually generated, and strategies are monitored and adjusted. The aim of each iteration of the cycle is to work towards the realisation of the desired emotional goal (Gross, 2024).

Justification for Using the Process Model of Emotion Regulation with Children and Adolescents with Intellectual Disabilities

The following section reviews the current emotion regulation recommendations for children and adolescents with intellectual disabilities (McClure et al., 2009). Specifically, the process model will be discussed in terms of its theoretical underpinnings, alignment with transdiagnostic approaches, and capacity for integration with other relevant models and frameworks. The section will conclude with an examination of the process model's applicability to children and adolescents with intellectual disabilities.

Recommendations for Emotion Regulation Research in Intellectual Disabilities

McClure et al. (2009) highlighted a lack of emotion regulation research concerning children and adolescents with intellectual disabilities. In particular they identified the transdiagnostic strength of emotion regulation and recommended exploring this concept within this demographic. Further, they recommended the use of a combination of qualitative and quantitative methods, and the development of patient-reported outcome measures (PROMs). McClure et al. (2009) noted that one potential framework for understanding the emotion regulation phenomena among children and adolescents with intellectual disabilities is the process model of emotion regulation. However, they did not justify their selection of

the process model, nor elaborate on whether the process model aligns with the transdiagnostic approach.

Process Model of Emotion Regulation: Theoretical Foundations

While McClure and colleagues (2009) did not discuss their rationale for applying the process model to children and adolescence with intellectual disabilities, one clear justification is the model's robust theoretical underpinning (Gross, 2014b; Gross & Ford, 2024). Currently, there is no standardised definition of emotion nor, by extension, a definition of emotion regulation (Gross, 2014a). This has resulted in the development of overlapping and sometimes contradictory models of emotion and emotion regulation (Larsen & Prizmic-Larsen, 2006). In response to this complex theoretical landscape, the modal and process models were developed by coalescing the intersecting elements of various emotion generation frameworks (Gross, 2014a, 2015). Izard's (2010) synthesis of emotion regulation definitions supported this convergent characteristic of the process model. Specifically, a survey was conducted with 35 leading emotion researchers to compare their definitions of emotion regulation. The findings were amalgamated into eight key features of emotion regulation (Izard, 2010). All are well aligned with the process model (Gross, 2015, 2024).

Spontaneous Neurophysiological Process. This process includes changes in neurotransmitters and/or hormones (Izard, 2010). Rumination (i.e., attention deployment) is associated with increased cortisol levels (Watkins, 2024), while reappraisal (i.e., cognitive change) is related to short-term increases in cortisol reactivity (Denson et al., 2014).

Emotion Interactions. This element includes emotional interactions within an individual, and social-emotional contagion (Izard, 2010). The process model is underpinned by cyclic valuation systems that influence emotion generation and regulation within an individual (Gross, 2015). Socially, the process model is inclusive of self and other regulation

goals, where the input (or world) of the valuation cycle refers to the emotion of someone else (Gross, 2024).

Cognitive Processes. This element includes executive functions such as monitoring reappraisal and cognitive restructuring (Izard, 2010). As seen above, the process model includes a monitoring emotion regulation stage, and cognitive restructuring components within the cognitive change domain (Gross, 2024).

Adaptive Use of Energy Gained from Neurobiological Processes. Studies using positron emission tomographic and functional magnetic resonance imaging have indicated that the use of reappraisal, an adaptive emotion regulation strategy, can decrease amygdala activation when exposed to negative situations (Johnstone & Walter, 2014). Likewise, positive appraisals are related to greater prefrontal activity (Neta, 2024).

Social Processes. This factor pertains to the social influence on appraisals, support seeking, emotion contagion, and approval or disapproval (Izard, 2010). The influence of cultural perspectives maps to the process model, as the model is considered "agnostic" with regard to regulation sources (Mesquita et al., 2014). Within this context, either cultural or social aspects can guide conscious or unconscious goals that prompt regulation (Mesquita et al., 2014).

Learning and Developmental Processes. This incorporates effective emotion regulation patterns within the context of personality (Izard, 2010). This element is similar to the above social process feature, as the process model allows for the incorporation of various regulation sources (Mesquita et al., 2014). Within this context, individual differences, such as, habits, beliefs, personality, can influence the implementation of suppression strategies (i.e., response modulation; John & Eng, 2014). Emotion regulation patterns also differ between developmental stages; for instance, maladaptive strategy use increases as children transition into adolescence (Cracco et al., 2017; Moltrecht et al., 2021).

Behavioural Processes. This element includes managing behavioural expressions, modifying situations, and avoidance (Izard, 2010). These processes, respectively, align with the following process model domain definitions: response modulation, situation modification, and situation selection (Gross, 2014a).

Discrete Emotions may have Differing Regulation Processes. When considering discrete emotions such as sadness and anger, sadness is related to reappraisal (i.e., cognitive change), and distraction (i.e., attentional deployment). Anger is associated with avoidance (i.e., situation selection) as well as verbal emotional expression and thought suppression (i.e., response modulation), as explained by Rivers and colleagues (2007). Similarly, emotion intensity levels influence strategy selection, for instance, distraction is a preferred strategy when emotion intensity is high, while reappraisal is preferred when emotion intensity is low (Sheppes et al., 2011).

Overall, the process model aligns with the key features of emotion regulation identified by Izard (2010). This alignment is unsurprising as the modal model and the process model were specifically developed to merge the common elements of emotion generation theories (Gross, 1998, 2014b).

Alignment with the Recommended Transdiagnostic Approach

Transdiagnostic approaches are being recommended in place of diagnostic organisational frameworks with regard to intervention, as "Transdiagnostic characteristics are more likely to reflect everyday life experiences and align with underlying mechanisms, neurobiology or potential interventions, than ill-fitting canonical diagnostic labels" (Astle et al., 2022, p.398). McClure and colleagues (2009) noted the transdiagnostic potential of emotion regulation and recommended exploring this concept in the context of children and adolescents with intellectual disabilities. On the basis of symptom overlap between varying neurological conditions, and the prevalence of co-occurring mental health conditions in this

population, a transdiagnostic approach for research pertaining to this demographic is recommended (Astle et al., 2022; Munir, 2016). In fact, it has been argued that co-occurring conditions are the rule, rather than the exception, when considering children and adolescents (Chu et al., 2017). Emotion regulation, as conceptualised by the selection phase of Gross's (2024) process model, is considered to be transdiagnostic and has been proposed as a topic deserving exploration within the context of children with intellectual disabilities (Chu et al., 2017; England-Mason, 2020). Additionally, it has been argued that emotion regulation should be included within the National Institute for Mental Health's Research Domain Criteria (RDoC) project, an initiative which seeks to identify transdiagnostic factors associated with mental health (Chu et al., 2017; Fernandez et al., 2016). However, determining whether the implementation phase of the process model is considered transdiagnostic—and ascertaining specific transdiagnostic strategies—is complicated by the multitude of possible strategies (Cludius & Ehring, 2024; Gross, 2014a).

Strategies are considered transdiagnostic if they are, (1) identifiable in at least four disorders, and (2) a causal link between the strategy and the disorder can be established (Harvey et al., 2004). Individual emotion regulation strategies often only meet the first criteria (Cludius & Ehring, 2024). A summation of eight meta-analyses evaluating three separate emotion regulation strategies (i.e., rumination/attention deployment, reappraisal/cognitive change, and suppression/response modulation) indicated that the strategies met the first criteria, as they were associated with nine mental illnesses (Cludius & Ehring, 2024). Nevertheless, the second transdiagnostic criteria was only partially met, as the causal evidence was mixed (Cludius et al., 2020; Cludius & Ehring, 2024). However, the diverse measurement tools captured by the meta-analyses, could contribute to these mixed findings, as there is an absence of validated PM-PROMs (Compas et al., 2017; Samson et al., 2022). Despite this, there is evidence that the overall use of emotion regulation strategies is

associated with a reduction in psychopathological symptoms (Sloan et al., 2017). A systematic review exploring the transdiagnostic aspect of implemented emotion regulation strategies concluded that maladaptive strategies significantly decreased across various disorders (e.g., depression, anxiety, substance use, eating disorders, and borderline personality disorders), regardless of the psychological intervention employed (Sloan et al., 2017). Likewise, a meta-analysis that reviewed psychological interventions used with children and adolescents, found a positive association between emotion regulation difficulties and psychopathology (Moltrecht et al., 2021). Of note, the meta-analysis also indicated that interventions that focused on emotion regulation were more likely to decrease emotion dysregulation than non-specific interventions (Moltrecht et al., 2021). Overall, these reviews suggest initial support that the process model as a whole meets Harvey et al's. (2004) transdiagnostic criteria, as, in general emotion regulation difficulties are related to psychopathology.

Incorporation of Relevant Models

A further strength of the process model is its ability to be incorporated into other theoretical models across the biopsychosocial landscape. Simply put, the process model is a framework that predominately focuses on how emotions are regulated, rather than why (Gross, 2024). While the process model does describe the role of goals and valuation systems in terms of "why" emotion is regulated, the model remains "agnostic" about the factors that influence goal development (Mesquita et al., 2014). While a review of all relevant models is beyond the scope of this dissertation, two models will be briefly discussed: Self-determination theory (Ryan & Deci, 2000) and the model of the relationships between parenting stress, parent behaviour, and child behaviour problems (Hastings, 2002).

The process model can be incorporated into the self-determination theory, one of the most widely used frameworks in the motivational and psychological wellbeing field (Benita,

2020; Ryan & Deci, 2000). Briefly, this theory posits that all individuals have an innate desire for psychological growth (Ryan & Deci, 2000). This need guides motivators, of which one type is extrinsic motivation. Extrinsic motivation is the completion of a behaviour in order to attain an outcome that is separate to the self. For example, completing homework for the purpose of achieving good grades (Ryan & Deci, 2000). Within the context of the process model these motivators shape goals (Benita, 2020). Specifically, should a situation occur wherein the student is unable to complete their homework, this will prompt the generation of emotion. More precisely, the student becomes aware of the difference between the perceived state and the desired state (i.e., not completing homework vs. wanting to complete homework), and this results in an emotion, such as sadness. This emotion then prompts an emotion regulation response, such as cognitive change.

A model specifically developed for parents of children with intellectual disabilities is the model of the relationships between parenting stress, parent behaviour, and child behaviour problems (Hastings, 2002). This model posits parental stress influences parental behaviour, which in turn leads to the development and maintenance of their child's behaviours of concern. Behaviours of concern result in increased parental stress, thus creating a feedback loop. In this way, the model predicts a reduction in parental stress will result in decreased behaviours of concern. This model aligns with the process model, as the goal to reduce parental stress in order to decrease the behaviours of concern of the child is considered other-focused emotion regulation using non-social means (Gross, 2024). In this way, emotion is regulated for the purpose of regulating the emotions of another individual.

The process model also aligns with evidence-based approaches commonly used with individuals with intellectual disabilities, such as functional analysis assessments that inform reinforcement-based interventions, including positive behavior support (Fisher et al., 2024). Reinforcement plays a significant role in shaping the emotions elicited within specific

environmental contexts and in influencing the strategies chosen for emotion regulation (Aldao, 2024). For instance, children and adolescents with intellectual disabilities use avoidance (Samson et al., 2022), despite it being maladaptive (Rudaz et al., 2017), as this strategy is reinforced by the effective removal of distressing stimuli, thereby reducing exposure to perceived threats or aversive situations. Within the process model framework, avoidance could be considered a situation selection-based emotion regulation strategy.

Process Model Applicability to Children and Adolescents with Intellectual Disabilities

Despite the strengths of the process model, it has been rarely directly applied to children and adolescents with intellectual disabilities (Samson et al., 2022). Samson and colleagues (2022) surveyed the emotion regulation strategies of children and adolescents with intellectual disabilities, using parental reports. While the process model of emotion regulation guided this survey, the study assumed the applicability of this model and did not comprehensively ascertain whether all five domains of the process model were supported (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2024). Also, only 14 emotion regulation strategies were evaluated, using an unvalidated survey developed specifically for this study, wherein each strategy was assessed via a single item. The authors indicated that the unvalidated survey was used in response to the lack of validated PM-PROMs for this demographic and recommended the development of such measures (Samson et al., 2022). Given the absence of validated measures, a qualitative approach could facilitate the exploration of the process model's applicability within this population.

Littlewood et al. (2018) qualitatively explored the process model framework and emotion regulation strategies used by adults with intellectual disabilities. However, the findings did not represent all five domains of the process model, as only three main themes were identified: regulatory talk, avoidance, and cognitive strategies. The authors suggested

this discrepancy may have been influenced by the interview structure, the cognitive-emotive behavioural assessment developed by Trower and colleagues (1988). Specifically, the interview structure focused on emotionally salient events and employed emotion regulation strategies (Littlewood et al., 2018). The interview did not explicitly discuss emotion regulation strategies associated with the five domains of the process model (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2024). The authors also suggested an alternative interpretation, that the process model domains are only partially relevant to this population (Littlewood et al., 2018). However, on examining the broader literature through the lens of the process model, it appears that children and adolescents with intellectual disabilities engage in all five process model domains, as seen below.

Situation Selection. Regarding the situation selection domain, this population can implement the following strategies to manage anxiety: isolation, withdrawal, and information avoidance (Samson et al., 2022). However, the maladaptive use of avoidance may lead to the development of specific phobias (Rudaz et al., 2017). This is specifically relevant to this population, as 17.5% of individuals with intellectual disabilities between the ages of 7 and 20 are diagnosed with a specific phobia (Dekker & Koot, 2003). Therapeutically, a systematic review of phobia treatments for individuals with intellectual disabilities found that effective treatment involves promoting continued engagement in a situation by reducing maladaptive avoidance (Jennett & Hagopian, 2008).

Situation Modification. Regarding the situation modification domain, a systematic review provided preliminary support for the use of music in the reduction of self-injurious behaviours (Schwartz et al., 2017). Likewise, a review of activity schedules for children and adolescents with intellectual disabilities also indicated that this environmental modification was associated with reduced self-injurious behaviours (Koyama & Wang, 2011). The use of

visual aids with students is also associated with positive emotions and independence (Duttlinger et al., 2013). Similarly, the use of earmuffs is associated with reduced behaviours of concern and assists children with intellectual disabilities to manage their distress when experiencing triggering auditory stimuli (Ikuta et al., 2016).

Attentional Deployment. The attentional deployment domain is associated with three common strategies: distraction, concentration, and rumination (Gross, 1998, 2014b). Distraction can be used to either redirect attention to non-emotional aspects of a situation or away from the situation entirely (Gross, 1998). One study piloted a mindfulness-based program with adolescents with mild intellectual disabilities and their parents (Heifetz & Dyson, 2017). The program successfully taught the cohort to shift their attention to the soles of their feet during emotionally triggering events, resulting in an overall improvement in mood (Heifetz & Dyson, 2017). Whilst concentration pertains to the occupation of finite cognitive resources and draws attention away from triggers and minimises emotional impact (Gross, 1998), children and adolescents with intellectual disabilities have a reduced ability to concentrate (Di Nuovo & Buono, 2009). However, mindfulness based therapeutic interventions are associated with improvements in concentration, in this population (Kim & Kwon, 2018). In comparison, rumination redirects attention to emotions and related consequences (Gross, 1998). Rumination in adolescents with intellectual disabilities is related to depressive symptoms and occurs at the same frequency in typically developing peers (Weeland et al., 2017; Young et al., 2016). Despite this, children and adolescents with intellectual disabilities overall express more anxiety symptoms than their same age peers (Young et al., 2016).

Cognitive Change. The literature regarding cognitive change typically emphasises reappraisal strategies (Gross, 2014a). Cognitive behaviour therapy, of which cognitive reappraisal is a common element, has been adapted to children and adolescents with

intellectual disabilities, and has successfully reduced anxiety symptoms (Hronis et al., 2019, 2022). Specifically, reappraisal by way of focusing on the positive, is a strategy more often used by children and adolescents with Williams syndrome, when compared with peers with an unspecified intellectual disability (Samson et al., 2022). It has been hypothesised that this profile difference could be due to the inherent positivity bias associated with Williams syndrome, however, further research is needed, as comparisons with typically developing peers were not conducted (Samson et al., 2022).

Response Modulation. Response modulation occurs late in the emotion regulation process and focuses on changing the trajectory of behavioural, experiential, or physiological responses (Gross, 1998). Effective response modulation can be difficult for children and adolescents with intellectual disabilities, due to inherent hyperarousal—a state that increases the likelihood of anxiety symptoms (Miller et al., 1999; Wadell et al., 2013). Furthermore, children and adolescents with intellectual disabilities express emotion dysregulation as behaviours of concern at a rate three times higher than the typically developing population (National Collaborating Centre for Mental Health (UK), 2015). Behaviours of concern can be successfully reduced with de-escalation and deep breathing techniques (Mitsea et al., 2022; Verret et al., 2019). Moreover, several meta-analyses and systematic reviews have indicated that guardian-led other-focused emotion regulation can be used to manage behaviours of concern (Grey & Hastings, 2005; Heyvaert et al., 2012). In this context, response modulation manifests as parent-based interventions (Hudson et al., 2003), restrictive practices (Menon et al., 2012), pharmacological interventions (McQuire et al., 2015), and/or reinforcement-based interventions (Heyvaert et al., 2012).

In summary, although the applicability of the process model to children and adolescents with intellectual disabilities has not been explicitly investigated, previous literature offers preliminary support for its suitability.

Barriers to Applying the Process Model

At present, the relevance of the process model to children and adolescents with intellectual disabilities has yet to be determined, as several barriers impede direct application. Specifically, including individuals with intellectual disabilities in research is complicated by informed consent requirements and also the absence of validated measures (Maes et al., 2021). Several accommodations can facilitate the inclusion of this population in research. For instance, informed consent can be gathered with the assistance of guardians, as well as the use of easy-read consent forms, visual aids, and appropriate language choices (Maes et al., 2021; McClure et al., 2009; McDonald et al., 2022). However, a lack of such accommodations often translates to an over-reliance on informant-based research (i.e., via parents and/or teachers). While the inclusion of relevant stakeholders is valuable, a comprehensive evaluation of target variables is incomplete without the lived experience of individuals with intellectual disabilities (Maes et al., 2021; McDonald et al., 2022).

Despite recommendations to develop outcome measures for children and adolescents with intellectual disabilities, and practical suggestions for both obtaining informed consent and conducting such research, there is an absence of PM-PROMs validated for this population (Maes et al., 2021; McClure et al., 2009; Samson et al., 2022). A systematic review examined emotion regulation measures commonly used in research with autistic children and adults, pointed to the limited availability of PM-PROMs (Weiss et al., 2014). Sixty-four measures were reviewed, of which six had been used with autistic children and adolescents with intellectual disabilities (Weiss et al., 2014). However, measures used with non-autistic individuals with intellectual disabilities were not discussed. Overall, only two measures assessed all five domains of the process model: the Effortful Control Scale, and the Response to Stress Questionnaire (Connor-Smith et al., 2000; Lonigan & Phillips, 1998). In order for a measure to be considered valid for children and adolescents with intellectual

disabilities, this population must be explicitly included during the PROM development phase (Mokkink et al., 2018). Neither of the identified measures explicitly included this demographic during PROM development, and they are therefore not appropriate for use with children and adolescents with intellectual disabilities (Connor-Smith et al., 2000; Lonigan & Phillips, 1998; Mokkink et al., 2018). Collectively, the results of the systematic review conducted by Weiss et al. (2014) highlights the lack of PM-PROMs. Given the absence of validated measures, this limits the exploration of emotion regulation difficulties in children and adolescents with intellectual disabilities through the perspective of the process model. This is problematic considering the implications of emotion dysregulation, such as, education restrictions, unemployment, social exclusion and reduced quality of life (Munir, 2016). In this context, qualitative methods could evaluate the suitability of the process model (McClure et al., 2009), but to date, this approach has only been used with adults with intellectual disabilities (Littlewood et al., 2018).

Current Research

To the author's knowledge, the relevance of the process model has not been directly evaluated within the context of children and adolescents with intellectual disabilities. Considering the literature review, and the process model strengths, such as its robust theoretical underpinning and alignment with the transdiagnostic approach, the relevance of the process model to children and adolescents with intellectual disabilities should be examined. This will be undertaken in this dissertation, utilising a three-pronged approach aligned with the COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) recommendations for the development of PM-PROMs (Mokkink et al., 2018; Swan et al., 2023), as outlined below:

1. First, a systematic review will be conducted to determine the availability of PM-PROMs validated for children and adolescents with intellectual disabilities

(Chapter 3; Girgis et al., 2021). This will build on Weiss and colleagues' (2014) systematic review of PM-PROMs for autistic children and adults and focus on non-autistic children and adolescents with intellectual disabilities (all other co-occurring conditions will be included). The aim is to identify informant and self-report PM-PROMs that included either children and adolescents with intellectual disabilities, or their parents and teachers, during the conceptualisation phase of the measure's development. This is of particular importance, as the inclusion of key stakeholders during conceptualisation adheres to best practice standards and also acts to determine the relevance of the process model (Terwee et al., 2018).

2. Next, service providers working with children and adolescents with intellectual disabilities will be surveyed. The aim is to assess the service providers' awareness of the process model, the model's perceived utility, and whether PM-PROMs would aid service provision (Chapter 5; Girgis, Paparo, & Kneebone, 2024c).

3. Following the survey, qualitative methods will be used to determine the applicability of the process model to children and adolescents with intellectual disabilities. The emotion regulation and dysregulation experiences of this population will be evaluated through the lens of the process model. Specifically, the perspectives of educators (Chapter 7; Girgis, Paparo, Roberts, et al., 2024), parents (Chapter 8; Girgis, Paparo, & Kneebone, 2024b), and children and adolescents (Chapter 9; Girgis, Paparo, & Kneebone, 2024a), will be gathered.

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Chapter 2: Methodology for Patient-Reported Outcome Measure Development

Children and adolescents with intellectual disabilities are more likely to experience emotion regulation difficulties, with negative impacts on their schooling, social functioning and quality of life (Munir, 2016). Considering the associated distress of emotion dysregulation alongside these implications, it is crucial to develop a greater understanding of these experiences, by assessing the relevance of the process model of emotion regulation to this demographic (Emerson & and Einfeld, 2011; Gross, 2024; Munir, 2016). The method of determining the relevance of the process model partially mirrors the methodology of developing process model-based patient-reported outcome measures (PM-PROMs). This chapter will discuss the steps involved in determining the relevance of the process model (Gross, 2015, 2024) to children and adolescents with intellectual disabilities, and the corresponding PM-PROM development steps. The proposed method is guided by the COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) group recommendations (Swan et al., 2023).

COSMIN is the only available international guideline on the methodological review of healthcare PROMs (Swan et al., 2023). It was developed in response to concerns within the measurement literature; specifically, conflicting and inaccurate terminology, insufficient evidence for PROMs, and inconsistent methodology (Mokkink et al., 2018; Prinsen et al., 2018; Swan et al., 2023). These factors are important to consider, as poorly designed PROMs yield inadequate validity and reliability, and impact both research results and client outcomes (Swan et al., 2023). COSMIN specifically recommends the use of qualitative methods to gather the experiences of target stakeholders during the conceptualisation phase of PROM development (Mokkink et al., 2018; Swan et al., 2023; Terwee et al., 2016). PROMs that exclude key stakeholders during conceptualisation are considered inadequate (Mokkink et al.,

2018; Terwee et al., 2016). However, within the intellectual disability field, measures developed for the typically developing population are often used with individuals with intellectual disabilities (Maes et al., 2021). This is problematic, as PROMs crafted for the typically developing population fail to adequately capture the experiences of this demographic (Barrowcliff et al., 2018; Brooks & Davies, 2008). In fact, a systematic review of mental health PROMs used with individuals with intellectual disabilities found better content validity in measures that incorporated this population during PROM development (Patel et al., 2023).

Although the COSMIN guidelines focus on evaluating the quality of PROMs (Mokkink et al., 2018; Prinsen et al., 2018), they have been adapted into a 10-step PROM development process (Swan et al., 2023). All 10 steps are summarised and described in Table 2.1. The focus of this dissertation is on Steps 1 to 5, as these steps are specifically related to determining the suitability of the process model. Steps 6 to 10 will not be considered, as these steps focus on PROM piloting and psychometric validation, which are outside the scope of this dissertation. This chapter will discuss Steps 1 to 3: (1) Identifying PROMs; (2) Extracting psychometrics; and (3) Evaluating psychometric properties.

Table 2.1

COSMIN-Based PROM Development Steps and Descriptions, Derived from Swan et al.

(2023)

Steps	Description
Review of PROMs:	
1. Identify PROMs within subject area and demographic.	Determine the present state of practice and collate relevant PROMs.
2. Extract the psychometrics of identified PROMs.	Manuscripts pertaining to PROM development and usage are reviewed, and relevant psychometric data is extracted. This can be captured in a systematic review.
3. Compare the obtained data with the predetermined criteria.	The psychometric properties of the identified PROMs are evaluated against the COSMIN risk of bias checklist. The PROMs are also examined to determine if the target construct has been evaluated.
Development of PROMs:	
4. The construct is identified.	The construct is defined, and relevant stakeholders are identified. The purpose of the PROM is defined.
5. Confirm construct relevance/Item pool generation.	Qualitative research is conducted in relation to the target demographic. The qualitative data is used to confirm the relevance of the construct and to generate items. Items can also be selected from existing PROMs.
6. Response Scales	Response scales are matched to the PROM. The selection of the response scales is influenced by the spectrum of the variable, and the data type intended for collection.

Steps	Description
7. Expert Review	Relevant experts in the field review the draft PROM and face validity is determined.
8. Piloting	The PROM is piloted in the target population, and adjustments are made as needed.
9. Refining Items	The items are reduced on the basis of feedback and statistical analysis.
10. PROM trial	The updated PROM is trialled in the target population, within a larger sample size. Psychometric properties are determined.

Note. This dissertation focuses on Steps 1 to 5, which assess the process model's suitability.

Steps 1, 2 and 3 of the COSMIN-based PROM development process focus on the identification of valid PROMs, as psychometric experts strongly advise against creating new instruments unless deemed necessary (Swan et al., 2023). The identification of valid PM-PROMs also serves to confirm the relevance of the process model to children and adolescents with intellectual disabilities, as PROMs adherent to the COSMIN guidelines must first ensure the relevance of the underlying theoretical framework. Specifically, the steps are informed by the COSMIN guidelines for systematic reviews of PROMs (Prinsen et al., 2018), and the COSMIN risk of bias checklist (Mokkink et al., 2018). This method also conforms to the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2015). It should be noted that while PRISMA provides recommendations for uniform reporting across systematic reviews, the COSMIN resources are quality assessment tools and guidelines for conducting systematic reviews that specifically evaluate psychometric measures (Moher et al., 2015; Mokkink et al., 2018; Prinsen et al., 2018).

Step 1: The Identification of PROMs

Step 1 focuses on assessing the current field and identifying any gold standard PROMs using the COSMIN guidelines for systematic reviews of PROMs, which were developed in response to several reoccurring limitations (Prinsen et al., 2018; Swan et al., 2023). Specifically, a review of the quality of systematic reviews found substandard practices, related to limited search strategies, terms, and scope. For instance, less than half of systematic reviews assessed the methodological quality of the included studies. Whilst 58% assessed the quality of the identified PROMs, and only 42% synthesised the psychometric data of PROMs across multiple studies (Terwee et al., 2016). This presents a challenge, as systematic reviews should provide robust overviews of PROMs, facilitating the selection of evidence-based PROMs suitable for an intended purpose. Reviews should also identify research gaps and outline future directions (Prinsen et al., 2018). The COSMIN systematic review recommendations aim to improve the overall quality of PROM systematic reviews. This process is divided into 10 sub-steps across three phases: (1) Literature search; (2) Assessment of psychometrics; and (3) Selection of PROMs (Prinsen et al., 2018), see Figure 2.1 for representation of phases, and Table 2.2 for detailed sub-steps.

Step 1 of the PROM development process focuses on the literature search phase, which includes sub-steps 1 to 4 (Prinsen et al., 2018). First, a clear systematic review aim is identified. The aim must include the following elements: a clear construct, target population, type of PROM, and a clear list of psychometrics of interest. The next step consists of refining the inclusion and exclusion criteria of studies, within the context of the aims. For instance, the inclusion criteria will need to capture PROMs that assess the primary construct within the target population, and the studies should either focus on PROM development or psychometric properties. Third, the search strategy should include multiple databases, and comprehensive search terms, preferably developed with the assistance of a librarian. Fourth, two independent

reviewers should select abstracts and full texts, and conflicting opinions should be discussed.

Figure 2.1

Alignment of Steps 1 to 3 of the PROM Development Process to COSMIN Guidelines, as

Derived from Swan et al. (2023)
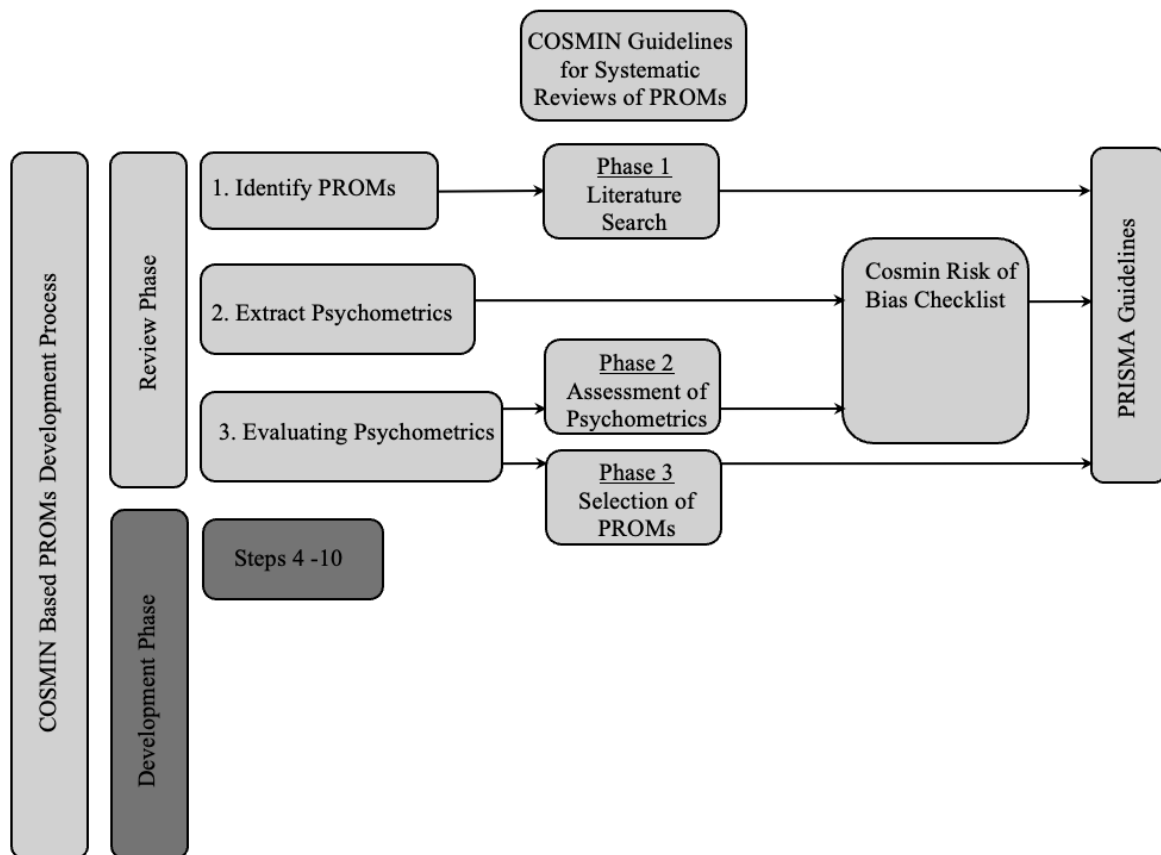
Table 2.2

Alignment of Steps 1 to 3 of the COSMIN-Based PROMs Development Process, COSMIN Guidelines for Systematic Reviews of PROMs, and

COSMIN Risk of Bias Checklist*

PROM Development Steps	COSMIN Systematic Review of PROMs Sub-Steps	COSMIN Risk of Bias Checklist
1. Identify PROMs within a predetermined subject area and demographic	**Phase 1: Literature Search** 1. Systematic review aim 2. Eligibility criteria 3. Search strategy 4. Extraction of abstracts and full texts	
2. Extract the psychometrics of identified PROMs		Extract: PROM design, content validity, structural validity, internal consistency, cross-cultural validity/measurement invariance, reliability, measurement error, criterion validity, construct validity, and responsiveness

PROM Development Steps	COSMIN Systematic Review of PROMs Sub-Steps	COSMIN Risk of Bias Checklist
3. Evaluating psychometrics with a predetermined criteria.	**Phase 2: Assessment of Psychometrics** 5. Evaluation of content validity 6. Evaluation of internal structure (i.e., internal consistency, structural validity, and cross-cultural validity/measurement invariance) 7. Evaluation remaining measurement properties (i.e., reliability, measurement error, criterion validity, construct validity, and responsiveness) **Phase 3: Selection of PROMs**. 8. PROMs interpretability/feasibility 9. Recommendation of PROMs 10. Systematic review report	Grade psychometric data across four levels: very good, adequate, doubtful, and inadequate.

Note. *Derived from Mokkink et al. (2018), Prinsen et al. (2018), Swan et al. (2023).

Step 2: The Extraction of Psychometrics

Step 2 of the PROM development process focuses on the retrieval of psychometric data and sets the stage for assessing the risk of bias (Swan et al., 2023); the process of determining the likelihood of misleading results (Mokkink et al., 2018). This is achieved via the COSMIN risk of bias checklist, which recommends the retrieval of the following psychometric information: PROM design, content validity, structural validity, internal consistency, cross-cultural validity/measurement invariance, reliability, measurement error, criterion validity, construct validity, and responsiveness (Mokkink et al., 2018).

Step 3: The Evaluation of Psychometric Properties

Step 3 evaluates the psychometric data collected in Step 2 and is achieved via adherence to the second and third phases of the COSMIN guidelines for systematic reviews of PROMs (Prinsen et al., 2018; Swan et al., 2023). Phase 2 pertains to the assessment of psychometrics, and phase 3 guides the selection of PROMs (Prinsen et al., 2018).

Phase 2 includes sub-steps 5 to 7 (Prinsen et al., 2018). Sub-step 5 consists of the evaluation of content validity, which can be achieved through the use of the COSMIN methodology for assessing the content validity of PROMs (Prinsen et al., 2018; Terwee et al., 2018). Sub-step 6 involves the assessment of internal structure, this includes internal consistency, structural validity, and cross-cultural validity/measurement invariance (Prinsen et al., 2018). Sub-step 7 guides the assessment of the remaining psychometrics (reliability, measurement error, criterion validity, construct validity, and responsiveness). The quality of the psychometric data captured across sub-steps 5 to 7 is assessed against the COSMIN risk of bias checklist (Mokkink et al., 2018). The comprehensive checklist ranks the quality of each psychometric category (Mokkink et al., 2018; Prinsen et al., 2018), as follows:

- Very Good: High confidence that the estimated and true psychometric properties closely align.

- Adequate: Moderate confidence that the estimated and true psychometric properties may closely align. However, it is possible that the true and estimated psychometric properties may significantly deviate.

- Doubtful: Limited confidence that the estimated and true psychometric properties align.

- Inadequate: Very limited confidence that the estimated psychometric properties reflect the true psychometric properties.

Phase 3 details the selection of an appropriate PROM and includes sub-steps 8 to 10 (Prinsen et al., 2018). Sub-step 8 relates to the PROM's interpretability and feasibility; sub-step 9 guides the selection of the highest quality PROM, and sub-step 10 concludes with generating a systematic review report. This final report is presented in accordance with the PRISMA guidelines (Moher et al., 2015).

Conclusion

Given the interest in a PM-PROM for children and adolescents with intellectual disabilities, a COSMIN-based PROM development process is appropriate for determining the relevance of the process model (Swan et al., 2023). A systematic review is the recommended starting point. This should be guided by the COSMIN guidelines for systematic reviews of PROMs and the COSMIN risk of bias checklist (Mokkink et al., 2018; Prinsen et al., 2018) and reported in accordance with the PRISMA guidelines (Moher et al., 2015).

The systematic review will aim to build on Weiss and colleagues' (2014) systematic review of PM-PROMs for autistic children and adults with and without intellectual disabilities (A-ID) and accordingly will focus only on non-autistic children and adolescents with intellectual disabilities (O-ID). In this way, the systematic review will aim to identify

PM-PROMs developed specifically for O-ID children and adolescents and capture any literature gaps. The focus will remain on the O-ID population, as measures developed for the A-ID population have previously been explored. The systematic review will adhere to the COSMIN guidelines for systematic reviews of PROMs (Prinsen et al., 2018), and so include the four key elements:

- Clear construct: The process model of emotion regulation (Gross, 2015, 2024).

- Target population: Non-autistic children and adolescents with intellectual disabilities. (all other co-occurring conditions will be included).

- Type of PROMs: Self- and informant-based.

- Clear list of psychometrics of interest: The systematic review intended to capture the psychometric properties included in the COSMIN risk of bias checklist (Mokkink et al., 2018).

The systematic review report is included in Chapter 3.

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Chapter 3. Study 1: A Systematic Review of Emotion Regulation Measurement in Children and Adolescents Diagnosed with Intellectual Disabilities

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LITERATURE REVIEW

A systematic review of emotion regulation measurement in children and adolescents diagnosed with intellectual disabilities

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ABSTRACT

Background: Emotion regulation is a challenge for many, in particular children with intellectual disabilities. To support understanding and the development of interventions in this area it is essential to identify valid and reliable measures.
Method: This systematic review aimed to identify measures that assess all five emotion regulation domains as described by the process model of emotion regulation; situation selection, situation modification, attention deployment, cognitive control, and response modulation. The validity and reliability of these measures was determined by the COSMIN Risk of Bias checklist.
Results: Of the 10 measures identified, only the Anxiety, Depression, and Mood Scale possessed moderate levels of evidence. However, this measure does not assess all five domains of emotion regulation.
Conclusions: Future research would benefit from the development of both informant and self-report measures for children and adolescents with intellectual disabilities, that assess all the five domains of emotion regulation.

Emotion regulation describes the process of responding, managing, and modifying emotional responses in order to achieve active goals (Gross, 2014). The mechanisms involved in emotion regulation have long been queried and this pursuit has led to the development of multiple overlapping and contradictory theories, each with corresponding methods of measurement (Larsen & Prizmic-Larsen, 2006). The proliferation of multiple theoretical underpinnings has made it difficult to universally conceptualise and measure emotion regulation (Adrian et al., 2011). Considering these complexities, measures need to be carefully selected to match the preferred theoretical framework, as the method of measurement will in part influence the definition and conceptualisation of emotion regulation (Larsen & Prizmic-Larsen, 2006). This literature review will focus on the process model of emotion regulation (Gross, 2014), as the model was developed to combine the common elements between theories of emotion (Gross, 2015), and is frequently used to conceptualise emotion regulation in emotion research (Gross, 2014; Weiss et al., 2014). While distinct in a number of ways from other frameworks for understanding emotion regulation, common

to the process model and other theories is the universal recognition that emotion regulation difficulties serve to decrease quality of life, particularly for children and adolescents diagnosed with intellectual disabilities (Munir, 2016).

Emotion regulation difficulties are more likely to develop in children and adolescents with intellectual disabilities (Carrasco et al., 2005; Di Nuovo & Buono, 2009; Einfeld et al., 2011; Kim & Kwon, 2018; Lalli et al., 1995; Munir, 2016). Approximately 1–3% of children and adolescents develop cognitive and adaptive functioning deficits in utero or due to environmental causes that result in an intellectual disability diagnosis (American Psychiatric Association, 2013; Munir, 2016). A feature of these deficits is increased emotion regulation difficulties, that are often expressed in children and adolescents with intellectual disabilities as reduced concentration (Di Nuovo & Buono, 2009), increased task avoidance (Kim & Kwon, 2018; Lalli et al., 1995), attention deficits (Carrasco et al., 2005), and mental health disorders (Einfeld et al., 2011). In fact, emotion regulation difficulties are implicated in over 50% of mental health disorders (Gross, 1998), and significantly reduce quality of life

Table 1. Definitions and examples of the five domains of the process model of emotion regulation as based on Gross (1998, 2014).

Domain	Definition	Example
Situation selection	An individual first becomes aware of an upcoming situation and the associated emotional reaction. This leads them to either initiate or avoid the situation.	A child avoiding bath time by hiding or a child requesting their birthday presents early.
Situation modification	When a situation has commenced the individual can modify the environment to alter the emotional impact.	Using headphones to help with homework or chores completion
Attention deployment	The ability to shift attentional focus. Redirecting attention can be grouped into three categories. Distraction: the ability to either redirect attention to non-emotional aspects of a situation or away from the situation entirely. Concentration: attention is sustained by the engagement of tasks that occupy finite cognitive abilities. Rumination: directs attention to emotions and related consequences.	Distraction: child averting their eye gaze and focusing on a toy rather than their parents arguing. Concentration: when a child is concentrating on a YouTube video Rumination: when an adolescent worries about hypothetical threats.
Cognitive change	The individual evaluates whether an event can be managed within the context of their goals.	Reframing is one strategy, wherein an adolescent engages in self talk about being excited instead of anxious when presenting a class speech
Response modulation	This domain occurs later in the emotion regulation process and focuses on changing the trajectory of behavioural, experiential, or physiological responses.	When an adolescent is behaving aggressively and then walks around their school to reduce this state.

more so than the severity of the intellectual disability (Munir, 2016) in this population. A systematic review evaluating the prevalence of mental health disorders in children and adolescents with intellectual disabilities found between 30% and 50% had a comorbid mental health disorder, compared to 8–18% of the typically developing population (Einfeld et al., 2011; Munir, 2016). The heightened risk of this population experiencing emotion regulation difficulties, and in turn reduced quality of life, has created an imperative for further research in this area. Currently, the process model is one of the most commonly used frameworks applied in emotion regulation based research and is becoming the leading model in this area (Gross, 2014). As this research continues, it is essential for this to be of quality to identify valid and reliable measures that can be used to assess emotion regulation as per the framework of the process model of emotion regulation (McClure et al., 2009).

In an attempt to identify a universal definition of emotion regulation, an endeavour made all the more difficult due to the multitude of conceptual frameworks, Izard (2010) surveyed the definitions endorsed by 35 prominent emotion researchers, and subsequently identified eight overlapping processes of emotion regulation. One model that overlaps with the majority of the components identified by Izard (2010) is the process model of emotion regulation (Gross & Thompson, 2007). This adopts Thompson's (1994) definition of emotion regulation as "the extrinsic and intrinsic processes responsible for monitoring, evaluating, and modifying emotional reactions, especially their intensive and temporal features to accomplish one's goals" (pp. 27–28). Currently, the process model of emotion regulation is one of the most commonly used theories in its area, as it was developed to combine the common elements between theories (Gross, 2015). As such, it is often

used to guide the conceptualization of emotion regulation in emotion research (Gross, 2014).

The process model of emotion regulation suggests individuals have psychologically and biologically informed goals, which influence emotion regulation. When a situation is appraised as relevant to an individual's goals, the individual regulates their emotions using five sequential opportunities: situation selection, situation modification, attention deployment, cognitive change, and response modulation; see Table 1 for domain definitions and examples. The process model is also dynamic, as the initial situation changes in response to the strategies used, which prompts the continuation of the emotion regulation cycle (Gross, 1998; Gross & Thompson, 2007). The process model is also versatile as it has commonly been evaluated in light of emotional development, aggression regulation, psychological and biological motives, attachment, and mental illnesses (Gross, 2014). The process model of emotion regulation has been successfully applied to multiple populations (Gross, 2014), and has been recommended as the guiding theoretical framework for research pertaining to children and adolescents with intellectual disabilities (McClure et al., 2009). The process model is particularly suited to this population, as it focuses on concepts that unify diverse symptom expressions and challenging behaviours (Gratz & Roemer, 2004). This is particularly relevant as children and adolescents with intellectual disabilities often have multiple mental health diagnoses (Einfeld et al., 2011; Munir, 2016).

Despite the recommendation to using the process model of emotion regulation as a guiding theoretical framework, it has rarely been directly applied in research examining emotion regulation in children and adolescents with intellectual disabilities (McClure et al., 2009). However, as the model uses categories to

differentiate between forms of emotion regulation, past research findings concerning children and adolescents with intellectual disabilities can be assessed in light of the model. A re-evaluation of the literature indicates that within the situation selection domain children and adolescents with intellectual disabilities express emotion regulation difficulties by way of excessive avoidance, with this behaviour leading to an increased occurrence of specific phobia compared to typically developing peers (Dekker & Koot, 2003; Jennett & Hagopian, 2008; Rudaz et al., 2017). Such emotion regulation difficulties are related to the innate elevated hyperarousal associated with the disorder, which can also manifest in the response modulation domain as aggression (Emerson & Einfeld, 2011; Hall et al., 2009; Miller et al., 1999; Wadell et al., 2013). In this way, the literature available suggests the inherent cognitive and adaptive functioning deficits of intellectual disabilities lead to increased emotion regulation difficulties. Considering these factors, it is unsurprising that children and adolescents with intellectual disabilities experience an overall reduction in quality of life (Munir, 2016). For quality research to consider the process model in this population, emotion regulation measures that adhere to the theoretical framework of the process model are required. An evaluation of the methods used will aide in the identification of valid and reliable measures, which subsequently could increase overall research quality. As there is limited research applying the process model of emotion regulation to children and adolescents with intellectual disabilities, the broader emotion regulation literature needs to be considered in such an evaluation.

There is currently no gold standard measure of emotion regulation, much less one guided by the process model of emotion regulation. Considering these limitations, Adrian et al. (2011) completed a review of emotion regulation assessment in children in order to gain clarity on the methodological state of emotion regulation research in this developmental group. The review identified 100 measures and categorised them into four methods of measurement (i.e., self-report, informant report, observation, or physiological-biological). The overall findings suggested the measures used various conceptualisations of emotion regulation. Despite also adopting Thompson's (1994) definition of emotion regulation, Adrian et al.'s (2011) review did not identify the measures that adhered to the process model of emotion regulation. Nor did the review identify emotion regulation measures validated for specific use in children and adolescents with intellectual disabilities or offer insights into the application of these methods to this population, thus supporting the need for a specific systematic review.

Building on Adrian et al.'s (2011) work, Weiss et al. (2014) reviewed emotion regulation measures for children and adults with a diagnosis of Autism Spectrum Disorder (ASD). The review identified 64 measures and categorised them into five methods of measurement (i.e., self-report, informant report, naturalistic observation/behaviour, physiological, or open-ended). The review focused on identifying measures that adhered to domains of the process model of emotion regulation, finding that only two measures assessed all five domains (i.e., situation selection, situation modification, attention deployment, cognitive control, and response modulation). The review also identified six measures as being used with children and adolescents with ASD and a comorbid intellectual disability, however, the review did not identify measures that were used in populations with intellectual disabilities without ASD. A further limitation of the review was that it did not include a category for measures that used video and audio formats; these methods are recommended for children and adolescents with intellectual disabilities to circumvent language difficulties (McClure et al., 2009). Although both Adrian et al. (2011) and Weiss et al.'s (2014) reviews significantly add to the literature, neither identified measures used for children and adolescents with various types of intellectual disabilities.

This systematic review will aim to build on Adrian et al. (2011) and Weiss et al.'s (2014) findings and focus on the measurement of emotion regulation in children and adolescents with intellectual disabilities. The primary aim is to identify valid measures of emotion regulation within this population and the use of multiple-modal methods, including mediums that circumvent language difficulties. The review will also evaluate whether the measures assess all five domains established in the process model of emotion regulation (i.e., situation selection, situation modification, attention deployment, cognitive control, and response modulation; Gross, 1998). This will serve to identify measures that are suitable for children and adolescents diagnosed with intellectual disabilities, that also comply with the process model of emotion regulation. In doing so, it is hoped that the results of this review can be used to promote theoretically-driven research relating to children and adolescents affected by intellectual disabilities and emotion regulation difficulties.

Method

The review followed the recommended guidelines established by PRISMA-P (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Protocol; Moher et al., 2015). In accordance with these guidelines the

authors published the protocol prior to the commencement of the systematic review; PROSPERO database, ID: CRD42019145099.

The systematic review searched the PubMed, PsycINFO, CINAHL, and EMBASE databases for published works available through July 2019, as found in similar systemic reviews there was no restriction on start dates (Weiss et al., 2014). The search terms were developed with the assistance of an information services librarian and based on prior literature reviews in this area (Adrian et al., 2011; Weiss et al., 2014). A sample of the keywords used were: intellectual disability, emotion regulation, and affect regulation; a detailed search term list can be found in the protocol. Specific search syntax are available in Supplemental file 1. After the removal of duplicates, the initial search yielded 1036 results. Titles and abstracts were screened against the following inclusion criteria:

(1) Studies that utilised self and informant based emotion regulation measures in a population of children and adolescents with intellectual disabilities (up to the age of 18 years).
(2) The emotion regulation measures must at least assess one domain of emotion regulation as per the process model of emotion regulation.

(3) Measures used children and adolescents with intellectual disabilities during the conceptualisation and validation phase of the measure's development.

The review excluded case designs, non-quantitative studies and non-English publications. In line with prior research, studies were also excluded if the measure used children and adolescents with ASD during the conceptualisation phase of the measure's development (Cuthill et al., 2003). This exclusion is necessary as the current focus is on the experiences of children and adolescents with intellectual disabilities and the emotion processing difficulties associated with ASD might impact item development. In line with this, studies that used children and adolescents with intellectual disabilities and ASD during the validation phase were permitted.

Two reviewers conducted a preliminary screen and excluded 110 case designs and non-quantitative studies, and 45 non-English publications. The remainder of the abstracts were screened and discrepancies were resolved via discussion. This resulted in 365 studies meeting the criteria; see Figure 1. The full text articles were reviewed and 139 were removed as they did not include a population with intellectual disabilities, leaving 217 eligible studies and 108 unique measures. Further, the articles pertaining to the development of each measure were
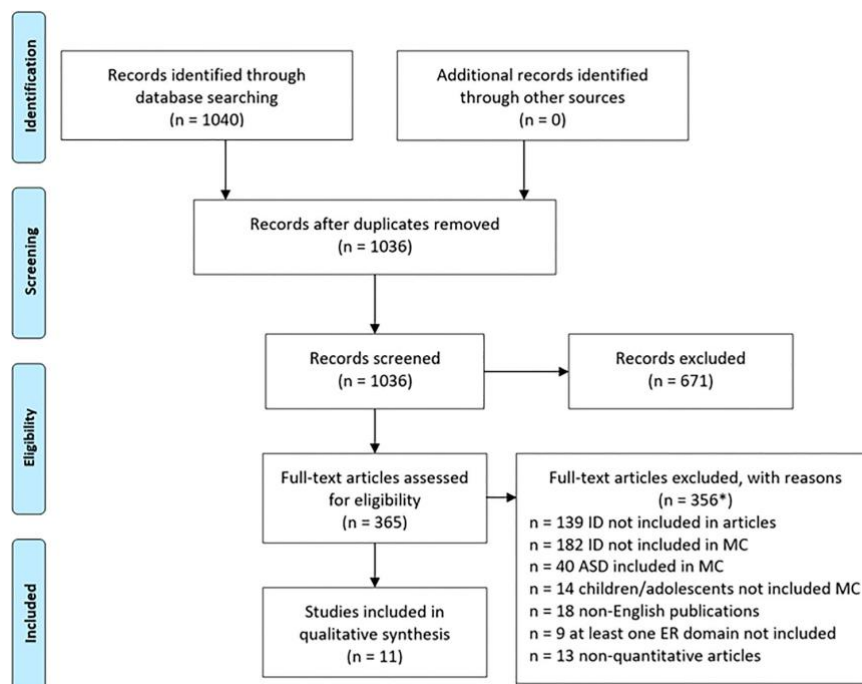

Figure 1. PRISMA flow diagram.

Note: *Breakdown of excluded articles do not equal 356, as the articles fit in to several categories. ID (intellectual disabilities); MC (measure conceptualisation); ASD (Autism Spectrum Disorder); ER (emotion regulation).

also evaluated to determine if the third inclusion criterion was met. It was essential that during the measure's development children and adolescents with intellectual disabilities be utilised, as measures designed for other populations do not completely capture the unique experiences of children and adolescents with intellectual disabilities (Barrowcliff et al., 2018; Farmer & Aman, 2009). This process removed 356 articles for the following reasons: intellectual disability was not included in the measure's conceptualisation (182), ASD was included in the measure's conceptualisation (40), children and/or adolescents were not included in the measure's conceptualisation (14), non-English publications (18), emotion regulation domain were not included (9), and non-quantitative studies (13). Overall, 11 studies and 10 unique measures met the criteria and were included in the review.

The articles were then evaluated with the COSMIN Risk of Bias checklist, a tool designed to assess the reliability and validity of outcome measures (Mokkink et al., 2018). The COSMIN tool assesses psychometric factors and determines if the quality is either very good, adequate, doubtful or inadequate, see Table 2. This information then informs the measure's overall final quality of evidence, otherwise known as its grade. The quality of evidence is ranked as either high, moderate, low, or very low.

Lastly, the measures were categorised into four groups: self-report, informant, observation, and

Table 2. COSMIN risk of bias checklist*.

Criteria	Description
1a. Development	Design
1b. Development	Cognitive interview study or other pilot test
2a. Content validity	Asking patients about relevance
2b. Content validity	Asking patients about comprehensiveness
2c. Content validity	Asking patients about comprehensibility
2d. Content validity	Asking professionals about relevance
2e. Content validity	Asking professionals about comprehensiveness
3	Structural validity
4	Internal consistency
5	Cross-cultural validity\Measurement invariance
6	Reliability
7	Measurement error
8	Criterion validity
9a. Hypotheses testing for construct validity	Comparison with other outcome measurement instruments (convergent validity)
9b. Hypotheses testing for construct validity	Comparison between subgroups (discriminative or known-groups validity)
10a. Responsiveness	Criterion approach
10b. Responsiveness (Construct approach)	Comparison with other outcome measurement instruments
10c. Responsiveness (Construct approach)	Comparison between subgroups
10d. Responsiveness (Construct approach)	Before and after intervention

Note: *Criteria derived from Mokkink et al., 2018.

physiological. The lead author also evaluated each measure against the five emotion regulation domains (i.e., situation selection, situation modification, attention deployment, cognitive change and response modulation).

Results

Collectively, the 11 studies sampled participants within the specified age range of interest of up to 18 years, with some of these including participants beyond this upper limit. As such, participants across all included studies ranged in age from 19 months to 79 years. Six studies did not report on the diagnosis of the participants, while two studies included Fragile X Syndrome, one included Prader-Willi Syndrome, one included Down Syndrome, and one included Williams Syndrome. The studies used the following assessment of intellectual disability: Standardised measures (4), school/facility attendance or prior reports (5), adaptive functioning assessment (1), no reported assessment (1). The cognitive ability across all studies ranged from high average to profound, however, two studies did not report on the intellectual disability severity (Marteau et al., 2016; Sherry & Algozzine, 1981). Regarding verbal ability, four studies did not report on the verbal ability of the participants, three studies included only verbal participants, two studies included both verbal and non-verbal participants, and two included only non-verbal participants.

A total of 10 unique measures were identified, however, whether participants with ASD were included during the item development of the Checklist of Challenging Behaviour (CCB; Harris et al., 1994) was unclear. All measures were assessed against the COSMIN Risk of Bias checklist (Mokkink et al., 2018) and provided with a final grade, see Table 3. The evaluation of the conceptualisation phase of all measures (i.e., criteria 1a–2e) indicated either doubtful or inadequate evidence. Similarly, little evidence was available regarding the structural and internal consistency of the measures (i.e., criteria 3–4). Evidence available for the reliability of the measures ranged from very good to inadequate (i.e., criteria 6). Overall, only the ADAMS possessed moderate quality evidence (Esbensen et al., 2003), while all other measures had very low evidence.

The measures were evaluated against the five emotion regulation domains (Gross, 2014). As seen in Table 4 one measure assessed four emotion regulation domains, two assessed two domains, and seven assessed one domain; No measures assessed all emotion regulation domains. Though the ADAMS (Esbensen et al., 2003) assessed four emotion regulation domains, the majority of the

Table 3. Measures assessed against the COSMIN checklist.

Measure	1a	1b	2a	2b	2c	2d	2e	3	4	5	6	7	8	9a	9b	10a	10b	10c	10d	Grade
Informant																				
ADAMS[a]	i[j]	i	i	d[i]	i	d	d	v[g]	v	n/a[k]	a[h]	n/a	n/a	n/a	a	n/a	n/a	a	n/a	m[l]
CCB[b]	i	i	d	d	d	i	i	n/a	n/a	n/a	a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	a**	vl[m]
Physiological																				
Heart rate/ Accelerometer*	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	i	n/a	n/a	i	n/a	n/a		vl
EEG[c]	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	i	n/a	n/a	n/a	n/a	n/a	n/a	n/a		–[n]
EA[d], ECG[e]	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	a	n/a	n/a	a	n/a	n/a		vl
Observation																				
EREEP[f]	i	i	i	i	i	i	i	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a		vl
Bull et al. (2015)	i	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	v	n/a	n/a	i	n/a	n/a	i	n/a	n/a	vl
Eden and Bezer, (2011)	i	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	i	n/a	n/a	i	n/a	n/a	i	n/a	n/a	vl
Sherry and Algozzine (1981)	i	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	i	n/a	n/a	i	n/a	n/a	i	n/a	n/a	vl
Thompson et al. (1985)	i	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	n/a	i	n/a	n/a	a	n/a	n/a	a	n/a	n/a	vl

Note: [a]Anxiety, Depression, and Mood Scale (Esbensen et al., 2003). [b]Checklist of Challenging Behaviour (Harris et al., 1994). [c]Electroencephalogram scalp activity (Gliddon et al., 1971). [d]Electrodermal activity. [e]Electrocardiogram (Jarvinen et al., 2015). [f]Scale of Emotional State for Children with Intellectual and Multiple Disabilities (Marteau et al., 2016). [g]Very good. [h]Adequate. [i]Doubtful. [j]inadequate. [k]Not applicable. [l]Moderate quality. [m]Very low quality. [n]Quality cannot be determined. *Extracted from (Bull et al., 2015). **Derived from (Gore & Umizawa, 2011).

scale's items assessed response modulation, with only 4 out of 28 items assessing situation selection (one item), situation modification (two items), and attention deployment (one item). Likewise, the observation measures that assessed both attention development and response modulation (Eden & Bezer, 2011; Sherry & Algozzine, 1981) primarily focused on response modulation. In order to assess the coding reliability of the emotion regulation domains, measures that overlapped with Weiss et al.'s (2014) systematic review were compared. Both this review and Weiss et al.'s (2014) review identified the same physiological measures, the coding of these measures were compared and yielded a 100% agreement.

The distribution of the 10 measures according to the type of method was as follows: informant (2), observation (5), and physiological (3). No self-report measures were identified. The informant measure ADAMS was used in three studies (Abbeduto et al., 2019; Esbensen et al., 2003; Oakes et al., 2016), while the CCB was used in one study (Gore & Umizawa, 2011). In terms of multi-informant approaches, the ADAMS was either completed by a parent or carer (Abbeduto et al., 2019; Esbensen et al., 2003; Oakes et al., 2016), and the CCB was completed by both a carer and teaching staff (Gore & Umizawa, 2011). Multi-method approaches were contained to one study that used both observation and physiological methods (Bull et al., 2015).

Discussion

This review aimed to identify valid and reliable emotion regulation measures for children and adolescents with intellectual disabilities; more specifically measures that have been developed for this population, that are also congruent with the five domains of the process model of emotion regulation (Gross, 2014). One hundred and eight measures were identified by the review, 98 of which were excluded; primarily as children and adolescents with intellectual disabilities were not included in the development of the measure. This is problematic as measures designed for typically developing individuals do not capture the unique experiences of participants with intellectual disabilities, and factor structures can differ between the typically developing and intellectual disability populations (Barrowcliff et al., 2018; Farmer & Aman, 2009; Marshall & Willoughby-Booth, 2007). These findings highlight the need to select measures designed for children and adolescents with intellectual disabilities; one such measure is the ADAMS (Esbensen et al., 2003).

Of the 10 measures identified by the review, only the ADAMS (Esbensen et al., 2003) demonstrated at most moderate level evidence i.e., very good structural validity and internal consistency, as well as adequate reliability and discriminative validity. Despite this, the overall conceptualisation phase possessed a high level of bias, as carers were not consulted on the relevance, item comprehension and comprehensiveness of the measure (i.e., criteria 2a–2c). A further limitation pertains to the assessment of the emotion regulation domains, as only four of the five domains were assessed (i.e., situation selection, situation modification, attention deployment, and response modulation). As such, the ADAMS does not adequately assess three of these four domains, as 24 out of 28 questions were dedicated solely to response modulation. Considering this, when assessing emotion regulation the ADAMS should only be used if response modulation is the focus of the assessment.

All measures identified by the review focused on response modulation, regardless of the method of measurement. The lack of available measures assessing the five domains of the process model is consistent with Weiss et al.'s (2014) systematic review. Similarly, both this review and Weiss et al. (2014) found most

Table 4. Properties of emotion regulation measures

Measure (completed by)	Study that used measure	Sample demographics (population, no. of males, mean age, age SD^a, ID^b assessment (assessment range), ID diagnosis, ID severity, verbal ability)	Construct assessed	Psychometrics	ER[c] domains SS[d]	SM[e]	AD[f]	CC[g]	RM[h]
Informant									
ADAMS[i] (parent)	Abbeduto et al. (2019)	N = 44; 100% male; 15.03–22.92 age range; M_{age} = 18.31; SD_{age} = 2.31; LIPS-R[j] (36–56); very low and mild delay to severe delay; FXS[k]; verbal	Manic/Hyperactive Behaviour, Depressed Mood, Social Avoidance, General Anxiety and Compulsive Behaviour.	—[y]	✓	✓			
ADAMS (carer)	Esbensen et al. (2003)	N = (sample 1 = 265; sample 2 = 268); male = (sample 1 = 51.9%; sample 1 = 53.2%); 10–79 age range; M_{age} = (sample 1 = 39.2; sample 1 = 39); SD_{age} = (sample 1 = 11.3; sample 1 = 13.0); service attendance; borderline-profound; verbal and non-verbal		α = Manic/Hyperactive Behaviour (.75), Depressed Mood(.80), Social Avoidance (.83), General Anxiety (.77) and Compulsive Behaviour (.82); retest = .81	✓	✓	✓		✓
ADAMS (carer)	Oakes et al. (2016)	N = 39; 100% male; 6–10 age range; M_{age} = 7.41; SD_{age} = 2.03; LIPS-R (mean=59.26); very low and mild delay; FXS; verbal		-					
CCB[l] (carer/teaching staff)	Gore and Umizawa (2011)	N = 37; male = 29; M_{age} = 9.6; SD_{age} = 3.4; ID based on school attendance; severe	Challenging behaviour	-					✓
Observation									
	Bull et al. (2015)	N = 16; male = 12; 9:7–47:10 age range; M_{age} = 25:0; SD_{age} = 13:9; VABS[m] (25–95); average-low; PWS; verbal	Temper outburst	Kappa = 0.6					✓
	Eden and Bezer (2011)	N = 87; male = 46; 9–21 age range; M_{age} = 14.77; SD_{age} = 3.14; ID based on reports; mild-moderate; verbal and non-verbal	Emotional, cognitive and physical behaviour	-			✓		✓
EREEP[n]	Marteau et al. (2016)	N = 7; male = 3; 6.5–13.5 age range; M_{age} = 10.1; ID based on attendance; non-verbal	Emotional intensity and valence	-					✓
	Sherry and Algozzine (1981)	N = ("emotionally disturbed" =11; ID = 11); missing age range; ID based on school attendance	Non-task orientated behaviour	-			✓		✓
	Thompson et al. (1985)	N = (DS[o] = 26; TD[p] = 43); male = (DS = 13; TD = 21); age range (DS = all 19 months; TD = 12.5–19.5 months); BSMD[q] (44–116); high average- moderate; DS; non-verbal	Separation distress	-					✓
Physiological									
Heart rate, accelerometer	Bull et al. (2015)	N = 16; male = 12; 9:7–47:10 age range; M_{age} = 25:0; SD_{age} = 13:9; VABS (25–95); average-low; PWS; verbal	Measuring heart rate and activity during challenging behaviours	-					✓
EEG[s]	Gliddon et al. (1971)	N = 9; 11–20 age range; M_{age} = 15.4; Assessment not reported; assessment range (39–71); borderline-moderate	Measuring electrical response on scalp during unpleasant stimuli	-					✓
EA[t], ECG[u]	Jarvinen et al. (2015)	N = (WS[v] = 11, ASD[w] (no-ID)=17, no-ID(control) = 20); male (WS = 2, ASD = 13, no-ID = 8); 7.5–13.9 age range; M_{age} = (WS=11.63, ASD = 10.6, no-ID = 10.7); SD_{age} = (WS=1.56, ASD = 1.8, no-ID = 1.6); WISC-III[x] (55–78); borderline-moderate; WS	Assessing autonomic activity during affective visual stimuli	-					✓

Note. [a]Standard deviation. [b]Intellectual Disability. [c]Emotion regulation. [d]Situation selection. [e]Situation modification. [f]Attention deployment. [g]Cognitive change. [h]Response modulation. [i]Anxiety, Depression, and Mood Scale. [j]Leiter International Performance Scale-Revised. [k]Fragile X Syndrome; [l]Checklist of Challenging Behaviour. [m]Vineland Adaptive Behaviour Scales. [n]Scale of Emotional State for Children with Intellectual and Multiple Disabilities. [o]Down Syndrome. [p]Traditionally developing. [q]Bayley Scales of Mental Development. [r]Prader–Willi syndrome. [s]Electroencephalogram scalp activity. [t]Electrodermal activity. [u]Electrocardiogram. [v]Williams Syndrome. [w]Autism Spectrum Disorder. [x]Wechsler Intelligence Scale for Children 3rd edition. [y]Unavailable.

studies did not include multiple methods of measurement. The current review identified a single study that utilised multiple methods, specifically, observation and physiological measures (Bull et al., 2015). The lack of multi-method emotion regulation assessments is problematic, as multiple tools are required to assess the multi-faceted nature of emotion (McClure et al., 2009; Thompson, 1994). The use of only one method provides an incomplete assessment of emotion regulation (Adrian et al., 2011; Larsen & Prizmic-Larsen, 2006), and as such can skew research findings. For instance, bias can be introduced into the research through the sole use of informant-based measures.

Collectively, the findings indicate a preference for informant-based emotion regulation measures, specifically, measures completed by carers or researchers. Informant measures are often developed to circumvent communication barriers associated with moderate to profound intellectual disabilities, in fact, this was one of the reported benefits of the ADAMS (Esbensen et al., 2003). Despite this advantage, three studies excluded non-verbal participants (Abbeduto et al., 2019; Bull et al., 2015; Oakes et al., 2016), and four studies neglected to report verbal ability (Gliddon et al., 1971; Gore & Umizawa, 2011; Jarvinen et al., 2015; Sherry & Algozzine, 1981). An effort needs to be made to include carers of non-verbal participants as this might help capture the unique emotion regulation experiences of this group. The results of this review indicate a research focus on informant measures. The experiences of children and adolescents with intellectual disabilities should also be captured through self-report means. The research would potentially benefit from the inclusion of personal accounts. Self-report might be captured via the use of emerging technologies and flexible modes of assessment. Admittedly, this information avenue has some limits, particularly regarding those with non-verbal presentations. The overall inclusion of personal accounts and carers of non-verbal participants might serve to better inform emotion regulation theory.

These findings need to be considered within the limitations of this review. Although an information services librarian assisted with the development of the search terms, the search strategy may not have captured all available measures. Further, the exclusion of non-English and non-data based works may have led to an incomplete list of emotion regulation measures. Of note, this review excluded a total of 63 non-English publications due to the language barrier rather than the psychometric quality of the measure. The review also aimed to exclude measures that included ASD during the item development phase. ASD was excluded as the emotion processing difficulties associated with this disorder do not reflect the primary experiences of children and adolescents with intellectual disabilities. Despite our efforts to exclude ASD, one study did not explicitly state the demographics of the intellectual disability population; thus, the measure could be skewed towards an ASD rather than intellectual disability demographic. Additionally, the COSMIN grades of the measures were largely based on information found in the studies, as such, omitted information could have improved the grades. Finally, only the lead author evaluated the measures against the five domains of the process model. Although agreement with Weiss et al. (2014) was 100%, only three of the 10 measures were cross checked, as such, coding reliability as a whole could not be assessed. Collectively, these limitations are similar to those reported in the systematic reviews by Adrian et al. (2011) and Weiss et al. (2014).

Considering the findings overall, measures assessing all five domains of the process model should be developed for children and adolescents with intellectual disabilities; particularly self-report measures. To ensure these measures are valid, the COSMIN checklist should also be used to guide the development of the measure (Mokkink et al., 2018). In line with prior recommendations, measures might also incorporate the following assistive technology: text to speech, dynamic images/videos, easy read language, large text size, accessible fonts and simple response options (McClure et al., 2009). Companion informant versions should also be developed, particularly teacher and parent supplements. The development of self and informant based measures are necessary, as when paired with observation and physiological measures, the full, multifaceted nature of emotion can be assessed (McClure et al., 2009; Thompson, 1994).

As measures can be used to identify emotion regulation difficulties and relevant strategies, therapeutic settings could benefit from the development of valid and reliable emotion regulation measures for children and adolescents with intellectual disabilities. For instance, the measure could identify dysregulation within the situation modification domain, prompting support personnel to facilitate modifications to the environment, such as encouraging the use of headphones. These measures also have the potential to further emotion research, improve mental health programs and track treatment progress in this population.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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PsycINFO search as seen in the database

(DE "Intellectual Development Disorder" OR DE "Anencephaly" OR DE "Crying Cat Syndrome" OR DE "Down's Syndrome" OR DE "Tay Sachs Disease" OR "intellectual development* disorder*") AND (DE "Emotional Regulation" OR DE "Emotional Style" OR "emotion*" OR DE "Child Psychopathology" OR DE "Adolescent Psychopathology" OR "psychopathology" OR DE "Self-Regulation" OR "self regulation" OR "Emotion* Regulation" OR "emotion* competence" OR "emotion* management" OR "Affect*" OR "Affect* regulation" OR DE "Self-Control" OR DE "Emotional Control" OR "effortful control") AND ("child*" OR "Adolesce*" OR "babies" OR "infant" OR "kids" OR "teen*" OR "toddler*" OR "Preschool" OR DE "Preschool Students")

CINAHL search as seen in the database

((MH "Child") OR "child*" OR (MH "Adolescence") OR "Adolesce*" OR "babies" OR (MH "Infant") OR "infant" OR "kids" OR "teen*" OR "toddler*" OR (MH "Child, Preschool") OR "Preschool") AND ((MH "Intellectual Disability+") OR "Intellectual Development* Disorder*") AND ((MH "Emotions") OR "Emotion*" OR "Self-Regulation" OR (MH "Self Regulation") OR "Emotion* regulation" OR (MH "Psychopathology") OR "Psychopathology" OR ((MH "Affect") OR "Affect*" OR "Affect* regulation" OR "effortful control" OR "emotion* competence" OR "emotion* management")

Pubmed search as seen in the database

(((((Intellectual Development* AND Disorder*[Title/Abstract]) OR Intellectual Disability[MeSH Terms])) AND ((((((((((((Emotion*[Title/Abstract]) OR EMOTIONS[MeSH Terms]) OR Self-Regulation[Title/Abstract]) OR Self-Management[MeSH Terms]) OR Emotion* AND regulation[Title/Abstract]) OR Self-

Control[MeSH Terms]) OR Psychopathology[Title/Abstract]) OR

PSYCHOPATHOLOGY[MeSH Terms]) OR Affect*[Title/Abstract]) OR Affect[MeSH

Terms]) OR Affect* AND regulation[Title/Abstract]) OR effortful control[Title/Abstract])

OR emotion* AND competence[Title/Abstract]) OR emotion* AND management)) AND

(((((((((((child[MeSH Terms]) OR child*[Title/Abstract]) OR Adolescent[MeSH Terms]) OR

Adolesce*[Title/Abstract]) OR babies[Title/Abstract]) OR infant[MeSH Terms]) OR

infant[Title/Abstract]) OR kids[Title/Abstract]) OR teen*[Title/Abstract]) OR

toddler*[Title/Abstract]) OR Preschool[Title/Abstract]) OR Child, Preschool[MeSH Terms])

EMBASE search as seen in the database

(child/ or child*.mp. or adolescent/ or Adolesce*.mp. or babies.mp. or baby/ or infant/ or

infant.mp. or kids.mp. or teen*.mp. or toddler/ or toddler*.mp. or preschool child/ or

Preschool.mp.) AND (intellectual impairment/ or Intellectual Development* Disorder*.mp.)

AND (emotion/ or Emotion*.mp. or Self-Regulation.mp. or Emotion* regulation.mp. or

Affect*.mp. or affect/ or Affect* regulation.mp. or effortful control.mp. or emotion*

competence.mp. or emotion* management.mp. or psychopathology.mp. or psychopathology/)

Addendum: Update on Systematic Review

Girgis and colleagues (2021) published a systematic review that aimed to identify process model-based patient-reported outcome measures (PM-PROMs) validated for children and adolescents with intellectual disabilities. It determined that validated PM-PROMs were not currently available for this demographic.

Method

The search was re-run using identical methodology, including syntax, in order to update the findings of the review. The search included studies published between 01.01.2019 and 17.05.2024, within the following databases: PubMed, PsycINFO, CINAHL, and EMBASE. The inclusion and exclusion criteria are reiterated below.

Inclusion Criteria

- The population must be diagnosed with an intellectual disability, and aged 18 years old or under. The study must include either self or informant-based emotion regulation outcome measures.

- The outcome measure must assess at a minimum, one domain of the process model (situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2024).

- Children and adolescents with intellectual disabilities are included during the conceptualisation and validation phase of the outcome measure's development.

Exclusion Criteria

- Non-English publications, non-quantitative studies, and case designs.

- The inclusion of children and adolescents with a co-occurring diagnosis of autism spectrum disorder, during the conceptualisation phase of the outcome measure.

The search yielded 507 publications and initial screening subsequently removed 324 records. The updated PRISMA flow diagram is reproduced in Figure 3.1.

Figure 3.1

Updated PRISMA Flow Diagram
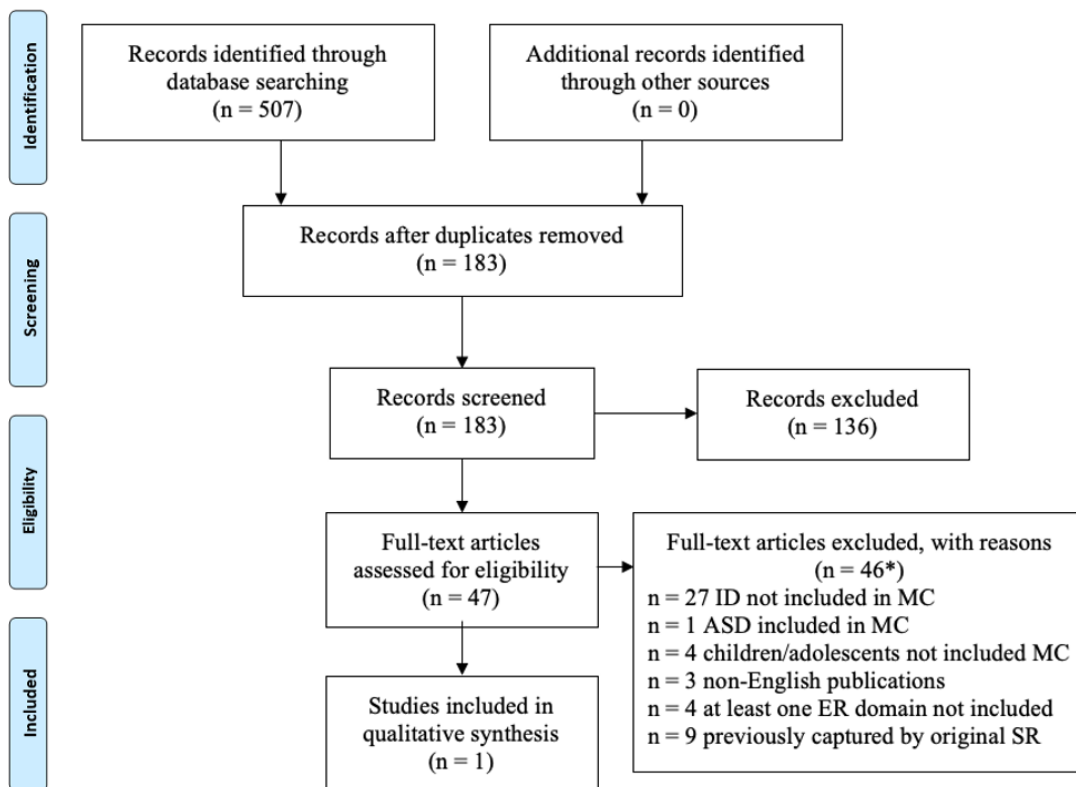
Note: *Does not equal 46 due to category overlap. ID (intellectual disabilities); MC (measure conceptualisation); ASD (autism spectrum disorder); ER (emotion regulation); SR (systematic review).

Royston et al. (2020) utilised the ADAMS, informant version, and the internal consistency was calculated (α = .93). The study consisted of 110 participants, M_{age} = 26.53, SD = 10.36, age range = 12–57. Participants were diagnosed with either Williams syndrome (WS), Fragile X syndrome (FXS), or Prader-Willi syndrome (PWS), see Table 3.1 for sample demographics. The diagnosis was confirmed via genetic testing, but the participants'

intellectual disability severity was not reported, nor was their speech or communication ability.

Table 3.1

Royston et al. (2020) Sample Demographics

	WS	FXS	PWS
N	35	49	26
Age, M (SD)	25.51 (12.39)	27.08 (9.18)	26.85 (9.77)
Age range	12–57	12–50	12–47
Males	14	49	11

Note. WS (Williams syndrome), FXS (Fragile X syndrome), PWS (Prader-Willi syndrome), M (mean), and SD (standard deviation).

Discussion

Overall, the updated systematic review did not identify any outcome measures that assess all five domains of the process model, validated for children and adolescents with intellectual disabilities. These results are consistent with Girgis and colleagues' (2021) systematic review and indicates a current gap in the literature.

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Girgis, M., Paparo, J., & Kneebone, I. (2021). A systematic review of emotion regulation measurement in children and adolescents diagnosed with intellectual disabilities. *Journal of Intellectual & Developmental Disability*, *46*(1), 90–99. https://doi.org/10.3109/13668250.2020.1784520

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Royston, R., Oliver, C., Howlin, P., Dosse, A., Armitage, P., Moss, J., & Waite, J. (2020). The profiles and correlates of psychopathology in adolescents and adults with Williams, Fragile X and Prader-Willi syndromes. *Journal of Autism and Developmental Disorders*, *50*(3), 893–903. https://doi.org/10.1007/s10803-019-04317-

Chapter 4: COSMIN-Based PROM Development Process, Step 4

The completion of Steps 1, 2 and 3 of the COSMIN-based patient-reported outcome measure (PROM) development process, was described in Chapter 3 (Girgis et al., 2021; Swan et al., 2023). The results of the systematic review indicated the relevance of the process model had yet to be established within the context of children and adolescents with intellectual disabilities (Girgis et al., 2021; Gross, 2024). The absence of process model-based PROMs (PM-PROMs) was also noted. Step 4 of the COSMIN-based PROM development process guides the evaluation of the relevance of the process model to children and adolescents with intellectual disabilities, as outlined in Table 2.1. This Step consists of clarifying the target construct, identifying end users and relevant stakeholders, and determining how the construct is reflected in current practice (Swan et al., 2023). In essence, this Step focuses on determining the relevance of the construct within the target population, which is also a necessary step in PROM development (Swan et al., 2023; Terwee et al., 2018).

Step 4 of the COSMIN-based PROM development process is guided by the COSMIN methodology for assessing the content validity of PROMs (Swan et al., 2023; Terwee et al., 2018). Specifically, this guideline recommends three content validation phases: (1) Evaluation of PROM development quality; (2) evaluation of PROM content validity studies; and (3) overall evaluation of PROM content validity using a grading system. Phase 1 of the COSMIN content validity guidelines consist of two parts (part A and part B); these parts assess PROM design, and pilot test quality, respectively. While Phase 1A consists of 13 sub-steps, Step 4 of the PROM development process is satisfied with the completion of sub-steps 1 to 3; see Figure 4.1 for sub-step representation. The remaining sub-steps will be discussed in Chapter 6.

Figure 4.1

Alignment of the PROM Development Process to the COSMIN Content Validity Guidelines,

as Derived from Swan et al. (2023) and Terwee et al. (2018)
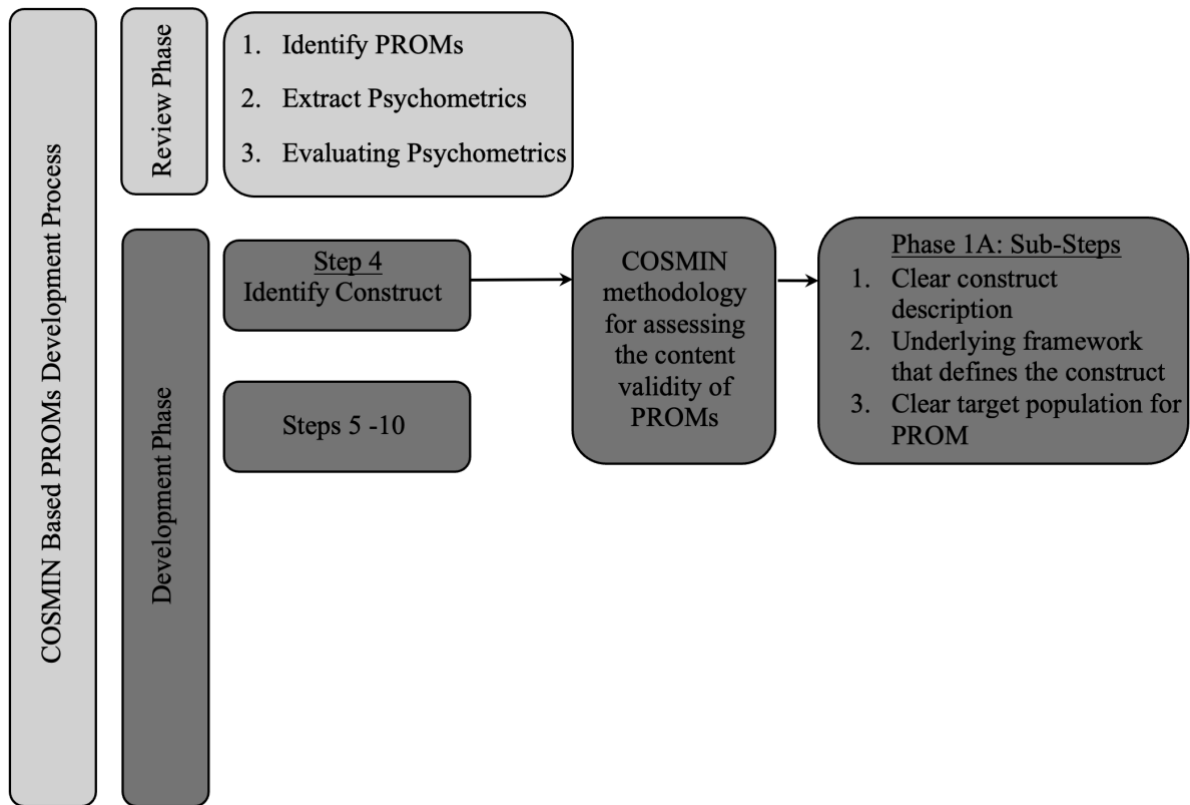
Sub-step 1 of Phase 1A of Step 4 of the COSMIN-based PROM development process

relates to the selection of a clear construct, while sub-step 2 relates to a well-described

theoretical framework underlying the construct (Swan et al., 2023; Terwee et al., 2018). It is

recommended these sub-steps be finalised prior to the development of PROMs, as the

identification of a clear construct and underlying framework is essential to ensuring PROMs

are accurately calibrated to the intended construct. This is particularly relevant with regard to

multidimensional constructs, as the individual dimensions must be clear to preserve the

integrity of the PROM (Swan et al., 2023). In the context of this dissertation, the construct of

interest is the process model of emotion regulation. Specifically, the multidimensional

constructs are the five domains of the process model (situation selection, situation

modification, attentional deployment, cognitive change, and response modulation; Gross, 2024).

Sub-step 3 of Phase 1A of Step 4 of the COSMIN-based PROM development process relates to clarifying the PROM's intended target population. The target population includes end users such as allied health professionals and emotion regulation researchers, and clients, such as children and adolescents with intellectual disabilities, as well as their parents and educators. The target population needs to be considered within the context of the construct, the scope of practice, and current clinical practices. Specifically, the wider literature should be consulted to evaluate the potential relevance of the construct to the target population, as well as the need for PM-PROMs. As seen in Chapter 1, there is evidence to suggest process model relevance to children and adolescents with intellectual disabilities. Additionally, the development of PM-PROMs for emotion regulation research purposes has been recommended for children and adolescents with intellectual disabilities (Samson et al., 2022). However, to the author's knowledge, the literature does not address whether the process model is considered relevant in clinical practice with children and adolescents with intellectual disabilities. Thus, prior to directly examining the relevance of the process model to children and adolescents with intellectual disabilities, practical relevance should be determined.

In order to address sub-step 3, Phase 1A of Step 4 of the COSMIN-based PROM development process, service providers of children and adolescents with intellectual disabilities will be surveyed. The aim of the survey is to examine the real-world utility of the process model, while also investigating how the process model domains are currently assessed in clinical practice in the absence of PM-PROMs (see Chapter 5 for results). Of particular importance is discerning whether providers adhere to the recommended transdiagnostic approach, rather than focusing on specific diagnoses in children and

adolescents with intellectual disabilities (Astle et al., 2022; Chu et al., 2017); as PM-PROMs would only be beneficial if transdiagnostic frameworks are preferred in clinical practice. Similarly, this study will evaluate whether providers prefer PROMs specifically developed for children and adolescents with intellectual disabilities, or whether they are content with measures created for use with the typically developing population. Collectively, this information will satisfy sub-step 3 of Phase 1A of Step 4 of the COSMIN-based PROM development process by assessing the relevance of the process model within clinical practice and determining whether service providers require PM-PROMs specifically validated for children and adolescents with intellectual disabilities.

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Chapter 5. Study 2: Would an Emotion Regulation Outcome Measure Be Helpful for Children and Adolescents with Intellectual Disabilities? A Survey of Service Providers.

The following chapter has been submitted for publication and is under peer review:

Girgis, M., Paparo, J., & Kneebone, I. (2024). *Would an emotion regulation questionnaire be helpful for children and adolescents with intellectual disabilities? A survey of service providers.* [Manuscript submitted for publication] University of Technology Sydney & Macquarie University.

Abstract

Background: Children and adolescents with intellectual disabilities experience ongoing emotion regulation difficulties. The leading emotion regulation model—the process model of emotion regulation—may offer a lens by which these difficulties might be understood and inform assessment and intervention. However, the extent to which service providers are aware of the model, consider it useful, and whether they consider a measure based on it helpful, remains unknown.

Method: Service providers ($N = 122$) working with children and adolescents with intellectual disabilities were surveyed to ascertain their knowledge of the process model, and whether a measure would have real-world utility.

Results: Most service providers (64.7%) indicated a need for process model-based outcome measures validated for children and adolescents with intellectual disabilities. A specific need for informant-based outcome measures was identified.

Conclusions: A measure founded on the process model should be developed and validated for children and adolescents with intellectual disabilities.

Emotion regulation difficulties are expressed by 38-49% of children and adolescents with intellectual disabilities as mental illnesses (Buckley et al., 2020). Often this population presents with multiple co-occurring disorders, with a fifth having two or more conditions (Munir, 2016). Of note, emotion dysregulation predominately presents as attention deficit hyperactivity disorder (ADHD), anxiety disorders, conduct disorders, externalising disorders, and depressive disorders (Buckley et al., 2020). Children and adolescents with intellectual disabilities also commonly express emotion dysregulation as behaviours of concern (BOC), namely: non-compliance, self-harm, temper "tantrums," absconding, repetitive questions, property damage, screaming, stripping, physical aggression, stealing, smearing faeces, overactivity, and sexualised behaviours (Emerson et al., 2001; Emerson & Einfeld, 2011). In this context it is unsurprising emotion dysregulation in this population is associated with reduced quality of life, limited social connection, and unemployment (Munir, 2016; Svetlana et al., 2018). Indeed, reduced wellbeing is better predicted by emotion dysregulation than intellectual disability severity (Munir, 2016). Despite the evident impact of emotion dysregulation on wellbeing, one of the prominent emotion regulation frameworks—the process model of emotion regulation (Gross, 2014)—has been largely overlooked within the context of children and adolescents with intellectual disabilities.

The process model of emotion regulation has been applied across numerous settings and has influenced the trajectory of emotion regulation research (Gross, 2014; Kobylińska & Kusev, 2019). The process model is composed of five cyclic families of emotion regulation: situation selection, situation modification, attentional deployment, cognitive change, and response modulation (Gross, 2014); see Table 1 for definitions. When strategies are chosen—regardless of efficacy—new situations are created, resulting in a cyclic emotion regulation process (Gross, 2014, 2015).

Table 1

Definitions and Examples of the Five Domains of the Process Model of Emotion Regulation as Based on Gross (1998, 2014)

Domain	Definition	Example
Situation Selection	An individual first becomes aware of an upcoming situation and the associated emotional reaction. This leads them to either initiate or avoid the situation.	A child avoiding bath time by hiding or a child requesting their birthday presents early.
Situation Modification	When a situation has commenced the individual can modify the environment to alter the emotional impact.	Using headphones to help with homework or chores completion.
Attentional Deployment	The ability to shift attentional focus. Redirecting attention can be grouped into three categories. <u>Distraction</u>: the ability to either redirect attention to non-emotional aspects of a situation or away from the situation entirely. <u>Concentration</u>: attention is sustained by the engagement of tasks which occupy finite cognitive abilities.	Distraction: child averting their eye gaze and focusing on a toy rather than their parents arguing. Concentration: when a child is concentrating on a YouTube video.

Domain	Definition	Example
	Rumination: directs attention to emotions and related consequences.	Rumination: when an adolescent worries about hypothetical threats.
Cognitive Change	The individual evaluates whether an event can be managed within the context of their goals.	Reframing is one strategy, wherein an adolescent engages in self talk about being excited instead of anxious when presenting a class speech.
Response Modulation	This domain occurs later in the emotion regulation process and focuses on changing the trajectory of behavioural, experiential, or physiological responses.	When an adolescent is behaving aggressively and then walks around their school to reduce this state.

Note. Reprinted from 'A systematic review of emotion regulation measurement in children and adolescents diagnosed with intellectual disabilities' by M. Girgis, J. Paparo, and I. Kneebone, 2020, *Journal of Intellectual & Developmental Disability*, p. 2. Copyright 2020 by Taylor and Francis Group.

The model is well-suited to comprehending the emotion regulation and dysregulation experiences of children and adolescents with intellectual disabilities as it focuses on symptom expression rather than diagnoses (Gross, 2014). In this way, the process model adheres to the recommended transdiagnostic approach for children with neurodevelopmental disorders, as this population presents with multiple comorbidities (Astle et al., 2022; Munir, 2016). Considering the impact of emotion dysregulation on quality of life, the relevance of the process model to children and adolescents with intellectual disabilities needs to be determined.

Gauging the relevance of the process model within the context of children and adolescents with intellectual disabilities is complicated by a lack of valid outcome measures (Girgis et al., 2021); as there are no validated measures for this population that assess all five domains of the model. Of note, most measures assessed in a recent systematic review of existing emotion regulation measures were excluded as children and adolescents with intellectual disabilities were not included in the conceptualisation phase of the measure's development (Girgis et al., 2021). This is problematic, as according to the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) methodology for evaluating the content validity of patient-reported outcome measures (PROMs), a measure's quality is reduced if the target population is omitted during conceptualisation (Terwee et al., 2018). Further support that exclusion impacts validity, comes by way of a systematic review of psychometric properties of emotion regulation measures (Halvorsen et al., 2023). This found that measures developed for the typically developing population have comparatively weaker psychometric properties when applied to children and adolescents with intellectual disabilities, as opposed to measures developed for this population. Additionally, measures developed for the typically developing population do not comprehensively reflect the distinct experiences of individuals with intellectual disabilities (Barrowcliff et al., 2018). Considering

these limitations, it is evident that a process model-based outcome measure (PM-PROMs) might be useful for service providers of children and adolescents with intellectual disabilities. Even so, it remains unclear whether service providers would find such a measure relevant and useful in their practice.

Current best practice standards recommend integrating multiple assessment modalities, such as clinical interviews and routine multi-informant PROMs to capture the multifaceted nature of emotion regulation in children and adolescents (De Los Reyes & Makol, 2019). Yet, service providers often rely on unstructured clinical interviews, a less valid assessment modality compared to PROMs and structured assessments (Jensen-Doss & Hawley, 2010). This nonadherence to best practice standards could be attributed to a lack of available and valid PROMs (De Los Reyes & Makol, 2019; Girgis et al., 2021).

This study aims to determine service provider awareness of the process model of emotion regulation, current trends in PROMs usage, and whether service providers require PM-PROMs. A subsidiary interest was evaluating differences between professional profiles and views on the need for PM-PROMs, as well as factors predictive of this need.

Method

Procedure

The online survey study was approved by the University of Technology Sydney ethics committee (approval number: ETH21-6627). The survey was shared on social media groups and with disability orientated organisations. Service providers with a minimum 20% caseload and 12 months experience working with children and adolescents (0-18 years old) with intellectual disabilities were invited to participate. Participants provided informed consent prior to completing the survey.

Measures

The authors developed a survey for the purpose of evaluating: PROMs usage, helpful features of PROMs, barriers to using PROMs, awareness of the process model, and confidence working with children and adolescents with intellectual disabilities, see supplementary file 1. The survey was pilot tested by three psychologists and one undergraduate psychology student; feedback was provided on clarity and understanding, resulting in minor amendments.

Participant Demographics

The survey was completed by 122 service providers, see Table 2 for demographic information. The participants were primarily female (84.4%), and the most common occupation was psychologist (43.4%) or behaviour therapist (30.3%). The mean age was 37.61 years old (SD = 10.18), and the average case load of clients with an intellectual disability was 45.7% (SD = 22.08). The average years of experience working with children and adolescents with intellectual disabilities was 10.31 years (SD = 8.98). Participants primarily worked with children and adolescents with a mild (90.98%) or moderate (95.9%) severity of intellectual disability.

PROMs Usage

With regard to children and adolescents with and without intellectual disabilities, participants were asked how often they routinely used PROMs, and how often PROMs are used in practice to track treatment baseline and progression. This was assessed using three items via a 5-point Likert scale (i.e., *always*, *often*, *sometimes*, *rarely*, and *never*). Participants also indicated how often they used the following PROMs: Depression Anxiety Stress Scale (DASS; Lovibond & Lovibond, 1995), Spence Children Anxiety Scale (SCAS; Spence, 1997), Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997), Beck Youth Inventory (BYI: Beck et al., 2001), Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 1992), Anxiety, Depression and Mood Scale (ADAMS; Esbensen et al., 2003), and

the Kessler Psychological Distress Scale (K-10; Kessler et al., 2002). Participants also had the option to report the use of outcome measures not captured above.

Table 2

Participant Demographic Information

Demographics	
Participants	$N = 122$
Gender	Female (103)
	Male (14)
	Non-Binary/Third Gender (4)
	Undisclosed (1)
Age	$M = 37.61$, $SD = 10.18$, Range = 23 - 71 years
Ethnicity*	Asian (6)
	African (2)
	Caucasian (85)
	European (18)
	Indian (1)
	Indigenous Australian or Torres Strait Islander (3)
	Middle Eastern (4)
	North American (2)
	New Zealander (4)
	South American (6)
	Other (5)

Demographics	
Profession	Applied behaviour analysis therapist (3)
	Behaviour therapist (37)
	General practitioner (1)
	Nurse (2)
	Occupational therapist (8)
	Psychiatrist (3)
	Psychologist (53)
	School counsellor (1)
	Social worker (6)
	Speech therapist (5)
	Other (3)
Years of experience working with intellectual disability	$M = 10.31$, $SD = 8.98$, Range = 1- 46 years
Total years of experience	$M = 11.11$, $SD = 9.22$, Range = 1- 47 years
Severity*	Mild (111)
	Moderate (117)
	Severe (89)
	Profound (51)
Caseload percentage	$M = 45.70$, $SD = 22.08$, Range = 20 -100%

Note. *Does not equal 122 as data overlapped.

The Helpfulness of Current PROMs in Practice

The helpfulness of current emotion regulation PROMs in relation to participant service provision to children and adolescents with intellectual disabilities was assessed using five items via a 5-point Likert scale (i.e., *very helpful*, *somewhat helpful*, *neither helpful nor unhelpful*, *not very helpful*, and *not at all helpful*).

Helpful Assessment Features of Emotion Regulation PROMs

The helpfulness of various features of emotion regulation PROMs (i.e., informant or self-report variations, useability in home or school settings etc) was assessed using 14 items via a 5-point Likert scale (i.e., *very helpful*, *somewhat helpful*, *neither helpful nor unhelpful*, *not very helpful*, and *not at all helpful*). Participants also indicated if they required additional resources to better identify emotion regulation difficulties; whether they preferred PROMs that more broadly identify emotion regulation difficulties, rather than diagnostic specific PROMs; and whether they preferred PROMs specifically developed for children and adolescents with intellectual disabilities, rather than measures developed for the typically developing population. This was assessed using three items via a 5-point Likert scale (i.e., *strongly agree*, *agree*, *neither agree nor disagree*, *disagree*, and *strongly disagree*).

Process Model Awareness

Participant awareness of the process model was evaluated, specifically, informal and formal awareness and assessment of the model. First, informal assessment of the process model domains was evaluated using seven items via a 5-point Likert scale (i.e., *always*, *often*, *sometimes*, *rarely*, and *never*). Assessment modality of each domain was also evaluated using seven items. Participants were then provided with a brief description of the process model, alongside definitions of the five domains (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014). Formal awareness of the process model and each of the five domains was assessed using six items via

a *yes* or *no* response. The usage of the process model during service provision to children and adolescents with intellectual disabilities, and whether PM-PROMs were needed, was assessed using seven items via a 5-point Likert scale (i.e., *strongly agree*, *agree*, *neither agree nor disagree*, *disagree*, and *strongly disagree*). Participant's confidence in "Identifying where in the emotion regulation process a break down occurs for children and adolescents with an intellectual disability?" was also assessed using one item, via a 5-point Likert scale (i.e., *highly confident*, *confident*, *moderately confident*, *slightly confident*, and *not confident*).

Barriers to Using Emotion Regulation PROMs

Barriers that impede the use of emotion regulation PROMs when working with children and adolescents with intellectual disabilities were assessed using 17 items via a 5-point Likert scale (i.e., *strongly agree*, *agree*, *neither agree nor disagree*, *disagree*, and *strongly disagree*).

Therapy Confidence Scale- Intellectual Disability (TCS-ID; Dagnan et al., 2014)

The TCS-ID measures a service providers confidence in working with individuals with intellectual disabilities using 14 items on a 5-point Likert scale (i.e., *highly confident*, *confident*, *moderately confident*, *slightly confident*, and *not confident*). The TCS-ID has an internal consistency of .93, and test–retest reliability of .83. For the purpose of this study, participants answered in relation to working with children and adolescents with intellectual disabilities, and references to "learning disability" were replaced with "intellectual disability," to reflect Australian terminology. The TCD-ID was included to evaluate the relationship between confidence and the need for PM-PROMs.

Results

Data Analysis

Descriptive statistics for usage trends, helpful features of PROMs, and barriers to

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using PROMs were examined. The current awareness of the process model was assessed, and an ANOVA was used to ascertain if there were significant differences between professional profiles and a need for PM-PROMs. Correlations were used to identify relationships associated with the need for PM-PROMs, and a multiple regression was used to determine if these relationships predicted the need for PM-PROMs. SPSS (version: 29.0.1.0) was used for data analyses.

PROMs Usage

Only 54.9% of participants used PROMs with children and adolescents with intellectual disabilities either *always* or *often* in their practice. Of these, 62.3% used PROMs at the start of treatment, and 51.6% to track progress. In comparison, 66.4% of participants used PROMs with typically developing children and adolescents; 65.6% at the start of treatment, and 58.2% to track treatment progression. A one tailed dependent t-test indicated there was a significant difference between how often participants used PROMs with children and adolescents with ($M = 3.67$, $SD = .97$) and without intellectual disabilities ($M = 3.8$, $SD = 1.04$), $t = -1.85$, $p = .033$, $d = .78$.

Participants most often used the Depression Anxiety Stress Scale (DASS; Lovibond & Lovibond, 1995) and the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997), over measures developed for this population such as the Developmental Behaviour Checklist (DBC; Einfeld & Tonge, 1992), see Table 3. The majority of participants either *strongly agreed* or *agreed* (78.7%) that more resources were needed to better identify emotion regulation difficulties in children and adolescents with intellectual disabilities. Participants considered parent-report (96.7%), teacher-report (93.5%), and self-report (72.9%) emotion regulation PROMs to be either *very helpful* or *somewhat helpful* in their practice with this population. Similarly, participants also considered school observations (94.3%) and PROMs that assist with case formulation development (91.8%) to be either *very helpful* or *somewhat*

helpful.

Table 3

Current Trends of PROMs Utilisation

Outcome measures	Author (year)	ID	Without ID
		% of use	% of use
Depression Anxiety Stress Scales (DASS)	Lovibond and Lovibond (1995)	58.2	54.9
The Spence Children's Anxiety Scale (SCAS)	Spence (1997)	28.7	30.3
Strengths and Difficulties Questionnaire (SDQ)	Goodman (1997)	43.4	43.4
Beck Youth Inventory (BYI)	Beck et al. (2001)	13.9	14.8
Developmental Behaviour Checklist (DBC)	Einfeld and Tonge (1992)	41.8	32
Anxiety, Depression and Mood Scale (ADAMS)	Esbensen et al. (2003)	4.1	8.2
Kessler Psychological Distress Scale (K-10)	Kessler et al. (2002)	29.5	30.3

Note. ID = Intellectual disability.

Helpful Assessment Features of PROMs

In general, 73% of participants found PROMs *helpful* or *somewhat helpful* ($M =$ 58.47, $SD =$ 11.45) when working with children and adolescents with intellectual disabilities. Of note, PROMs which could identify emotion regulation difficulties within the following contexts were considered *very helpful* or *somewhat helpful*: home-based settings (85.2%), antecedent strategies (84.4%), physiological or somatic experiences (85.2%), preferred

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environmental modifiers (87.7%), and the function of behaviour (86%), see Table 4.

Additionally, 77.9% of participants either *strongly agreed* or *agreed* that they preferred

PROMs that more broadly identify emotion regulation difficulties, rather than diagnostic

specific PROMs. Similarly, 91.8% indicated they would use emotion regulation PROMs

specifically developed for children and adolescents with intellectual disabilities, rather than

measures developed for the typically developing population.

Table 4

Helpful Assessment Features of Emotion Regulation PROMs

Features	Very helpful or somewhat helpful	*M*	*SD*
Emotion regulation difficulties in school-based settings	82%	4.59	.5
Home-based settings	85.2%	4.63	.48
Antecedent strategies	84.4%	4.59	.49
Breakdown in emotion regulation process	82%	4.65	.48
Preventative strategies	78.7%	4.68	.47
Response to environment	83.6%	4.65	.48
Efficacy of distraction	77.9%	4.54	.5
Effect of concentration on emotion regulation	78.7%	4.44	.5
Occurrence of rumination	74.5%	4.47	.5
Cognitive reframing	72.9%	4.7	.5
Themes of successful emotion regulation	80.3%	4.53	.5
Physiological/somatic experiences	85.2%	4.55	.5
Preferred environmental modifiers	87.7%	4.67	.47
Function of behaviour	86%	4.69	.47

Barriers to Utilising Emotion Regulation PROMs

Participants either *strongly agreed* or *agreed* that the following were substantial barriers to using emotion regulation PROMs with this population: client reading difficulties (92.6%), limited availability of reliable and valid emotion regulation PROMs (91.8%), client comprehension difficulties (91%), see Table 5. While, only 27.1% of participants expressed they either *strongly agreed* or *agreed* that a lack of training in using PROMs was a barrier to usage.

Awareness of the Process Model of Emotion Regulation

Only 45.9% of participants had specific awareness of the process model when the elements of the model were described to them. Overall, the formal awareness of specific domains differed: Situation selection (46.7%), situation modification (53.3%), attentional deployment (44.3%), cognitive change (50.8%), and response modulation (50.8%). Most participants reported the process model was not the predominate framework used in their respective professions with children and adolescents with intellectual disabilities; 70.5% 'neither agreed/disagreed,' 'disagreed' or 'strongly disagreed.' Similarly, 67.2% of participants indicated the process model was not the predominate framework used in their personal practice with this population. However, when asked informally whether the domains of the process model were assessed in their practice, participants chiefly indicated assessments were completed *always* or *often*: situation selection (65.5%), situation modification (83.6%), attentional deployment (78.7%), cognitive change (73%), and response modulation (78.6%). Additionally, distraction (82%) and rumination (67.2%) were also predominantly assessed *always* or *often*. These domains were typically assessed using clinical interviews, by 80.3-89.3% of participants, and 23-41.8% also reported using PROMs, with standardised assessment being the least used assessment modality, see Table 6. Clinical assessment and PROMs usage rates were also highest for the situation selection domain,

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respectively 89.3% and 41.8%.

Table 5

Barriers to using PROMs

Barrier	Strongly Agreed or Agreed
Client reading difficulties	92.6%
Limited availability of reliable and valid emotion regulation PROMs	91.8%
Client comprehension difficulties	91%
PROMs do not capture lived experience	77.8%
Easy-English PROMs are unavailable	69.6%
PROMs do not inform treatment planning	61.4%
PROMs do not offer real-world utility	56.5%
Length of PROMs	55.8%
Client supports have reading difficulties	51.7%
PROMs do not inform clinical assessments	49.2%
PROMs do not inform diagnostic assessments	39.4%
Lack of non-English translations	45.9%
Cost	43.4%
PROMs impact rapport	39.3%
PROMs are not aligned with the Diagnostic and Statistical Manual of Mental Disorders	37.7%
PROMs scoring duration	32%
Lack of training in PROMs	27.1%

Table 6

Informal Assessment of the Process Model Domains

Domains	Clinical Interview	Outcome Measures	Standardised Assessments	Not Assessed
Situation selection	89.3%	41.8%	27%	5.7%
Situation modification	86.9%	31.1%	20.5%	8.2%
Attentional deployment	86.1%	25.4%	23.8%	8.2%
Distraction	86.9%	23.4%	11.5%	9.8%
Rumination	80.3%	23%	16.4%	15.6%
Cognitive change	83.6%	27.9%	12.3%	13.1%
Response modulation	82.8%	31.1%	18.9%	13.1%

Interest in PM-PROMs

Only 16.4% of participants *strongly agreed* or *agreed* they would use PM-PROMs; however, participants either *strongly agreed* or *agreed* (64.7%) that PM-PROMs should be developed. Participants reported the greatest intent to use parent-report (82%) and teacher-report (78.7%) measures. Participants were relatively less inclined to use client self-report (64.7%) PM-PROMs.

Differences Between Professional Profiles and Requiring PM-PROMs

An ANOVA was used to evaluate professional profiles in the perceived necessity of PM-PROMs based on the four severity levels of intellectual disability (i.e., mild, moderate, severe, and profound) that participants worked with. The mild and moderate levels were combined due to the smaller sub-sample, and 12 outliers were corrected to the next most extreme score by one unit, as recommended by Tabachnick and Fidell (2018). All levels were

non-significant, $F(2, 119) = .972$, $p = .38$. Likewise, there was no significant difference between profession (i.e., psychologists, behaviour therapist, and allied health/medical professionals) and the perceived necessity of PM-PROMs, $F(2, 117) = .315$, $p = .73$.

Predictors for Requiring PM-PROMs

Correlations were used to discern relationships associated with requiring PM-PROMs. The need for PM-PROMs was negatively correlated with years of experience working with intellectual disability, $r(120) = -.276$, $p = .002$, and confidence (TCS-ID; $M = 57.74$, $SD = 9.21$), $r(120) = -.222$, $p = .014$), such that those with more experience and confidence perceived less need for PM-PROMs; see Table 7. There was no significant relationship between the need for PM-PROMs and intellectual disability caseload percentage.

Table 7

Correlations

	1	2	3	4
1. Should PM-PROMs be developed	-			
2. TCS-ID	-.222*	-		
3. ID caseload percentage	-.159	.197*	-	
4. Gender	-.075	-.013	-.019	-
5. Years of ID experience	-.276**	.298**	.137	.036

Note. *p < .05, **p < .01, *n* ranges from 117 to 122. PM-PROMs = process model-based outcome measures, TCS-ID = Therapy Confidence Scale-Intellectual Disability, ID = Intellectual Disabilities.

To further analyse these relationships, a multiple regression was conducted to evaluate whether years of experience working with intellectual disability, caseload percentage, or confidence predicted the need for PM-PROMs. Overall, the regression was statistically significant, $R = .351$, $R^2 = .123$, $F(4, 112) = 3.935$, $p = .005$, consistent with the reported

correlations. Experience working with intellectual disability remained the only significant predictor of the perceived need for PM-PROMs, $\beta = -.109$, $p = .003$.

Discussion

The aim of this survey was to determine service provider awareness of the process model of emotion regulation and whether service providers are in need of PM-PROMs, as well as PROMs usage trends, and barriers to PROMs utilisation. Participants were generally unaware of the process model, and thus understandably were not guided by this framework. As anticipated, few participants used PROMs guided by the process model, likely due to their limited awareness, and the absence of valid and reliable measures (Girgis et al., 2021). Despite this, the majority of participants indicated a need for such measures. Participants particularly endorsed a need for parent and teacher informant PM-PROMs. However, there was relatively less need identified for self-report measures, perhaps unsurprising as an identified barrier to using PROMs was this population's reading and comprehension ability. Participants also demonstrated informal awareness and assessment of relevant process model domains with clients.

Most participants were informally aware of the process model domains (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014). These were reported to be commonly assessed using clinical interviews, with PROMs and standardised assessments used less often. In particular, the situation selection domain was most often assessed, which may be linked to the prevalence of anxious avoidance in this population (Buckley et al., 2020). However, response modulation was assessed relatively less often, despite this domain being associated with expressions of BOC, another common presentation in this population (Emerson & Einfeld, 2011). This discrepancy may reflect the high proportion of psychologists and behaviour therapists

amongst the participants, as their training commonly includes identifying BOC triggers, the informal assessment preference for situation selection (Allen et al., 2005; Gore et al., 2013). This informal acknowledgment and assessment indicates the process model is relevant to children and adolescents with intellectual disabilities.

Participants preferred emotion regulation PROMs specifically developed for children and adolescents with intellectual disabilities, rather than PROMs developed for the typically developing population. Further, participants preferred PROMs that broadly identified emotion regulation difficulties, rather than diagnostic specific PROMs. This aligns with the recommended transdiagnostic approach in assessing emotion regulation in children and adolescents with intellectual disabilities (Astle et al., 2022). In this sense, PROMs founded on the process model are well positioned to adhere to transdiagnostic frameworks, given that the process model is aligned with such frameworks (Gross, 2014). Despite these preferences and views, participants more often used measures developed for the typically developing population.

Although participants preferred measures specifically developed for the intellectual disability field, they more often used measures used in the general population such as the Depression Anxiety Stress Scale (Lovibond & Lovibond, 1995) and Strengths and Difficulties Questionnaire (Goodman, 1997), which are poxy measures that do not directly measure the components of emotion regulation within this population. Participants also reported current PROMs did not inform treatment planning, capture lived experience, offer real-world utility, nor inform assessments. Overall, these shortcomings support the need for the development of measures validated in the target population.

Only slightly more than half of participants routinely used PROMs, preferring instead to use clinical interviews to assess emotion regulation and dysregulation. The preference of clinical interviews over other modalities is consistent with assessment practice habits

amongst therapists, despite this being a less valid form of assessment (Jensen-Doss &

Hawley, 2010). The current under-utilisation of PROMs may stem from both a scarcity of

available measures—a known barrier to best practice standard adherence (De Los Reyes &

Makol, 2019)—and beliefs shaped by experiences with inappropriate measures. For instance,

participants may have negative experiences with PROMs, such as issues with reliability, real-

world applicability, or measures that fail to capture their clients' experiences. These

challenges may then be incorrectly attributed to client reading difficulties, a reported barrier

to PROMs usage, rather than to the inappropriate application of PROMs. These barriers may

explain the comparatively greater PROMs use when assisting the typically developing

population. Yet relatively, participants did not consider insufficient administration training a

barrier to utilising PROMs. Despite this, the current findings suggest experience levels may

influence the utilisation of PROMs. Although confidence and experience were both

significantly correlated with the need for PM-PROMs, only experience was a predicting

factor. Specifically, less experienced service providers predicted the need for PM-PROMs.

This aligns with the literature, as service providers adhere less to evidence-based practice as

experience grows (Cook et al., 2017).

There are four limitations to our research. The purpose-specific survey has not been

validated and used single item measures. Thirdly, the views obtained are primarily those of

female therapists, as such, it is unclear if males share similar views or equivalent assessment

habits. Finally, the survey predominantly captured the views of psychologists and behaviour

therapists, with limited insights into views held by other professionals practicing in this area.

Overall, the findings indicate service providers working with children and adolescents

with intellectual disabilities require PM-PROMs for this population. Future research should

focus on the development of PM-PROMs. This endeavour might be guided by the COSMIN

methodology (Terwee et al., 2018). COSMIN recommends the incorporation of relevant

stakeholders (i.e., children and adolescents, parents, and teachers) during a measure's conceptualisation phase via qualitative methods such as interviews and focus groups. This process serves to comprehensively capture stakeholder experiences and determine the relevance of the framework of interest to the target population. Although, participants in our survey reported self-report measures were relatively unhelpful compared to informant measures; perspectives on their emotion regulation experiences should be gathered from children and adolescents with intellectual disabilities in order to maintain a person-centred approach and to adhere to multi-informant best practice guidelines (De Los Reyes et al., 2015; Gore et al., 2013). Collectively, these perspectives will further determine whether the process model of emotion regulation is relevant to this population, and inform the development of PM-PROMs, which can be psychometrically validated. These measures would also include the incorporation of accessibility aides, such as easy-read English, visuals, and binary choices, to enhance understanding and engagement. By integrating these components, PM-PROMs can be accessible, ensuring they are appropriate for a broader range of individuals within this population.

Encouraging the adoption of these validated measures among service providers, coupled with dedicated training, may facilitate their integration but also dismantle barriers impeding adherence to best practice. In doing so, these PM-PROMs could be used to monitor treatment progression, guide interventions, and further emotion regulation research concerning children and adolescents with intellectual disabilities, thus aligning with the gold standard for assessments (De Los Reyes & Makol, 2019).

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Supplementary file: Survey

Introduction

At present there are not many questionnaires available to assess emotion regulation in

children and adolescents (0 to 18 years old) diagnosed with Intellectual Disabilities (ID). This

survey aims to determine if professionals working within the intellectual disability sector

need such questionnaires and what might be included in them.

Screener

1. What is your profession?
    - ABA therapist
    - Behaviour therapist
    - Counsellor
    - Occupational therapist
    - Psychiatrist
    - Psychologist
    - School counsellor
    - Speech therapist
    - Other (please type response)

2. Are you currently working with children and adolescents (0 to 18 years old) diagnosed with ID? **Yes/No**
3. Please indicate which level of ID severity you work with? (Choose as many as apply)
    - Mild
    - Moderate
    - Severe
    - Profound
    - Unknown
4. How many years of experience do you have working with children and adolescents with ID, excluding breaks? (criteria is 12 months)
5. How many years total have you been working in your profession?
6. What percentage of your time/caseload do you spend working with children and adolescents with ID? (criteria 20% or more)

Demographics

- 7. What is your age?

- 8. What gender do you identify with?
  - o Female
  - o Male
  - o Non-binary/third gender
  - o Prefer not to say
  - o Prefer to self-describe/other (please specify)

- 9. What is your ethnicity (Choose as many as apply)?
  - o Indigenous Australian or Torres Strait Islander
  - o Caucasian
  - o Middle Eastern
  - o Asian
  - o African
  - o North American
  - o South American
  - o New Zealander
  - o Indian
  - o European
  - o Other (please specify)

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The following questions refer to your child and adolescent clients <u>with</u> Intellectual

Disabilities (ID):

<u>Likert scale</u>

- Always
- Often
- Sometimes
- Rarely
- Never

10. How often do you use:

a) Questionnaires in your practice?
b) Questionnaires in your practice before you start treatment (tracking baseline)?
c) Questionnaires in your practice after you start treatment (tracking progression)?

11. Do you use any of the following screener questionnaire(s)? Choose as many as apply.

- Depression Anxiety and Stress Scale (DASS)

- Spencer Children Anxiety Scale
- Strengths and Difficulties Questionnaire (SDQ)
- Beck Youth Inventory
- Developmental Behaviour Checklist
- Anxiety, Depression and Mood Scale (ADAMS)
- Kessler Psychological Distress Scale (K-10)
- Emotion Regulation Questionnaire (ERQ)
- Difficulties in Emotion Regulation Scale (DERS)
- The Mood and Feelings Questionnaire (MFQ)
- Screen for Child Anxiety Related Disorders (SCARED)
- Perth Emotion Regulation Competency Inventory (PERCI)
- Not Applicable
- Other (type response)

The following questions refer to your child and adolescent clients <u>without</u> Intellectual

Disabilities (ID):

<u>Likert scale</u>

- Always
- Often
- Sometimes
- Rarely
- Never

12. How often do you use:

a) Questionnaires in your practice?
b) Questionnaires in your practice before you start treatment (tracking baseline)?
c) Questionnaires in your practice after you start treatment (tracking progression)?

13. Do you use any of the following screener questionnaire(s)? Choose as many as apply.

- Depression Anxiety and Stress Scale (DASS)
- Spencer Children Anxiety Scale
- Strengths and Difficulties Questionnaire (SDQ)
- Beck Youth Inventory
- Developmental Behaviour Checklist
- Anxiety, Depression and Mood Scale (ADAMS)
- Kessler Psychological Distress Scale (K-10)
- Emotion Regulation Questionnaire (ERQ)
- Difficulties in Emotion Regulation Scale (DERS)

- The Mood and Feelings Questionnaire (MFQ)
- Screen for Child Anxiety Related Disorders (SCARED)
- Perth Emotion Regulation Competency Inventory (PERCI)
- Not Applicable
- Other (type response)

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14. Do you assess the following emotion regulation factors when working with children and adolescents with intellectual disabilities (ID)?

Likert scale

- Always
- Often
- Sometimes
- Rarely
- Never

a) Their ability to seek out positive or negative situations?
b) Their ability to modify situations to lessen the emotional impact e.g., Choosing to wear headphones or using sensory items when in stressful situations?
c) Their ability to use distraction as a strategy?
d) Their ability to shift their attention?
e) Their tendency to ruminate?
f) Their ability to change the way they are thinking, whether positively or negatively?
g) Their physiological or somatic experiences?

15. How do you assess the following emotion regulation factors when working with children and adolescents with Intellectual Disabilities (ID)?

Multiple choice. Choose as many as apply.

- Assessed using Clinical Interview
- Assessed using Questionnaires
- Assessed using Standardised Assessments
- Is Not Assessed (if chosen cannot choose other items)

a) Their ability to seek out positive or negative situations?
b) Their ability to modify situations to lessen the emotional impact e.g., <u>Choosing</u> to wear headphones or using sensory items when in stressful situations?
c) Their ability to use distraction as a strategy?
d) Their ability to shift their attention?
e) Their tendency to ruminate?
f) Their ability to change the way they are thinking, whether positively or negatively?
g) Their physiological or somatic experiences?

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<u>Likert scale</u>

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

16. Please indicate your preference regarding emotion regulation questionnaires for children and adolescents with Intellectual Disabilities.

a) Would you prefer questionnaires that more broadly identify emotion regulation difficulties over diagnostic specific questionnaires?
b) Would you prefer diagnostic specific questionnaires over questionnaires that more broadly identify emotion regulation difficulties?
c) Do you need more resources to better identify emotion regulation difficulties?
d) Would you use an emotion regulation questionnaire specifically developed for children and adolescents with ID, over a questionnaire developed for the general population?

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These questions aim to determine which aspects of questionnaires would be helpful in your current work with children and adolescents with Intellectual Disabilities.

<u>Likert scale</u>

- Very Helpful
- Somewhat Helpful
- Neither Helpful nor Unhelpful
- Not Very Helpful

- Not At All Helpful

17. In your practice, how helpful would the following be for your work with children and adolescents with Intellectual Disabilities?

a) Self-report emotion regulation questionnaires?
b) Parent-report emotion regulation questionnaires?
c) Teacher-report emotion regulation questionnaires?
d) School observations for identifying emotion regulation difficulties?
e) Questionnaires that assist with developing your case formulation (i.e., Identifying the cause of symptoms and maintaining factors?)

18. How helpful are questionnaires identifying the following for children and adolescents with Intellectual Disabilities?

a) Emotion regulation difficulties in school-based settings?
b) Emotion regulation difficulties in home-based settings?
c) Antecedent based strategies?
d) Where a break down occurs in the emotion regulation process?
e) Preventative strategies for emotion regulation difficulties?
f) Responses to environments and subsequent emotion regulation difficulties?
g) The usefulness of distraction for emotion regulation difficulties?
h) The relationship between concentration and emotion regulation?
i) The presence of rumination?
j) The ability to cognitively reframe situations?
k) The themes of successful emotion regulation?
l) Physiological or somatic experiences?
m) The preferred environmental modifications needed to assist with emotion regulation?
n) The function of behaviour?

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19. What are some barriers to using emotion regulation questionnaires for children and adolescents with intellectual disabilities?

Likert scale

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

a) Your client's parents/supports have difficulties with reading?
b) Your clients have difficulties with reading?
c) Your clients are unable to comprehend the questions?
d) The cost of the available questionnaires?
e) It is difficult to acquire the questionnaires?
f) The limited availability of reliable and valid questionnaires for this population?
g) The available questionnaires take too long to fill out?
h) The available questionnaires take too long to score?
i) The available questionnaires do not inform diagnostic assessments?
j) The available questionnaires are not aligned with the DSM 5?
k) The available questionnaires do not inform treatment planning?
l) The available questionnaires do not capture the client's lived experience?
m) The available questionnaires do not add anything extra to clinical assessments?
n) The available questionnaires do not offer any real-world utility?
o) I am not trained in how to use the available questionnaires?
p) The use of available questionnaires impacts rapport?
q) The available questionnaires do not have non-English translations?
r) The available questionnaires do not have Easy-English translations?

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One of the most used emotion regulation frameworks is the process model of emotion regulation (Gross, 1998, 2014). Below is a description of the process model. Please answer the following questions regarding the emotion regulation of children and adolescents with intellectual disabilities (ID) with this framework in mind.

The process model of emotion regulation has 5 domains:

- **Situation Selection**
- **Situation Modification**
- **Attention Deployment**
- **Cognitive Control**
- **Response Modulation**

Below are the associated definition

Domain	Definition	Example
Situation Selection	Avoiding or seeking out situations	A child avoiding bath time by hiding or a child requesting their birthday presents early.
Situation Modification	Modifying the environment to alter the emotional impact.	Using headphones to help with homework
Attention Deployment	Redirecting attention: this can be grouped into three categories. Distraction Concentration Rumination	Distraction: child averting their eye gaze and focusing on a toy rather than their parents arguing.
Cognitive Change	Changing their thinking	Using self-talk to say your excited instead of anxious when presenting a class speech
Response Modulation	Changing behavioural, experiential, or physiological responses.	Using deep breaths to feel calmer

Please consider these definitions when answering the questions below.

20. Have you heard of the following elements of the process model?

Yes/No

    a) The process model of emotion regulation?
    b) The domain situation selection?
    c) The domain situation modification?
    d) The domain attention deployment?
    e) The domain cognitive change?
    f) The domain response modulation?

21. These questions aim to determine if the above framework is used in your practice.

Likert scale

    - Strongly Agree
    - Agree
    - Neither Agree nor Disagree
    - Disagree
    - Strongly Disagree

    a) Is the process model the dominate framework used with children and adolescents with ID in your field?
    b) Is your practice informed by this framework when working with children and adolescents with ID?
    c) Do you use questionnaires based on this framework?
    d) Should a questionnaire be developed using this framework for children and adolescents with ID?
    e) Would you use a self-report questionnaire based on this framework for children and adolescents with ID?
    f) Would you use a parent-report questionnaire based on this framework for children and adolescents with ID?
    g) Would you use a teacher-report questionnaire based on this framework for children and adolescents with ID?

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Therapy Confidence Scale—Intellectual Disabilities (TCS-ID; Dagnan et al., 2015)

These questions aim to determine how confident you are at each stage of the therapeutic relationship development when working with children and adolescents with Intellectual Disabilities.

<u>Likert scale</u>

- Highly Confident
- Confident
- Moderately Confident
- Slightly Confident
- Not Confident

22. How confident are you that you can:

a) Identifying where in the emotion regulation process a break down occurs for children and adolescents with an intellectual disability?
b) Listen carefully to concerns presented by a client with an intellectual disability?
c) Be empathetic towards a client with an intellectual disability?
d) Understand special issues related to having an intellectual disability and their impact on a person's life?
e) Communicate with a client who has an intellectual disability?
f) Develop a therapeutic relationship with a client who has an intellectual disability?
g) Gather information from a client with an intellectual disability so that their difficulties can be better understood?
h) Use assessments in a way that a client with an intellectual disability will understand?
i) Explain results of an assessment process to a client with an intellectual disability?
j) Use knowledge about mental health issues in formulating the problems of a client with an intellectual disability?
k) Help a client with an intellectual disability to identify issues that need to be considered in sessions?
l) Use knowledge of mental health interventions to work effectively with a client who has an intellectual disability?
m) Identify therapeutic approaches that will be effective for a client with intellectual disability?
n) Work with care-givers and other important people in the lives of people with an intellectual disability?
o) End intervention with a client who has an intellectual disability in an effective manner?

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End of Survey

We thank you for your time spent taking this survey. Your response has been recorded.

Please see below for relevant references:

Dagnan, D., Masson, J., Cavagin, A., Thwaites, R., & Hatton, C. (2015). The Development of

    a Questionnaires of Confidence in Delivering Therapy to People with Intellectual

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Chapter 6: COSMIN-Based PROM Development Process, Step 5

The completion of Step 4 of the COSMIN-based patient-reported outcome measure (PROM) development process, was described in Chapter 5 (Girgis et al., 2024; Swan et al., 2023; Terwee et al., 2018). In summary, Step 4 reflected Phase 1A, and sub-steps 1 to 3 out of 13 sub-steps of the development process. These sub-steps guide the process of determining a construct's real-world relevance (Swan et al., 2023; Terwee et al., 2018). This was accomplished by means of a survey of service providers, which found providers informally assess the process model domains when working with children and adolescents with intellectual disabilities. This supports the real-world utility and applicability of the process model to this population (Girgis et al., 2024; Gross, 2024). Additionally, providers indicated a need for process model-based PROMs (PM-PROMs), as well as a preference for measures specifically developed for children and adolescents with intellectual disabilities. As shown in Table 2.1., Step 5 of the COSMIN-based PROM development process allows for evaluation of the relevance of the process model to children and adolescents with intellectual disabilities. This Step consists of confirming construct relevance and item pool generation. Fundamentally, this Step is dedicated to assessing the construct's relevance to key stakeholders, which is also an essential step in PROM development (Swan et al., 2023; Terwee et al., 2018).

Step 5 reflects the remaining sub-steps, specifically, sub-steps 4 to 13, of the COSMIN methodology for assessing the content validity of PROMs (Swan et al., 2023; Terwee et al., 2018). See Figure 6.1 for sub-step representation. While these sub-steps address construct relevance and PROM item development, this dissertation focuses solely on construct relevance, as the latter is beyond the intention of this body of work.

Figure 6.1

Alignment of Step 5 of the PROM Development Process to the COSMIN Content Validity

Guidelines, as Derived from Swan et al. (2023) and Terwee et al. (2018)
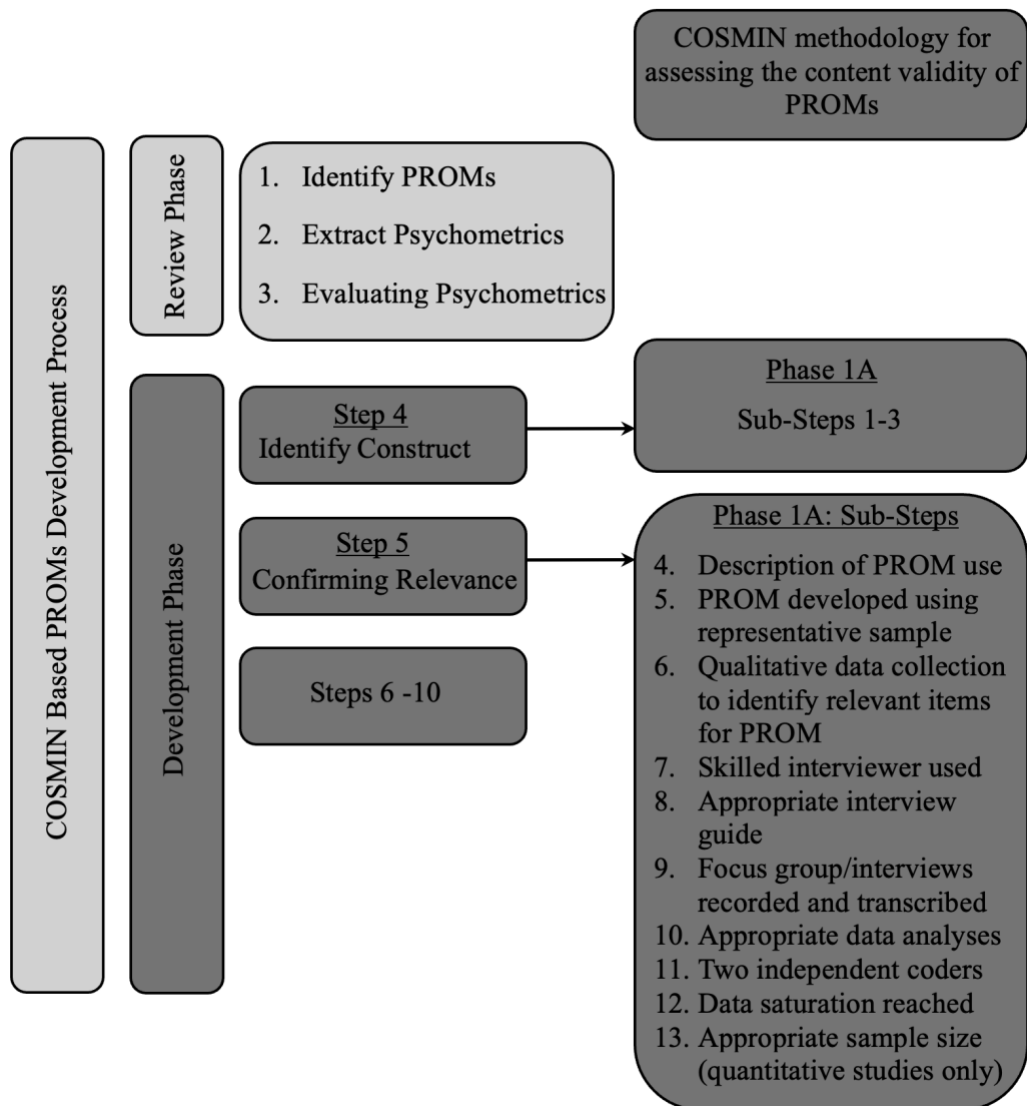
Sub-step 4 relates to the development of a clear description of the PROM and identifies relevant stakeholders (Terwee et al., 2018). In this context, a PM-PROM would be used to assess the emotion regulation of children and adolescents with intellectual disabilities, as conceptualised by the process model domains (situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2024). Additionally, the relevant stakeholders are considered, teachers, parents, and children and adolescents with intellectual disabilities. Sub-steps 5 and 6 relate to the completion of qualitative studies with key stakeholders, using a recognised and well justified data collection method. The method should allow for the synthesis of themes and sub-themes, and facilitate item development; to determine construct relevance, only theme and sub-theme formation is required. While sub-steps 7 to 9 require the use of a skilled interviewer with an appropriate interview guide, as well as the recording and transcribing of focus groups or interviews. Sub-steps 10 to 12 relate to the use of a well-justified analysis method, with two independent coders used, and confirmation of data saturation. Sub-step 13 sets a sample size minimum when using quantitative methods to develop PROM items and is not relevant to this dissertation.

In order to satisfy these sub-steps, focus groups and interviews will be used to evaluate the relevance of the process model to children and adolescents with intellectual disabilities. Specifically, focus groups will be conducted with teachers to capture their collective experience (see Chapter 7) while interviews will be used to capture parental perspectives, and the perspectives of children and adolescents (see chapters 8 and 9, respectively). A skilled interviewer will use an appropriate interview guide (see Appendix D and E). Additionally, the focus groups and interviews will be recorded and professionally transcribed, and data collection will also cease once saturation is confirmed. This data collection method, when combined with the reflexive deductive analysis approach, will

facilitate the synthesis of themes and sub-themes (Braun & Clarke, 2006, 2019). It should be noted, that whilst data saturation is not required when using the reflexive deductive analysis approach, saturation will be sought in order to comply with the COSMIN-based PROM development process (Braun & Clarke, 2022; Swan et al., 2023; Terwee et al., 2018). Furthermore, according to the reflexive deductive approach, construct relevance can be determined by a single coder (Braun & Clarke, 2019). For the purpose of this dissertation, one coder is sufficient to determine the relevance of the process model. Although item development is beyond the intention of this dissertation, items could be derived from the themes at a later stage, as a second coder can review the raw data when item development becomes necessary for PM-PROM development.

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Chapter 7. Study 3: How Do Children with Intellectual Disabilities Regulate Their

Emotions? The Views of Teachers

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How Do Children with Intellectual Disabilities Regulate Their Emotions? The Views of Teachers

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ABSTRACT

Background: Children and adolescents with intellectual disabilities commonly experience emotion regulation difficulties. To better understand emotion regulation in this population, the views of their teachers were considered.

Methods: Twenty-nine teachers participated in two focus groups. This study utilized qualitative methods to determine if the emotion regulation experiences of this population, as perceived by their teachers, map onto the five domains of the process model of emotion regulation: situation selection, situation modification, attentional deployment, cognitive change, and response modulation.

Results: A thematic analysis indicated the data from both focus groups was consistent and mapped onto the five domains of the process model; with several additional themes and subthemes identified.

Conclusions: Perspectives provided by teachers affirmed that the process model of emotion regulation is relevant to children and adolescents with intellectual disabilities. Future research might consider developing the themes identified in this qualitative study into quantitative questionnaire items and validating that measure.

INTRODUCTION

Approximately 30–50% of children and adolescents with intellectual disabilities experience emotion regulation difficulties (Emerson et al., 2001). These difficulties are typically expressed as co-occurring mental illnesses and behaviors of concern (BOC). BOC are most commonly categorized as: physical aggression, self-harm, property damage, noncompliance, temper "tantrums," repetitive questions, screaming, running away, overactivity, stealing, inappropriate sexualized behavior, stripping, and smearing feces (Emerson & Einfeld, 2011; Emerson et al., 2001). These behaviors are associated with restricted access to school-based activities and facilities (Stoesz et al., 2014), interrupted schooling, reduced social acceptance and academic achievement, and social isolation, all of which results in a reduced quality of life (Einfeld

et al., 2011; Eisenhower et al., 2007; Munir, 2016). These impacts may have implications well into adulthood, as adults with intellectual disabilities have higher rates of mental health difficulties, associated with reduced emotional wellbeing, community integration and employment opportunities (Munir, 2016; Svetlana et al., 2018).

Children and adolescents with intellectual disabilities can become especially overwhelmed in school settings due to the inherent demands of this environment, resulting in emotion regulation difficulties (Eisenhower et al., 2007). These difficulties can exacerbate BOC and impact the student-teacher relationship, which is a predictor of ongoing social competence (Eisenhower et al., 2007). Limited social skills also exacerbate BOC, as students mistakenly perceive peer behavior as directed toward them; this misattribution results in an increased likelihood of interpersonal conflict (Larkin et al., 2012). In this way, increased interpersonal conflict results in increases in BOC, which then impacts the student-teacher relationship. This relationship can be cyclical and result in a reduced quality of life with far reaching implications (Einfeld et al., 2011; Eisenhower et al., 2007; Munir, 2016). Based on the importance of the student-teacher relationship, as well as the opportunity for skilled observational insights, it is important to consider the perspectives of schoolteachers on the emotion regulation and dysregulation experiences of children and adolescents with intellectual disabilities. One way to do this systematically is to consider schoolteacher observations against a prevailing conceptualization of emotion regulation.

The application of the process model of emotion regulation has been widespread across different groups and contexts (Gross, 2014). However, its exploration within the context of children and adolescents with intellectual disabilities has been limited. This model also aligns with the recommended transdiagnostic approach, which emphasizes assessing the expression of symptoms rather than focusing on specific diagnoses (Astle et al., 2022). This perspective is highly significant for this particular population, as it is recommended due to the notably high prevalence of co-occurring mental health conditions in these individuals (Einfeld et al., 2011; Gratz & Roemer, 2004; Munir, 2016). Incorporating this model has the potential to offer deeper insights into the regulation of emotions within this demographic, carrying implications for effective emotional and behavioral management. The process model proposes five emotion regulation stages: situation selection, situation modification, attentional deployment, cognitive change, and response modulation (Gross, 2014), see Table 1 for the domain definitions. When emotion regulation strategies are used – whether adaptive or maladaptive – new situations are created. The strategy used will then alter the situation, thereby creating a new variant situation and another opportunity to choose strategies, resulting in a propagating cyclical process (Gross, 2015). Understanding

Table 1. Definitions and examples of the five domains of the process model of emotion regulation as based on gross (1998, 2014).

Domain	Definition	Example
Situation Selection	An individual first becomes aware of an upcoming situation and the associated emotional reaction. This leads them to either initiate or avoid the situation.	A child avoiding bath time by hiding or a child requesting their birthday presents early.
Situation Modification	When a situation has commenced the individual can modify the environment to alter the emotional impact.	Using headphones to help with homework or chores completion.
Attentional Deployment	The ability to shift attentional focus. Redirecting attention can be grouped into three categories. Distraction: the ability to either redirect attention to non-emotional aspects of a situation or away from the situation entirely. Concentration: attention is sustained by the engagement of tasks which occupy finite cognitive abilities. Rumination: directs attention to emotions and related consequences.	Distraction: child averting their eye gaze and focusing on a toy rather than their parents arguing. Concentration: when a child is concentrating on a YouTube video. Rumination: when an adolescent worries about hypothetical threats.
Cognitive Change	The individual evaluates whether an event can be managed within the context of their goals.	Reframing is one strategy, wherein an adolescent engages in self talk about being excited instead of anxious when presenting a class speech.
Response Modulation	This domain occurs later in the emotion regulation process and focuses on changing the trajectory of behavioral, experiential, or physiological responses.	When an adolescent is behaving aggressively and then walks around their school to reduce this state.

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how this emotion regulation process is expressed in children and adolescents with intellectual disabilities is vital, considering the implications of emotion dysregulation (Einfeld et al., 2011; Eisenhower et al., 2007; Munir, 2016).

Given the importance of emotion regulation, the aim of the current research is to assess the relevance of the process model of emotion regulation to children and adolescents with intellectual disabilities in school settings. This is assessed by considering the perspectives of teachers working in these contexts. Focus will be placed on evaluating the emotion regulation and dysregulation experiences of this population, and the emotion regulation assistance provided by teachers. These perceptions are useful, as teachers can identify emotion regulation difficulties that may impact learning and overall mental health within school settings (Nelson & Harwood, 2011). Additionally, evaluating schoolteacher perspectives aligns with emotion regulation assessment recommendations, as multi-informant input is consistent with best practice standards for youths (De Los Reyes et al., 2015). Given the absence of validated

emotion regulation measures for teachers of this demographic (Girgis et al., 2021), and in order to capture the full breadth of views, a qualitative approach will be undertaken.

METHOD

Setting

Participants were recruited from six specific purpose schools in New South Wales, Australia (i.e., schools providing specialist and intensive support in a dedicated setting for students with mild to high learning and support needs).

Participants

Twenty-nine schoolteachers were recruited from six specific purpose schools. The study consisted of two focus groups. The first focus group ($n = 18$) consisted of all female schoolteachers from a single specific purpose school, which catered to students with moderate and severe intellectual disabilities. The second focus group ($n = 11$; Female $= 10$) consisted of schoolteachers from five schools catering to students with mild to moderate intellectual disabilities. Both focus groups were conducted over one hour.

Procedure

The study was approved by the University of Technology Sydney ethics committee (approval number: ETH16–0925). Specific purpose schools and schoolteacher networks were emailed about the study and offered an opportunity to participate. Teachers primarily working with students with intellectual disabilities were invited to take part. Teachers were reimbursed with an AUD \$20 gift voucher, and refreshments were provided. The first focus group took place at a school educating students with moderate to severe intellectual disability ($n = 18$). As this school did not cater to children and adolescents with mild intellectual disabilities, a second focus group was conducted during a teacher networking event for teachers working with children and adolescents with a mild intellectual disability in order to capture the experiences of this cohort. As this focus group was conducted at a networking event, the teachers represented five schools ($n = 11$). This focus group was included in order to collect a greater breadth of data. No comparative hypotheses between these two groups were made.

The focus groups were led by the lead author, a female PhD candidate and clinical psychologist, and followed a semi-structured format. The focus group concentrated on observations of overall student emotion regulation and dys-regulation behavioral expressions, as well as specific behavioral expressions

within the context of the domains of the process model (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014). Initially, the focus group discussion consisted of open-ended questions regarding the general emotion regulation experiences of children and adolescents with intellectual disabilities. After which, both open and closed ended questions were used to discuss the five domains of the process model (Gross, 2014). Teachers were encouraged to discuss observations as a group, without naming the student. Teachers were also asked to provide examples of emotion regulation experiences in order to avoid agreeableness. The interviewer managed these relatively large groups by having a clear agenda, guiding the discussion, and carefully supporting participation by encouraging participants to contribute to comments made by others, either by indicating their agreement/disagreement, and adding comments. Both focus groups were audio recorded and transcribed. Field notes were also taken during the focus groups. The study was evaluated against the COnsolidated criteria for REporting Qualitative research Checklist (COREQ; Tong et al., 2007), see Appendix for checklist.

Measures

Demographic Information

Demographic information pertaining to the teachers was collected, specifically: age, gender, ethnicity, general years of teaching experience, and years of teaching experience with students with intellectual disabilities; see Table 2.

Analysis

The transcripts were thematically analyzed using NVivo 12, a qualitative analysis software (QSR International Pty Ltd, 2019). The thematic analysis was guided by Braun and Clarke (2006), with a focus on the reflexive deductive method. This method allows data to be considered through the lens of an existing framework, in this case the process model of emotion regulation (Gross, 2014), and also allows the inclusion of identified unrelated themes. This method has also previously been used in research

Table 2. Teacher and student demographic data.

Demographics	
Participants	$N = 29$
Gender of Teacher (Female: Male)	28:1
Teacher Age	41.7 (8.74)
Teacher Ethnicity	Caucasian (9)
	Middle Eastern (1)
	Undisclosed (19)
Years of teaching experience	14.20 (8.51)
Years of teaching students with intellectual disabilities	11.90 (7.87)

pertaining to individuals with intellectual disabilities (Emonson et al., 2022; Littlewood et al., 2018; St John et al., 2018). Only one coder considered the transcripts; this was completed by the lead author (MG). This decision was based on the elaboration of Braun and Clarke's (2006) method by the same authors in a more recent paper (Braun & Clarke, 2019), in which they argued assessing reliability via the use of independent coders is against the essence of thematic analysis. Braun and Clarke (2019) maintain the goal of thematic analysis is to engage thoughtfully with the data and to build layers of codes and themes, through the lens of theoretical assumptions. If multiple researchers evaluate the data, then the process is collaborative rather than driven by a need for consensus. In line with this philosophy, teacher perspectives and the perspectives of individuals with neurodevelopmental disabilities have been evaluated using only one coder (Head, 2020; Lester, 2014; Maciejewska, 2020).

A deductive thematic analysis was used to evaluate the data, at each stage NVivo 12 was used and reference was made to the field notes. Initially, the transcripts were read several times for familiarity and to form initial thoughts. Next, codes associated with the five domains of the process model (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014) were identified, and unrelated reoccurring codes were highlighted; codes were only considered if participants provided examples in order to avoid agreeableness. Codes related to the process model were consolidated into potential sub-themes and rechecked against the transcripts; likewise, codes unrelated to the process model were consolidated into additional themes. These themes and sub-themes were then refined and renamed, and associated definitions were established. Lastly, extracts from the transcripts were selected to represent the themes and compiled into a report.

RESULTS

Twenty-nine schoolteachers participated in two focus groups examining the emotion regulation experiences of students with intellectual disabilities between the ages of 6 and 18. The findings between the two focus groups were consistent, and a thematic analysis indicated the data mapped onto the five domains of the process model (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014). These findings, as well as additional themes and sub-themes, are further explored below and summarized in Table 3.

Situation Selection

Descriptions from teachers were consistent with this domain, as they reported their students avoided known distressing situations, and often

Table 3. Thematic analysis themes and sub-themes.

Domain	Sub-themes
Situation Selection	Managing Stimulation
	Routine
Situation Modification	Incorporating or Removing Sensory Elements
	Changing the Classroom/Relationship Dynamic
Attentional Deployment	Rumination
	Distraction
	Concentration
Cognitive Change	Reframing Thoughts
	Blaming Others
	Mislabeling Emotions
Response Modulation	Self-Harm
	Aggressive Behaviors
	Non-Compliance, Stripping (Non-Sexual), and Playing with Bodily Fluids
	Physiological Responses
	Repetitive Behaviors
	Escape
	Strategies
	Meditation
	Medication
	Meeting Sensory Needs
	Communication
Preventative Strategies	
Prompting	
Limited Emotional Granularity	

selected alternative environments when attempting to regulate their emotions. This location or setting shift was usually expressed as " ... request to go home ... request to go. Requesting to see a different adult as well, so they might request to come to the office and talk to the principal or see a different teacher, different staff member." These requests often occurred after an inciting incident, and in turn created a new situation, and overlapped with the response modulation domain. In addition, the following sub-themes were also identified.

Managing Stimulation

Teachers indicated their students sought out environments that could meet their sensory needs, typically by way of seeking or removing stimulating items. These needs could be fulfilled by either seeking out sensory items, often within a sensory room, or seeking environments with minimal sensory input: "They like weighted things, like weighted blankets and all that sort of stuff. Safe rooms or quiet rooms," and "another student used to take herself to the backroom, she shut the door and just [sat] there."

Students also managed their sensory needs by seeking environments that allowed social connection. However, these attempts at social connections were at times perceived by teachers as being manipulative and facilitative of further emotion dysregulation:

Sometimes they seek a situation where they know that it will put them over the edge. So, one particular student will try and seek out other students who may not be at their social level... so talking excessively for no reason with another student, waving, screaming, silly behavior so they'll get a rise.

Routine

Routine was used as an external prompter of situation selection, as routines were often coupled with social stories which facilitated transitions between environments, situations, and classes, "I think it always just comes back to having those routines and transitions and social stories so that you are getting them prepared for changes."

Situation Modification

Descriptions were cohesive with the situation modification domain as teachers reported instances of modifications being made, as noted by the sub-themes below.

Incorporating or Removing Sensory Elements

The teachers reported several students engaged in sensory stimulation in the classroom, for instance, accessing sensory toys, using an iPad, listening to music, or choosing items from the classroom toolbox. Similarly, the data indicated students often modified their environment by removing stimulation. For instance, blocking out sounds with headphones, covering their eyes and ears, screaming or singing to cover external sounds, requesting more physical space, and locking other students out of the classroom when they are disruptive. Students also attempted to cover the ears, eyes, and mouth of staff.

Teachers also used routine to externally manage modification choices by enforcing the schedule or offering a selection of modifiers, "Offering them choices of things that I know can soothe them. Like bubble wrap or sensory [items] or and even choices of the room that they'd like [to] go into so [they can feel more] safe in there."

Teachers also modified the environment by facilitating classroom movements, either by moving the dysregulated student to another location or moving the class to another area and leaving the dysregulated student in the classroom with a teacher's aide. This element also overlaps with the situation selection domain.

Changing the Classroom/Relationship Dynamic

Teachers perceived certain student behaviors as attempts to modify the environment via changing the classroom dynamic or teacher's responses,

such as through self-harm, distracting others, or engaging only with certain staff: "They're trying to seek sympathy. They're changing the situation and then, sympathetic [eliciting sympathy after they've self-harmed]. Then they get what they want, but it is not going to happen," "He tries [to] distract other students, because he realizes that he is making the wrong choices. He wants other students to make the wrong choices as well. So that the focus is not just on you," and "He would go and talk to her [teacher aide] and he will look at me, and he will keep ignoring, [they will only] talk to each other."

Attentional Deployment

Descriptions were compatible with the attentional deployment domain. The identified sub-themes below also aligned with pre-established sub-themes of attentional deployment (i.e., rumination, distraction, and concentration; Gross, 1998).

Rumination

Displays of rumination were observed, which was typically expressed via asking repetitive questions, making repetitive requests, and checking items:

> Repeating something that they want or repeating like who they want to see like, "I want to see Joe, I want to see Joe, I want to see Joe." Or . . . asking where someone is or asking where something is or asking what time an activity is going to happen even though they've been told and shown when it's going to happen. . . as if trying to self-calm. In the sense of repetitive actions . . . . Trying to find things and people that will help them I suppose.

Distraction

Similar to the rumination sub-theme, distraction was expressed via asking repetitive questions and making repetitive requests, as distraction attempts from the current environment. Students were also reported to use other forms of distraction, such as using sensory items, accessing technology such as an iPad, listening to music, singing, and quoting popular phrases. One teacher indicated students can also distract themselves from the task at hand by ignoring the teacher and conversing with the teacher aide, with shifts in eye gaze observed: " . . . Even when he would not approach me because that is not what we are doing [classroom task], but he would go and talk to her and he will look at me, and he will keep ignoring."

Self-injurious behavior such as head banging was also perceived as a form of distraction when students were in a heightened state of arousal, which is further explored in the self-harm sub-theme.

At times students also appeared to be distracted without a known attentional focus, and in these moments, teachers attempted to refocus them, "just zoning out. It depends on the child, do what works for him."

Concentration

Distraction could progress into concentration. When this occurred, teachers reported observing sustained eye contact or "staring" in relation to the student's interests. Students typically concentrated on iPads, sensory items, as well as special interests which were typically associated with repeating facts.

Cognitive Change

Teacher reports were consistent with the change domain. However, this was dependent on the student's intellectual disability severity and language ability, as teachers noted they were often unaware of the student's cognitions, " . . . one of my students who's non-verbal and there was quite a lot that I really don't know [cognitions]. Because he doesn't have the skills to express that . . . I don't know what he's thinking." As such, use of speech was heavily relied on to deduce cognitive change, which excluded non-speech using students. Within this theme, the following sub-themes were also identified.

Reframing Thoughts

The teachers noted instances of student's reframing their thoughts, with the assistance of social stories, which are regularly used in the classroom setting, "Yes, social stories, and even when they talk sometimes, they are the same . . . like talking like a social story case." Reframed thoughts also manifested as mantras, which were typically developed based on the language used in the classroom, "They're so used to that language we've been using they know what it means. They soothe along with their self-thought like saying, 'It's okay, it's okay.' Over and over like they're saying that to themselves." The teachers also indicated cognitive change typically occurs after other emotion regulation strategies are used:

> We just kind of go take a deep breath. Then after she is better, she always says the same, "I am good again," every time. . . So, we are like, "Okay, when you have had your break, come back and tell me when you are ready to learn." That is a phrase I have said to them so that they will come back and say, "I am ready to learn."

> Multiple teachers indicated that the phrase "I am ready to learn" is commonly used in their classrooms.

Blaming Others. The focus groups reported students may at times negatively reframe situations by redirecting blame toward others: "He focuses on why it is

him [teachers reacting to the student's BOC] . . . the government is against him at school."

Mislabeling Emotions. Teachers reported students also attempted to reframe situations by mislabeling emotions or as one teacher stated, " . . . saying the opposite of the directive." Further to this, one teacher reported students would say, " . . . 'I'm not happy' or 'I am happy' or 'I won't finish' or 'I am finished' or for students that are crying, a student will say, 'he's happy,' so like the opposite to the emotion that he is."

Response Modulation

Teacher descriptions were compatible with the response modulation domain. The response modulation domain was associated with a significant portion of the findings, due to the observability of the related behaviors. The data also mapped onto the following established categories of BOC (Emerson & Einfeld, 2011; Emerson et al., 2001): physical aggression, self-harm, property damage, noncompliance, temper "tantrums," repetitive questions, screaming, running away, overactivity, stripping, and smearing feces. However, the data did not map onto the categories of inappropriate sexualized behavior and stealing (Emerson et al., 2001). These sub-themes, as well as additional findings, are further explored below.

Self-Harm

Students were reported to often engage in a wide variety of self-harm behaviors, including but not limited to "hair pulling . . . head banging . . . kick[ing] themselves . . . . Picking." Teachers indicated these self-harm behaviors can be significant, reporting students at times hit their heads on cement surfaces. Teachers hypothesized around the function of these behaviors, "Their pain receptors are not functioning and some of them . . . actually like try to commit self-injury to calm down." The teachers further hypothesized that these self-harm behaviors assist students in managing overstimulation, "They might use their self-injurious behavior to block it out."

Aggressive Behaviors

The teachers reported aggressive behaviors and provided multiple examples, including property damage "destroying furniture," verbal aggression, "F-off . . . go away," and physical aggression. The teachers reported "some can become violent, just running around excitedly," indicating an element of hyperactivity. The teachers also indicated the aggressive behavior can be directed toward others "Biting . . . injuring others . . . pinching . . . hitting

others . . . throwing people . . . hair pulling . . . big chunks of it, out of my head."
Aggressive behaviors were also expressed as "Stamping feet, yelling . . . scream-
ing . . . banging walls . . . [banging] on the tables, standing on tables." At times
these behaviors were reported to be accompanied by vocalizations "Groaning
or moaning . . . growls," and matched facial expressions " . . . sometimes they
contort their faces . . . angry look." These behaviors are collectively well
summarized by one teacher:

> . . . a lot [BOC] when they're stressed or when they're angry. So, it's nothing too serious
> in general. Head banging, making themselves vomit or smearing food. Pacing. Charging.
> Hitting objects into people, smacking or shrieking. Crying across the room. Throwing
> heads through windows, arms through windows, legs through windows.

Non-Compliance, Stripping (Non-Sexual), and Playing with Bodily Fluids
Teachers reported the students at times used "oppositional language" when
given tasks, these findings also overlapped with the cognitive change domain.
Students were also reported to engage in "stripping," and would induce
vomiting, as well as urinate and defecate, at times engaging in sensory play
with these substances when distressed.

Physiological Responses
Teachers reported that physiological responses were evident when stu-
dents were dysregulated "Shake . . . heavy breathing . . . sweating.
Depending on where they are and the meltdown that's either a pale
face or a red face." One teacher also indicated the use of the freeze
response when confronted with aggression, "I've got one student who
would freeze. He would sit there and not move. Even if you tell them,
even if someone's charging toward them, they'll just sit there and freeze
and not react at all."

Repetitive Behaviors
As noted earlier, teachers reported the occurrence of repetitive behaviors
when students were dysregulated, particularly, repetitive requests and ques-
tions. One teacher also reported checking behaviors "I have one student . . .
she just checks . . . not touching. So just to check if everything is
organized."

Escape
The teachers indicated that it is common for students to attempt to escape
when distressed, "running or escaping." Typically, this occurs by running out
of the classroom.

Strategies

Teachers indicated students were able to use various strategies to regulate their emotions.

Meditation. Teachers reported instances of deep breathing:

> Sometimes, it's more successful when they're right at their heightened and it starts that de-escalation process, like a routine that they have to go through. You start with the deep breathing and then you can engage them in other ways of helping de-escalate.

Medication. One teacher indicated that medication successfully assisted in distress de-escalation, "I had a student that overall, their most [frequent] request is PRN [as needed] medication, so to calm himself down."

Meeting Sensory Needs. Teachers indicated sensory items are used to assist in minimizing distress "rocking … chewing … bubbles … playdough … sensory box … trampoline and other break out area … weighted blankets and all that sort of stuff. Safe rooms or quiet rooms." The removal of sensory stimulation also assisted in emotion regulation, "So if something scares him, he would just sit outside in a safe spot, that is his response … it is just outside the [classroom] door kind of." Going for walks also reduced sensory load and was beneficial for de-escalation, "So that they can get a [leaving the classroom] pass and give me the pass and say, 'I need a break' and go for a walk around the main garden." Students at times also engaged in harmful sensory seeking behaviors, such as, self-harming behaviors, playing with urine and feces, and eating inedible items, "They're kind of just eating random stuff that they're not supposed to eat … so like leaves."

Communication. Teachers indicated that students could communicate their emotions, but this was limited, as seen in the below limited emotional granularity theme. They also reported that teaching emotional literacy facilitated student emotion regulation, " … they recognize it [emotive language]. We've been very specific in my class about verbalizing it for them."

An evaluation of the data identified three additional themes to the process model, as seen below.

Preventative Strategies

Teachers often engaged in preventative strategies to minimize any distress or emotion dysregulation experienced by the students. Typically, the teachers would remove potential triggers and position calming elements throughout the classroom:

It might be reminding them to take ten deep breaths four or five times throughout the day as their emotional regulation goes up and down. And because we know them so well and you've got your one class, I think we come into the situation like we know where they're at by their behavior, to try and stop it from getting to here [BOC] by offering things to slow it down before [BOC escalation]. And some [teachers] start off with sensory time into the timetable, so the students have time to self-regulate or whatever time you have from being taught really. And students will also seek out [sensory items] independently as well, and staff are pretty flexible to allow that to occur.

Prompting

Teachers reported that most preventative emotion regulation strategies were externally prompted by the teachers, as students are often unable to initiate these independently:

> Offering them choices of things that I know can soothe them. Like bubble wrap … even choices of the room that they'd like go into … and on the other side of what was just said, is sometimes a case of telling them what they're gonna have [sensory item or activity]. Because they can't make those decisions, so it's this is what's gonna happen depending where they're at. [activities and sensory items provided based on BOC escalation level]

The choices offered to the students were typically predetermined, "There is sort of agreed choices which we implement at the start the year, ways that they can have a break."

Limited Emotional Granularity

The teachers indicated students had limited emotional granularity, and often struggled to understand their emotions and triggers. Students also had limited descriptors for emotions, and typically relied on the following descriptors: happy, sad, excited, angry, frustrated, sick, hurt, crazy, silly, upset, anxious, homesick, bored, mad, and funny. Although, students did struggle with distinguishing between emotions:

> They still haven't quite known the difference between individual's happy and sad and strained. But they'll know something's wrong or something's not right … But I think most of our kids realize … they might not be able to name it, they might be able to describe it [emotions], but they know.

DISCUSSION

This study aimed to explore the emotion regulation and dysregulation experiences of children and adolescents with intellectual disabilities from the perspective of schoolteachers. Emphasis was placed on viewing the data through the lens of the five domains of the process model of emotion regulation (i.e., situation selection, situation modification, attentional deployment, cognitive

change, and response modulation; Gross, 2014). The qualitative data gathered was largely consistent across the two focus groups and mapped onto all five domains of the process model; additional themes and sub-themes were also identified namely "preventative strategies," "prompting," and "limited emotional granularity," as seen in Table 3.

The findings indicated students with intellectual disabilities engaged in situation selection, primarily through stimulation management (i.e., removing or adding sensory inputs). Teachers assisted students by following routines and selecting suitable environments, which provided an external source of emotion regulation. This aligns with the current recommendations for supported routines, which are used to manage BOC (Emerson & Einfeld, 2011). At times, these environmental selections occurred after distressing incidents, creating a new variant situation, and further propagating the cyclic emotion regulation response. Consistent with the literature, it was found that students were able to independently regulate their emotions by way of avoidance (Dekker & Koot, 2003; Rudaz et al., 2017). Teachers also indicated students sought environments with social connections when distressed. However, these attempts were perceived as being manipulative; a perception that is not currently established in the literature. It may be the case that these perspectives can be partially explained by the challenges teachers experience when there are increased BOC, which has been found to result in poorer student-teacher relationships (Larkin et al., 2012).

Teachers reported students also engaged in situation modification, specifically by incorporating or removing sensory elements and changing the classroom/relationship dynamic; teachers also provided external regulation by modifying the environment for their students. The use of aides to manage sensory inputs, specifically the use of music and headphones, is consistent with the findings of other research (Schwartz et al., 2017; Smith & Riccomini, 2013). Teachers also indicated they perceived self-harming behaviors by students as attempts to change the classroom dynamic, which often triggered location shifts. Teachers perceived the function of self-harm to be an attempt to garner "sympathy." However, responses by others to self-harm may further reinforce this behavior (Emerson & Einfeld, 2011). As with the situation selection domain, at times teachers perceived students as attempting to influence others negatively in order to shift attention away from themselves. However, this behavior could be explained by the increased likelihood of interpersonal conflict in this population, which may be attributed to an increased likelihood of poor student-teacher relationships, and limited social skills (Eisenhower et al., 2007; Emerson & Einfeld, 2011; Garrote, 2017; Larkin et al., 2012).

The data also mapped onto the attentional deployment domain and established sub-themes of this domain (i.e., rumination, distraction, and concentration; Gross, 2014). The rumination sub-theme relied on observed speech-

based responses, and therefore may not be generalizable to non-speech using students. The endorsement of rumination is consistent with the current literature, as within speech using populations rumination typically occurs at the same frequency in children and adolescents with and without intellectual disability (Young et al., 2016). The data from the distraction and concentration sub-themes overlapped, as students with intellectual disabilities were reported as often using sensory inputs as a distraction, which then progressed to sustained attention. However, it should be noted that children with intellectual disabilities are three times more likely to struggle with sustained attention when compared to their typically developing peers (Neece et al., 2011).

Cognitive change was also evident, however like the rumination sub-theme, this could only be determined using reports on speech using students. The teachers reported students with mild intellectual disabilities were more likely to possess expressive language, while those with moderate or severe intellectual disabilities were typically non-speech users. Teachers indicated that speech using students engaged in cognitive reframing, which was evident based on their use of expressive language. Reframing was also found to include components of blaming others and mislabeling emotions. These findings are aligned with the cognitive reframing literature, pertaining to mild intellectual disability (Hronis et al., 2019).

The response modulation domain had the greatest breadth and quantity of reporting. This is unsurprising, as this is the most researched domain due to its observable nature (Emerson & Einfeld, 2011). The data was consistent with the most common displays of response modulation (i.e., physical aggression, self-harm, property damage, noncompliance, temper "tantrums," repetitive questions, screaming, running away, overactivity, stripping, and smearing feces; Emerson & Einfeld, 2011; Emerson et al., 2001). However, the findings did not map onto other established expressions (i.e., inappropriate sexualized behavior and stealing). The data also revealed that students engaged in response modulation in a variety of ways, including: physiological responses, repetitive behaviors, escape, meditation, medication, meeting sensory needs, and communication.

Overall the findings support the cyclic nature of the process model of emotion regulation (Gross, 2015), within this population. It was confirmed that the use of strategies creates new situations, which perpetuates a new variant cycle of emotion regulation. The data also indicated the boundaries between the domains was blurred, which is consistent with the literature (Gross, 2014), as several data points mapped onto multiple domains and sub-themes. For instance, "routines" and "managing stimulation" were associated with both the "situation selection and modification" domains, "sensory inputs" were related to both "situation modification" and "response modulation," while "location shifts" were supported in both the "response modulation" and "situation selection" domains. These overlapping themes highlight

the importance of context, as behaviors are not uniquely associated with particular domains. Furthermore, the findings also suggest this population uses social dynamics to modify situations, however, this domain is typically limited to physical environmental changes. This suggests the boundaries of the situation modification domain should be further investigated, in order to comprehensively investigate how this population regulates their emotions.

Separate from the domains of the process model, the following themes were identified: "preventative strategies," "prompting," and "limited emotional granularity." The data also suggested that although students could self-regulate, particularly when using escape or avoidance-based strategies, teachers externally regulated student emotions by removing known triggers, accounting for regular emotion regulation maintenance in their classroom schedules, fostering emotion-based communication, and by using prompting. Overall, the relationship between these factors and BOC prevalence should be further investigated in the classroom setting. Particularly as the negative implications of school-based BOC are well documented, specifically, interrupted learning, social isolation, reduced social acceptance and academic achievement, and overall reduced quality of life (Einfeld et al., 2011; Eisenhower et al., 2007; Munir, 2016).

There are several limitations to the current study. Conducting relatively large focus groups is a potential limitation of this study in that this limited in-depth individual contributions. However, this method was used as emotion regulation was well-defined and a dynamic discourse between participants was actively encouraged. The data did not map onto all established response modulation sub-themes, notably "inappropriate sexualized behavior" and "stealing" (Emerson et al., 2001). It should also be noted that students may regulate their emotions differently when in home-based settings. As such, the current data may not be generalizable to non-school based environments and interactions with persons other than schoolteachers. Furthermore, although support was found for the "rumination" sub-theme and "cognitive change" domain for speech using students, this may not be generalized to non-speech using students with intellectual disability, as observations of expressive language were used to determine the relevance of these domains. Additionally, male teacher perspectives were limited in the current research.

At present, substantial gaps in the literature exist in relation to the emotion regulation and dysregulation experiences of children and adolescents with intellectual disabilities. One significant barrier to further research in this area is the lack of emotion regulation measures tailored for school-based settings (Girgis et al., 2021). In order to further this field, future work might focus on developing valid and reliable emotion regulation measures that can be completed by teachers of students with intellectual disabilities. These measures would be able to assess emotion regulation and dysregulation difficulties within school settings that may impact

learning and overall mental health. The findings from this study could be used to inform questionnaire items, with future research to determine if these items are consistent with the domains of the process model. Parent and student perspectives should also be investigated, in order to better understand this populations emotion regulation and dysregulation processing across multiple settings. These perspectives may also assist with item development for parent and student versions of the questionnaire. Attempts should also be made to determine whether the cognitive change domain applies to non-speech using students with intellectual disabilities, with special consideration placed on the method of assessment; for instance, using assistive technology, sign language, or visual aids. Practically, teachers should also be provided with training opportunities which focus on assisting children and adolescents with intellectual disabilities to regulate their emotions. Interventions which align with the process model and use strength-based approaches should also be evaluated for this demographic, for example meditation programs which assist with response modulation.

This study is the first to examine teacher perspectives on the emotion regulation and dysregulation experiences of children and adolescents with intellectual disabilities, through the process model of emotion regulation lens. These findings assist in better understanding the perceptions of teachers on the emotion regulation and dysregulation experiences of their students, and the identified themes and sub-themes can be used to inform questionnaire development which could be used to track treatment progression and further emotion regulation research in this area.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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Appendix

The COnsolidated criteria for REporting Qualitative research Checklist (COREQ; Tong et al., 2007).

No.	Item	Description	Section #
Domain 1: Research team and reflexivity			
Personal characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Method
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	Method
3.	Occupation	What was their occupation at the time of the study?	Method
4.	Gender	Was the researcher male or female?	Method
5.	Experience and training	What experience or training did the researcher have?	Method
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Method
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? *E.g. Personal goals, reasons for doing the research*	Method
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *E.g. Bias, assumptions, reasons and interests in the research topic*	n/a
Domain 2: Study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? *E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Method
Participant selection			
10.	Sampling	How were participants selected? *E.g. purposive, convenience, consecutive, snowball*	Method
11.	Method of approach	How were participants approached? *E.g. face-to-face, telephone, mail, email*	Method
12.	Sample size	How many participants were in the study?	Method
13.	Non-participation	How many people refused to participate or dropped out? What were the reasons for this?	n/a
Setting			
14.	Setting of data collection	Where was the data collected? *E.g. home, clinic, workplace*	Method
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Method
16.	Description of sample	What are the important characteristics of the sample? *E.g. demographic data, date*	Method
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Method
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Method
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Method
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Method
21.	Duration	What was the duration of the interviews or focus group?	Method
22.	Data saturation	Was data saturation discussed?	n/a
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	n/a

Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Method
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Results
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Method
27.	Software	What software, if applicable, was used to manage the data?	Method
28.	Participant checking	Did participants provide feedback on the findings?	n/a
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *E.g. Participant number*	Results
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Results
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Results
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Results

Prelude to Chapter 8 and 9

Educator perspectives on the emotion regulation experiences of children and adolescents with intellectual disabilities were evaluated in Chapter 7 (Girgis et al., 2024). The findings indicated all five process model domains were relevant to this demographic (situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2024). In order to comprehensively investigate the relevance of the process model, the perspectives of additional key stakeholders, including parents, and children and adolescents, need to be gathered. Incorporating these perspectives will fulfill Step 5 of the COSMIN-based patient-reported outcome measure (PROM) development process (Swan et al., 2023; Terwee et al., 2018), as discussed in Chapter 6.

Next, the parent study and child and adolescent study, will need to address the limitations identified in the teacher perspectives study (Study 3). Specifically, the emotion regulation differences between autistic children and adolescents with a co-occurring intellectual disability (A-ID) and children and adolescents only diagnosed with an intellectual disability (O-ID), were not considered. There is value in doing this, given the known co-occurring prevalence of autism in individuals with intellectual disabilities, and the known emotion regulation variations between these two groups (Bakken et al., 2010; Samson et al., 2022).

Between 18% and 35% of children and adolescents with intellectual disabilities have a co-occurring diagnosis of autism spectrum disorder (Dunn et al., 2018; Maenner et al., 2020). Overall, A-ID are more than twice as likely to develop difficulties with emotion regulation, when compared to O-ID (Bakken et al., 2010). This increased susceptibility could be attributed to autistic traits, such as, sensory sensitivity, and inflexible thoughts and behaviours (American Psychiatric Association, 2022; Hollocks et al., 2022; Mazefsky et al.,

2013). Emotion regulation profiles also differ between A-ID and O-ID (Samson et al., 2022).

Specifically, A-ID more often use aggressive and repetitive behaviours, while O-ID more

often use strategies such as humour, focusing on the positive, and communicating concerns

(Samson et al., 2022). Given these profile differences, it is important to ensure the emotion

regulation experiences of A-ID do not overshadow O-ID. For this reason, future parent, and

child and adolescent qualitative studies will differentiate between A-ID and O-ID.

Distinguishing between these two groups remains consistent with the transdiagnostic process,

as all co-occurring diagnoses can be included, while also acknowledging the emotion

regulation differences between A-ID and O-ID (Astle et al., 2022; Chu et al., 2017).

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**Chapter 8. Study 4: How Do Children with Intellectual Disabilities Regulate Their**

Emotions? The Views of Parents

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How do children with intellectual disabilities regulate their emotions? The views of parents

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ABSTRACT

Background: Compared to their typically developing peers, children and adolescents with intellectual disabilities are at an increased risk of developing emotion regulation difficulties, this is especially the case for autistic individuals with intellectual disabilities. To better understand the emotion regulation experiences of children and adolescents with intellectual disabilities, the views of parents were considered through the lens of one of the leading emotion regulation frameworks, the process model of emotion regulation.

Method: Twenty parents participated in semi-structured interviews.

Results: Thematic analysis supported the relevance of the process model to this population; and identified additional themes and sub-themes. Parental perspectives also differed between parents with autistic children with intellectual disabilities, compared to parents whose children were reported to only have a diagnosis of intellectual disability.

Conclusions: These identified themes could guide the development of an emotion regulation measure founded on the process model for this population.

Children and adolescents with intellectual disabilities experience elevated emotion dysregulation compared to their typically developing peers (Munir, 2016). For between 30% and 50% of these children, this dysregulation presents as a co-occurring mental illness (Einfeld et al., 2011), while 48–100% present with behaviours of concern (BOC) in home settings (Grenier-Martin & Rivard, 2022). BOC are often categorised as: property damage, non-compliance, physical aggression, overactivity, self-harm, temper "tantrums," running away, repetitive questions, screaming, sexualised behaviour, stealing, stripping, and smearing faeces (Emerson et al., 2001; Emerson & Einfeld, 2011). For individuals with intellectual disabilities, the occurrence of both co-occurring mental illnesses and BOC are associated with reduced emotional wellbeing, quality of life, future community integration, and employment success (Munir, 2016; Svetlana et al., 2018).

A common co-occurring diagnosis in this population is autism, which is diagnosed in 18–35% of individuals with an intellectual disability (Dunn et al., 2018; Maenner et al., 2020). Of note, a dual diagnosis is related to different mental illness profiles. For instance, autistic individuals with intellectual disabilities (A-ID), are 2.5 times more likely than individuals with only an intellectual disability (O-ID) to experience emotion dysregulation (Bakken et al., 2010). Interestingly, anxiety is thought to occur more often in A-ID, while depression relatively occurs more often in O-ID (Bakken et al., 2010). The heightened prevalence of emotion dysregulation among A-ID is associated with a combination of autistic traits, such as, sensory sensitivity, inflexible behaviours, and rigid thoughts (American Psychiatric Association, 2022). These factors are typically correlated with emotion dysregulation (Hollocks et al., 2022; Mazefsky et al., 2013). Additionally, this increased risk may be exacerbated by the use of maladaptive strategies, such as suppression or avoidance (Mazefsky et al., 2013; Samson et al., 2012). Considering these complexities, we need to employ a well-accepted emotion regulation theoretical framework in order to better understand the emotion regulation experiences of O-ID.

Emotion regulation is comprised of several elements: shaping emotions, timing emotions, and how emotions are expressed or experienced (Gross, 2014). In this

Box 1. Definitions and examples of the five domains of the process model of emotion regulation as based on Gross (2014).

Domain	Definition	Example
Situation selection	An individual first becomes aware of an upcoming situation and the associated emotional reaction. This leads them to either initiate or avoid the situation.	A child avoiding bath time by hiding or a child requesting their birthday presents early.
Situation modification	When a situation has commenced the individual can modify the environment to alter the emotional impact.	Using headphones to help with homework or chores completion.
Attentional deployment	The ability to shift attentional focus. Redirecting attention can be grouped into three categories. *Distraction:* the ability to either redirect attention to non-emotional aspects of a situation or away from the situation entirely. *Concentration:* attention is sustained by the engagement of tasks which occupy finite cognitive abilities. *Rumination:* directs attention to emotions and	Distraction: child averting their eye gaze and focusing on a toy rather than their parents arguing. Concentration: when a child is concentrating on a YouTube video. Rumination: when an adolescent worries about hypothetical threats.
Domain	Definition related consequences.	Example
Cognitive change	The individual evaluates whether an event can be managed within the context of their goals.	Reframing is one strategy, wherein an adolescent engages in self talk about being excited instead of anxious when presenting a class speech.
Response modulation	This domain occurs later in the emotion regulation process and focuses on changing the trajectory of behavioural, experiential, or physiological responses.	When an adolescent is behaving aggressively and then walks around their school to reduce this state.

Note: Reprinted from "A systematic review of emotion regulation measurement in children and adolescents diagnosed with intellectual disabilities" by Girgis et al., 2021, Journal of Intellectual & Developmental Disability, p. 2. Copyright 2020 by Taylor and Francis Group.

sense, emotion regulation is inclusive of adaptive and maladaptive strategies. Additionally, the emotion regulation process can be influenced by numerous factors across the biopsychosocial landscape (Gross, 2014). One of the leading emotion regulation frameworks, the process model of emotion regulation, is particularly suited to conceptualising the emotion regulation experiences of children and adolescents with intellectual disabilities, as the model focuses on expressions of emotion dysregulation, regardless of diagnosis (Gross, 2014). As such, the process model is aligned with the recommended transdiagnostic approach for this population, recommended due to the high prevalence of co-occurring diagnoses (Astle et al., 2022; England-Mason, 2020). The model highlights five cyclic emotion regulation opportunities: situation selection, situation modification, attentional deployment, cognitive change, and response modulation (Gross, 2014); see definitions in Box 1. In essence, when an individual becomes aware of a situation and the associated emotional valence, they may either seek out or avoid the situation (i.e., situation selection). When a situation occurs, the individual may also modify the physical environment to regulate their emotions (i.e., situation modification), as well as shift their attention to facilitate regulation (i.e., attentional deployment). The individual may then modify their appraisal of a situation to manage the emotional impact (i.e., cognitive change). After an emotional response has been activated, the individual may attempt to alter the associated experiential, behavioural and physiological response (i.e., response modulation). The activation of these emotion regulation domains then alters the original situation, thus creating a new situation and

propagating the emotion regulation process (Gross, 2015). Although the process model is one of the leading emotion regulation paradigms (Gross, 2014), the framework has only sparsely been applied to children and adolescents with intellectual disabilities (Girgis et al., 2024).

One attempt has been made to better understand the emotion regulation experiences of children and adolescents with intellectual disabilities within the context of the process model. Teacher perspectives from schools for students with intellectual disabilities were considered using focus groups, and the findings indicated the process model was applicable to children and adolescents with intellectual disabilities. Various adaptive and maladaptive emotion regulation strategies used by this population were also identified, for example, sensory supports, meditation, self-harm, and aggression. However, differences between autistic and non-autistic children and adolescents with intellectual disabilities were not considered, nor were home settings or parental perspectives. As such, further confirmation is needed as to whether the process model generalises to both these populations and are applicable in these broader contexts. This can be achieved through the input of key observers, such as parents.

This study aimed to build on teacher viewpoints of emotion regulation through the lens of the process model of emotion regulation (Girgis et al., 2024), by examining parental perspectives on the emotion regulation and dysregulation experiences of children and adolescents with intellectual disabilities. This will serve to further clarify the emotion regulation experiences of children and adolescents with intellectual disabilities,

consistent with best practice standards which promote multi-informant perspectives on childhood difficulties (De Los Reyes et al., 2015). Given the prevalence of autism in this population, it follows that co-occurring autism should also be considered. The study used a qualitative approach as an initial step to evaluate the suitability of the process model for children and adolescents with intellectual disabilities.

Method

Participants

Parents with children with intellectual disabilities, were recruited from social media groups, specific purpose schools, and specialist service providers. Twenty parents representing 19 children and adolescents with intellectual disabilities participated in this study. An intellectual disability diagnosis was confirmed either via the provision of a psychological report, specialist funding approval from the Australian National Disability Insurance Scheme (NDIS), or the child's attendance at a purpose-built school (a school specifically catering for students with intellectual disabilities). Intellectual disability severity was determined via the provision of a psychological report, or disclosure from either the parent or school. Communication type was determined on the basis of parental disclosure. The children and adolescents of participating parents had mild to severe intellectual disabilities, and several had co-occurring diagnoses. On the basis of psychological and parent reports, six of the children and adolescents had a diagnosis of autism, while a further six met the threshold for autism via the Developmental Behaviour Checklist-Autism Screening Algorithm (DBC-ASA; Brereton et al., 2002).

Ethics approval was granted for this study by the *University of Technology Sydney* Human Research *Ethics* Committee (approval number: ETH16-0925).

Measures

Developmental behaviour checklist-autism screening algorithm (DBC-ASA)

The DBC-ASA (Brereton et al., 2002) is a 29-item measure that screens for autism spectrum disorder in children and adolescents with intellectual disabilities and has good sensitivity 0.86 (95% CI 0.80–0.91), specificity 0.69 (95% CI 0.62–0.76), and internal consistency ($\alpha = .94$). The DBC-ASA was completed by parents to screen for autism, and the recommended score of ≥ 17 was used as the threshold. In total, 12 of the 19 children and adolescents either had a reported diagnosis of autism or were above threshold for autism on the DBC-ASA (Brereton et al., 2002).

The COnsolidated criteria for REporting Qualitative research Checklist (COREQ; Tong et al., 2007) was used to assess the procedure, see Appendix.

Procedure

Individual phone interviews were completed by the lead author, a female clinical psychologist and PhD candidate. The interviews were approximately one hour and occurred once per parent participant; one interview included both parents. Interviews were semi-structured. Participants were first asked about their child's emotion regulation and dysregulation experiences and any known triggers or uses of adaptive/maladaptive strategies across the home setting. Likewise, participants were then asked if their child experienced emotion regulation or dysregulation experiences within the context of the process model domains, with each domain being explored independently and in order (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014). Interviews were recorded and transcribed by a transcription service provider, and field notes were taken during and after the interviews. Participants were compensated for participation with an AUD\$20 ($\approx$USD \$13.00) gift card.

Data analysis

NVivo 12, a qualitative analysis software (QSR International Pty Ltd, 2019) was used to organise transcripts to aide with the thematic analysis process. Field notes were also consulted during the analysis. The analysis was directed by Braun and Clarke's (2006) guide and used a reflexive deductive approach as the data was considered through the process model of emotion regulation (Gross, 2014). The analysis consisted of forming initial thoughts after reading the transcripts several times. These thoughts were organised into several codes associated with the five process model domains (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014). Unconnected reoccurring codes were also noted. These codes were consolidated into preliminary sub-themes and themes, and cross-verified against the transcripts. The sub-themes and themes were then clarified, named, and definitions were established. Finally, quotes were selected to represent the themes in a consolidated report.

As only one coder is recommended by Braun and Clarke (2006) only the lead author (MG) completed

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the thematic analysis. The second (JP) and third (IK) authors reviewed the identified themes and sub-themes, offered insights, and further refined the consolidated report. Reliability checks are not recommended as Braun and Clarke (2006) state the purpose of the analysis is to thoughtfully engage with the data and synthesise themes guided by theoretical frameworks, rather than to seek consensus. Consistent with this underpinning, prior disability research has explored perspectives using a single coder (Lester, 2014; Maciejewska, 2020).

Results

Demographic data

Demographic information of parents and their children was collected, specifically: age, identified gender, ethnicity of the parent and their child, parental employment and marital status, total number of children in the family, the child's intellectual disability diagnosis and severity, co-occurring diagnoses, and communication type (see Table 1).

Table 1. Demographic data of parents and their children.

Demographics	
Parents	N = 20
Age	42.77 (6.35)
Gender (F:M)	15:5
Ethnicity	Caucasian (10)
	Aboriginal and/or Torres Strait Islander (2)
	Asian (3)
	South African (1)
Employed	N = 11
Marital status	Married (13)
	De facto (1)
	Single (5)
	Widowed (1)
Total children in family	2.6 (1.12)
Children and adolescents	N = 19
Age	13.26 (4.28)
Age range	6–21
Demographics	
Identified gender (F:M)	11:8
Diagnosis	Intellectual disability (14)
	Global developmental delay (2)
	Downs Syndrome (3)
Severity of intellectual disability	Mild (7)
	Mild-Moderate (2)
	Moderate (7)
	Severe (3)
Co-occurring diagnoses*	Autism (12; N = 6 based on parental/psychological reports, N = 6 based on DBC-ASA threshold)
	Anxiety (2)
	Oppositional defiant disorder (2)
	Attention-deficit/hyperactivity disorder (2)
	Epilepsy (1)
	Obsessive compulsive disorder (1)
	Communication disorder (1)
	Cerebral palsy (1)
Communication type	Speech-based communication (18)
	Non-speech using (1)

Note. *Several children and adolescents had multiple co-occurring conditions.

Table 2. Themes and sub-themes.

Themes	Sub-themes
Situation selection	Managing stimulation
	Location shifts
	Selection acceleration and deceleration
	Selection inflexibility
	Selection incapable
Situation modification	Incorporating or removing sensory elements
	Security within connection
Attentional deployment	Distraction
	Concentration
	Rumination
	Worry
Cognitive change	Cognitive distortions
	Cognitive restructuring
	Prompting cognitive change in others
Response modulation	Self-harm
	Aggressive behaviours
	Non-compliance
	Physiological responses
	Repetitive behaviours
	Escape
	Expressive suppression
	Meditation
	Medication
	Meeting sensory needs
	Communication
Limited emotional granularity	
Limited metacognition	
External emotion regulation	External situation selection
	External situation modification
	External attentional deployment
	External cognitive change
	External response modulation

Findings indicated the five domains of the process model were relevant for children and adolescents with intellectual disabilities (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014). Further analysis also identified additional themes and sub-themes, see Table 2. Relevant participant demographics were paired with example quotes and are displayed in the following order: mother/father, child's age, child's gender, severity of intellectual disability, and whether the child was deemed to have a dual diagnosis of autism and intellectual disability (i.e., A-ID) or only a diagnosis of intellectual disability (i.e., O-ID). For example, in the case of a mother reporting about their 14 year old male autistic child with a moderate intellectual disability, this would be indicated by: mother, 14, male, moderate ID, A-ID. Whereas if that child was reported to have a diagnosis of intellectual disability only, this would be indicated by: mother, 14, male, moderate ID, O-ID.

Situation selection

Parental descriptions were consistent with this domain, as the children and adolescents were described as

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selecting situations by either seeking out or avoiding environments or interactions to self-regulate. The following sub-themes were also identified: managing sensory stimulation, location shifts, selection acceleration and deceleration, selection inflexibility, and selection incapable.

Managing stimulation
Parents reported their children indicated preferences for and sought out the following situations: TV, games, sensory items, gifts, activities, pets, trampoline, water-based activities like swimming or bathing, iPad, slime, help from family, and social connection (i.e., they sought out friends and family). Time outs were sought, "Well, more recently we've had a few issues with situations arising, and so him having to learn [strategies]. So, one of them is, he can ask for time out" (mother, 14, male, moderate, A-ID). Situations were prevented or circumvented via avoidance, escape, absconding, and withdrawing into bedrooms or other quiet areas. The data indicates an overlap between avoiding new situations and simultaneously seeking out pleasant or preferred situations. The self-management of sensory stimulation was emphasised with speech-based requests, arguments, refusal to leave the room, physically blocking access, ignoring, and/or speech-based aggression.

Location shifts
Location shifts were reported within the context of managing overstimulation, such as moving to another area, " … sometimes he goes and sits on the toilet and plays games" (mother, male, 12, mild/moderate, O-ID). Likewise, withdrawing and walking or running away, were used to avoid the arrival of situations. At times, these location shifts were enforced via hiding under blankets, placing barriers, and requesting others to leave.

Selection acceleration and deceleration
Parental reports indicated the arrival of new situations could be sped up, by seeking out gifts early (i.e., birthday or Christmas present), waiting in the car ahead of the family, or waiting by the front door. Similarly, tasks could also be sped up to finish the situation sooner, "She will come home and start a project or homework … she wanted [it] over, and once it's done, it's done" (mother, 11, female, mild, O-ID). Alternatively, the arrival of new situations could also be slowed down with excuses, negotiations, requests, or dawdling, "She's taking [her] time [doing chores]" (father, 16, female, mild, O-ID).

Selection inflexibility
Difficulties transitioning to new situations were also reported within the situation selection domain, particularly if a required sequence or task needed to be completed, "changing schedule is a big thing" (mother, 12, male, mild, A-ID).

Selection incapable
Parental reports suggested their children were at times unable to select situations "I think that's more of a danger type phase … [I tell him to] 'move, move, move' or something and he'll just freeze and look at me … he doesn't know what to do" (mother, 14, male, moderate, A-ID). At times their children could not direct situation selection due to minimal curiosity regarding their environments "When she's overwhelmed, she'll withdrawal … and just kind of sit there and be … a passive observer" (mother, 6, female, mild/moderate, O-ID).

Situation modification
Parental descriptions were aligned with this domain, as their children were able to modify situations with environmental adjustments. Two sub-themes were also identified, incorporating or removing sensory elements, and security within connection.

Incorporating or removing sensory elements
Environmental situation modifications were made by adding or removing sensory stimuli. The following situation modifications were described: phones, headphones, holding favourite toys or items, repetitive movements, listening to music, eating, sensory items and activities, wandering or pacing, holding onto pets or parents, and using iPads, "We find the iPad, is like a security blanket, he's safe. Not just safe, he can cope within, when he's got that, when he's in his safe zone and … [in] control" (mother, 7, male, severe, A-ID). Likewise, children and adolescents were reported to reduce sensory input by covering their face or eyes, closing their eyes, using noise cancelling headphones, whispering, refusal to move locations or to communicate via speech, avoiding triggers, sitting under blankets, staying in the bathroom, ignoring others, removing soiled clothing, and hiding items. They also covered the eyes, ears, and mouths of their parents. The children and adolescents also engaged in self-directed rules, which included, sitting in the same seat in the car, sleeping with a preferred item, engaging in a set sequence of sensory play, organising and lining up items, encouraging others to follow rules (i.e., knocking before entering their bedroom), and moving around furniture.

As seen in the situation selection domain, children and adolescents also modified situations via managing sensory elements through the incorporation of routine, location shifts, and by accelerating or decelerating situations.

Security within connection

Situation modification was also described as attempts to feel safe via social connection. This was evidenced by seeking physical proximity to their parents when distressed, which also included, holding their parent's hand, and following them or other familiar individuals, "For instance, he's really scared of the stair escalator … he refuses to go up and down it unless I'm either behind him or in front of him and he's holding on to me" (mother, male, 12, mild/moderate, O-ID).

Attentional deployment

Parental accounts were compatible with the attentional deployment domain. Four sub-themes were identified: distraction, concentration, rumination, and worry.

Distraction

Parental reports indicated attentional deployment was in part expressed as distraction via the following: sensory items, daydreams, special interests, using an iPad, phone or computer, live streaming, gaming, interacting with pets, listening to music or the radio, eating, singing, watching YouTube, reading books, playing with toys, colouring in, crafting, cooking, dancing, and gardening. Parents also externally prompted these interests. They also ignored others and would avert their eye gaze, particularly when others were arguing. The children and adolescents could also be easily distracted, and easily forgot about distressing events; while others were unable to be distracted.

Concentration

Parental accounts suggested concentration was one manifestation of attentional deployment, which was expressed as directed eye gaze, repetitive questions, and focused engagement. Parents reported distractions could progress into sustained concentration, particularly if related to a specific interest. However, this level of concentration could lead to transition difficulties, "… you can wave your hand in front of him, and you've got to really get him back [when using the iPad]" (mother, 13, male, moderate, A-ID). Along this line, some distractors were used as a mode of escapism. Additionally, concentration occurred in the presence of confrontation (i.e., argument with parent) or when

exposed to danger (i.e., seeing a snake). Medication was also reported to be used to aide concentration.

Rumination

Parental reports indicated rumination was one expression of attentional deployment. Rumination was based on past distressing events and was related to cognitive rigidity "he just could not let it go" (mother, 14, male, moderate, A-ID). Speech-based rumination content included: changes in routine, fear of animals, fear of change, interactions with peers, being told no, social pressures, past grievances with others, and the health of their family and friends. Ruminations could also be expressed as repetitive circular conversations and could be triggered by incorrect recall. Parents did acknowledge difficulties discerning their child's ruminations due to limited expressive language.

Worry

Parental accounts indicated worry regarding future concerns was one representation of attentional deployment. Common topics included: changes in routines, exposure to new places, attending school camps, being taken away from their family, the health of family members, and death, " … he'll ask questions [about] death, thinking it's going to happen to him" (mother, male, 12, mild/moderate, O-ID).

Cognitive change

Parental descriptions were congruent with this domain. However, as this is a domain with limited behavioural representations, this was primarily assessed via speech-based expressions, although the use of assistive technology was also considered for non-speech users. Parents also reported limited insights into their child's cognitions, further impacting the evaluation of this domain. Overall, the following sub-themes were identified: cognitive distortions, cognitive restructuring, and prompting cognitive change in others.

Cognitive distortions

Parental reports indicated the cognitive change domain could be expressed as the following cognitive distortions:

- **Labelling.** They label themselves and others " … She'll call [herself] stupid" (mother, 21, female, mild, A-ID).
- **Mental filter, selective abstraction.** Focus was placed on the negative aspects of events " … she did bring up the negatives" (father, 9, female, severe, A-ID).

- **Dichotomous, black and white thinking.** Cognitions were "very black and white" (father, 16, male, mild, A-ID), and they responded to grievances with extreme options, "... [he would say] 'People just treating me so poorly ... just feel like bashing them'" (mother, male, 12, mild/moderate, O-ID).
- **Overgeneralisation.** Beliefs were generalised, "... everyone's stupid" (father, 16, male, mild, A-ID).
- **Catastrophising.** Focus was placed on the worst outcome, "... he'll catastrophise every situation, he'll blow it completely out of proportion" (mother, 12, male, mild, A-ID).
- **Emotional reasoning.** Negative self-beliefs were treated as fact, "... she started questioning herself. Like ... 'I'm very rude ... I'm not good'" (mother, 13 female, moderate, A-ID). This distortion could also be expressed without speech, "... he [thinks he's] naughty, so he'll go to ... the word naughty [on his communication device] and [I say] you're not naughty, you're just not making good choices ... " (mother, 14, male, moderate, A-ID).
- **Personalisation and blame.** Blame was unnecessarily directed towards themselves and others, "... sometimes it's not [her] fault, but I don't know what comes in her mind and she thinks that it's her fault" (mother, 13 female, moderate, A-ID).

Cognitive restructuring

According to parental reports, the cognitive change domain could manifest as cognitive restructuring. However, this skill was described as diminished when the child/adolescent was dysregulated. At such times external support was required alongside time to deescalate, "... if he calms down and wants to say something he'll say, 'I'm sorry, I'm ready to talk to you'" (mother, male, 12, mild/moderate, O-ID). The following cognitive restructuring sub-themes were evident:

- **Positive affirmations or mantras.** Common repetitive phrasings were used when distressed, "I'm better now," "don't worry, I'm fine," "I'm ready now," and using "I'm not scared" when encouraging themselves. This was also reflected without speech via a thumbs up.
- **Generate alternative.** Alternatives were considered when distressed, "She starts saying ... 'I will act according to that person and try to be his friend, because he says that you are not a good girl. God is not happy. So, I try my best to show that no, God is happy for me'" (mother, 13 female, moderate, A-ID).

- **Reframing.** Interpersonal difficulties with friends could be reframed, "She said '[he] is angry [with] me ... I'm going to throw [his] bag in the garbage now.' And ... after ... she said, 'no, he's my best friend. And ... I am not good. He's a good boy'" (mother, 13 female, moderate, A-ID).
- **Perspective taking.** Some children were reported to comprehend others distress and offer solutions, "He will tend to ask if you're okay, he will sometimes offer a hug" (mother, 14, male, moderate, A-ID).
- **Problem solving.** They engaged in negotiation and select solutions, particularly requesting help, "If he's very frustrated or angry he'll come sit by me and say, 'Mum, I don't like this'" (mother, male, 12, mild/moderate, O-ID). Additionally, they could also offer aide, "... when her sister's upset, she'll [get] ... her a water ... doll ... cuddle" (mother, 6, female, mild/moderate, O-ID).
- **Asking questions/seeking clarification.** They asked questions and sought clarification, particularly to clarify social situations and dynamics, "He'll usually ask 'what's going on' ... 'what are you talking about'" (mother, 12, male, mild, A-ID).
- **Positivity reorientation.** They used a positive lens, "If ... he feels ... he's being reprimanded ... [he'll] try to change the subject, try to point out something good he's done instead" (mother, 14, male, moderate, A-ID). Alternatively, another strategy was augmenting the story to have a better outcome.

Prompting cognitive change in others

The children and adolescents assisted others with cognitive change via problem solving, offering help, and reframing events, "... if I'm really upset, [he'll say] 'It's okay Mum, let's try something else,' or, 'Don't worry about it, it's alright'" (mother, male, 12, mild/moderate, O-ID).

Response modulation

Parental disclosures were aligned with the response modulation domain. This domain was associated with observable behaviours. The following sub-themes were also identified: self-harm, aggressive behaviours, noncompliance, physiological responses, repetitive behaviours, escape, expressive suppression, meditation, medication, meeting sensory needs, and communication.

Self-harm

Response modulation was expressed as the following self-harm behaviours when distressed: biting, scratching, pinching, head banging, punching head, pulling

hair, squeezing limbs, hitting self with objects, cutting self, and hitting their body. Self-harming behaviours could progress to significant injury, and threats of self-harm were also reported. Self-harm could also occur within the context of excitement, "head banging that's actually used as an excitement thing, when he's very, very excited. When he's going to bed. He'll head butt his pillow" (mother, 7, male, severe, A-ID).

Aggressive behaviours

Response modulation also manifested as aggressive behaviours. Parents reported aggressive behaviours were accompanied by vocalisations and were expressed as physical and verbal/speech-based aggression, such as: yelling, screaming, swearing, threats, arguing, shouting, slamming doors, stomping feet, and refusal to move. When the aggression was directed towards others, the behaviour included: spitting, kicking, punching, shoving, pushing, fighting, grabbing, pinching, and hitting. Property damage occurred by way of breaking doors and windows, and throwing items, which could escalate to police involvement.

Non-compliance

Response modulation included non-compliance, which was described as refusals, laying on the floor and refusing to move, as well as barring entry to their room, "[she] … sits [behind] the door and you can't get in the room" (mother, 18, female, moderate, A-ID).

Physiological responses

Response modulation manifested as physiological responses including: crying, clenching hands, tense body, "Not breathing properly," hyperactive, restless, clenching fist, fidgeting, squirming, and "stimming." Parents also broadly described "meltdowns" and "tantrums." Parents also indicated a "freeze" or "shut down" response during distressing events, which was accompanied by a "quiet voice," and congruent facial expressions. Overexcitement was also related to increased psychomotor movement "bouncing on the spot" and pressured speech.

Repetitive behaviours

Response modulation included the following repetitive behaviours: saying phrases from movies, questions, storytelling, watching movies, organising items, and movements such as running, and vocalisations.

Escape

Response modulation was expressed as escape via playing video games, walking away, removing oneself from situations, running away, going to another room, absconding, withdrawing, and leaving a room, " … it happens at school a bit … he will just get up and leave the classroom if there's a situation that he's not comfortable with" (father, 16, male, mild, A-ID).

Expressive suppression

Parental reports indicated response modulation encapsulated expressive suppression. This was expressed as hiding positive and negative emotions, denying emotions, and reporting distress due to an unrelated event. Suppression was also used to facilitate social connection, " … when she's trying to … please others [she'll] say, 'I'm not angry'" (father, 13 female, moderate, A-ID).

Meditation

Meditative practices were used to regulate emotion within the response modulation domain, such as counting to 10, yoga, visualisation, and deep breathing, though usually these required prompting. However, for some, mentioning meditation could lead to escalation, " … if they're suggested, he gets quite aggressive" (mother, 12, male, mild, A-ID).

Medication

Medication was used to assist with heightened states and reducing baselines within the response modulation domain, " … it still depends on what point his regulation is under control. So, on the dextroamphetamine, the regulation is a lot more and he's a lot more regular and there's not so many extremes" (mother, 7, male, severe, A-ID).

Meeting sensory needs

Parents reported sensory elements were used to manage distress within the response modulation domain, such as, surrounding oneself with favourite items, listening to music, looking at favourite images, jumping on the trampoline, arts and crafts, bouncing, accessing a sensory box, squishing and squeezing sensory items, swinging rope, taking a preferred toy with them, watching TV, playing with toys or video games, riding a bike, petting animals, engaging in vocalisations, running, walking, pacing, massages, sensory brush, using weight or pressure, and watching items move back and forth. Sensory stimulation was also managed by removing stimuli such as noise, asking for time out, going to sleep, walking away, and going to their room. Parents would also give their child personal space, " … you just move everyone and everything away from him and don't engage, absolutely no eye contact and just wait for him to calm down" (mother, 12, male, mild, A-ID).

Communication

Parents encouraged their children to communicate their emotions when distressed (i.e., within the response modulation domain). Communication was either via speech or assistive technology, " … with the App [communication device] … it's [got] visuals … so it can really help him to calm down. I mean it takes a while, but it does work" (mother, 14, male, moderate, A-ID). However, communication for some was made difficult by expressive language difficulties.

Additional themes

Three additional themes distinct from the process model domains were identified: limited emotional granularity, limited metacognition, and external emotion regulation.

Limited emotional granularity

Parents reported emotion identification was limited; this skill was further compromised when the children and adolescents were distressed. Additionally, the breadth of emotional descriptors was limited to: sad, happy, frustrated, annoyed, good, pissed off, excited, awesome, unreal, down, unhappy, not very happy, mad, upset, hopeless, nervous, sick, afraid, naughty, tired, cranky, silly, love, hate, bad mood, jealous, moody, worried, overwhelmed, and "shitty." Parents reported that they were unsure if their children understood the emotional descriptors or if they were copying others, " … it's very rare that he would actually say the word without [you] saying it first" (mother, 7, male, severe, A-ID). Emotions were also mislabelled, for instance, " … [she would say] 'I hate them' … so we just figured that [it was] her way of saying I miss him … because her brother, he lives with us, but he works … and he's not here [at home]" (mother, 7, male, severe, A-ID). Parents assisted their children by providing visual aids, language suggestions, and extra time. Although some expressive language difficulties could not be overcome, "she doesn't have the … vocabulary to really hone in on if you wanted to get too specific" (mother, 21, female, mild, A-ID).

Limited metacognition

Metacognition pertains to cognitive insight, which influences the ability to use cognitive change. Insight was demonstrated via speech-based disclosures to parents, siblings, and toys, or via self-talk. Insight was also aided by assistive technology. Parents observed metacognitive ability at four levels:

1. Limited awareness of current emotional status and duration, "she'll say to me, 'I had a bad day today mum. I'm upset now, or I've been upset all day'" (mother, 11, female, mild, O-ID).
2. Less nuanced expressions, "me not very happy about that … me don't like it, me don't like it" (father, 9, female, severe, A-ID).
3. Difficulty expressing cognitions, "I think he doesn't tell anyone there's something wrong because he doesn't know how to express that" (mother, 14, male, moderate, A-ID).
4. General unawareness of cognitions, " … he's not aware of them" (mother, 13, male, moderate, A-ID).

External emotion regulation

Parents reported they assisted their children to regulate their emotions across all emotion regulation domains:

- **External situation selection.** Parents facilitated situation selection by removing or avoiding triggers and managing sensory stimulation by either offering distractions, redirecting their child to move into a quiet space or removing themselves to form a quiet space. Alternatively, they also enticed their children to return to family settings with preferred items, encouraged their child to join activities, and provided reassurance around selected situations, " … if we reassure [her] about things or that something's okay … she'll believe us and then do it" (father, 19, female, mild, O-ID).
- **External situation modification.** Parents provided aide during difficult situations via the following: engaging in redirection, negotiation, prompting quiet time or location shifts, enticing their children back with the use of their favourite TV programs, providing mediation between their children and others, and assisting with transitions by using well-timed reminders regarding upcoming events. Parents also provided sensory items or removed sensory elements during difficult situations, "Generally no eye contact, not touching him and giving him space and just moving everybody away from him" (mother, 12, male, mild, A-ID).
- **External attentional deployment.** Parents utilised distractions and redirection, particularly: iPads, sensory items, food, snacks, water, music, massages, and engaged in singing, humour and/or play. Distractions could be quickly cycled through, " … just quick engagement … like blowing bubbles real quick … and we move on to the next thing" (mother, 6, female, mild/moderate, O-ID). Dependent on the child's interest, concentration could occur once

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redirected. Regarding rumination and worry, parents encouraged flexibility by explaining the reasoning behind routine changes, as well as providing general reassurance, and discouraged repetitive thinking, " … we know you're sad, but we can't keep going back to that" (mother, 21, female, mild, A-ID). These strategies also overlapped with the cognitive change domain.

- **External cognitive change.** Parents offered reassurances, reframed situations, used positivity, encouraged problem solving, perspective taking and reflection, and normalised and validated experiences, "it's okay to feel like that. It sucks that you feel like that" (mother, 21, female, mild, A-ID). Parents also discouraged blaming others.
- **External response modulation.** The assistance provided by parents overlaps with the above domains. Parents managed sensory stimulation, provided reassurance, encouraged meditative practices, removed triggers, and facilitated access to medication.

Variations between parental perspectives

It was apparent parental perspectives varied depending on whether their child had a dual diagnosis of autism and intellectual disability (A-ID) or if their child was only diagnosed with an intellectual disability (O-ID). Parents with A-ID children tended to provide examples relating to location shifts, rumination, concentration, selection inflexibility, cognitive distortions, self-harm, aggressive behaviours, medication, expressive suppression, escape, limited emotional granularity, and all external regulation sub-themes; particularly, external situation selection and modification. Parents with children with O-ID more often reported security within connection, cognitive restructuring, promoting cognitive change in others, and worry. All other subthemes were reported relatively equally by both parent groups. Extensive comparisons could not be completed due to the qualitative nature of this study and the limited sample size.

Discussion

This research is the first we know of to investigate the views of parents on the emotion regulation experiences of children and adolescents with intellectual disabilities, through the process model of emotion regulation (Gross, 2014). The findings indicated the five domains of the process model were applicable to this population (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation).

The additional themes of limited emotional granularity, limited metacognition, and external emotion regulation, were also identified. Moreover, some variation between reported emotion regulation and dysregulation was noted between parents with A-ID children and parents with children with O-ID.

Parents reported their children used situation selection to regulate their emotions, as demonstrated through the sub-themes of "managing stimulation," "location shifts," and "selection acceleration and deceleration." The "managing stimulation" sub-theme was endorsed by all participants, the utility of this strategy is unsurprising considering adverse sensory stimulation impacts emotion regulation strategies (Mazefsky et al., 2013). Although this strategy supported emotion regulation, it included maladaptive avoidance, which is a commonly used coping strategy among this population and known to moderate levels of anxiety (Dekker & Koot, 2003; Rudaz et al., 2017). In addition, expressions of situation selection were also demonstrated through the sub-themes: "selection inflexibility," and "selection incapable." Parental reports also suggest the situation selection sub-themes overlap with the situation modification domain, with modification in this population presenting as "incorporating or removing sensory elements" and "security within connection."

Based on parental reports, the attentional deployment domain was relevant to this population. The "distraction" and "concentration" sub-themes overlapped, as distraction could lead to concentration when children and adolescents were engaged in a preferred activity. Parents also indicated concentration difficulties, this is known to occur at an increased rate when comparing children with and without intellectual disabilities (Neece et al., 2011). Parents also supported the "worry" and "rumination" sub-themes; typically, worry is associated with anxiety based disorders, while rumination is associated with depression (Watkins et al., 2005).

The cognitive change domain appeared to be relevant for this population, however, as with the "rumination" sub-theme, the evaluation of this domain was reliant on speech-based expressions. Although, the use of communication devices offered additional insight. The data overlapped with the pre-established categories of "cognitive distortion" and "cognitive restructuring" (Hofmann, 2013; Yurica & DiTomasso, 2005). The "rumination" and "worry" sub-themes also overlapped with this domain.

The response modulation domain yielded the greatest breadth of information, due to the associated externalising expressions. The data overlapped with several of the categories of BOC (i.e., property damage, non-

compliance, physical aggression, overactivity, self-harm, temper "tantrums," running away, repetitive questions, and screaming; (Emerson et al., 2001; Emerson & Einfeld, 2011)). However, the BOC categories of sexualised behaviour, stealing, stripping, and smearing faeces were not reported by parents. This could be due to the current sample predominately ranging between the mild-moderate severity range, as BOC are typically expressed more often by individuals with severe and profound intellectual disabilities (Emerson & Einfeld, 2011). Additional sub-themes were also identified: "physiological responses," "escape," "repetitive behaviours," "medication," "meditation," "meeting sensory needs," "expressive suppression," and "communication."

Parental perspectives varied between parents with A-ID children, and parents with children with O-ID. Namely, parents with A-ID children more often provided examples in relation to "selection inflexibility," which aligns with the autism diagnostic sub-criteria of restrictive and repetitive behaviour patterns (American Psychiatric Association, 2022). Likewise, examples typically focused on "incorporating or removing sensory elements," over "security within connection." Whilst anxiety is typically more prevalent in the A-ID population, and depression occurs relatively more often in the O-ID population (Bakken et al., 2010); an inverse trend was reported, as parents with A-ID children provided examples of rumination more often, while parents with children with O-ID more often provided examples of worry. This inverse trend could be due to the internal nature of rumination and worry, and the associated observational difficulties. Additionally, parents with A-ID children often provided examples of cognitive distortions. This is unsurprising as cognitive inflexibility tends to predict emotion dysregulation in this population (Hollocks et al., 2022). Conversely, parents with children with O-ID frequently provided examples of cognitive restructuring. This may act as a protective strategy against distortions and associated mental illnesses, as seen in neurotypical children and adolescents (Oud et al., 2019). This protective coping mechanism may also contribute to the relatively lower mental illness prevalence of children and adolescents with O-ID, when compared to A-ID (Bakken et al., 2010). Further trends included higher reports of non-compliance from parents with children with O-ID, while parents with A-ID children more often reported meeting sensory needs, escape, meditation, medication, self-harm, aggressive behaviours, and expressive suppression. However, perceived expressive suppression could be due to intersubjective misunderstanding, as neurotypical individuals can struggle to understand autistics (Mitchell et al., 2021). Overall, the findings supported the

suitability of the process model as an emotion regulation framework for this population, and identified differences in parental perspectives between parents with A-ID children and parents with children with O-ID.

In addition to the general support of the applicability of the process model to children and adolescents with intellectual disabilities, the findings also supported the cyclic nature of the process model (Gross, 2015), as several themes and sub-themes overlapped. Primarily, the use of emotion regulation strategies across the five domains of the process model (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014), resulted in the formation of new situations and subsequent emotion regulation strategies. The five domains of the process model also overlapped. Specifically, the situation selection and situation modification domains overlapped, while attentional deployment primarily overlapped with cognitive change, and response modulation-based strategies propagated new situations. Additionally, the findings transcended the definition of situation modification, which is defined as "modifying external, physical environments" (Gross, 2014, p. 10). The results indicated this population modifies situations via social connection, in addition to external modifications; which was consistent with teacher perspectives (Girgis et al., 2024). In order to comprehensively reflect this population's emotion regulation processing, it is recommended the parameters of the situation modification domain be further investigated.

Outside of the process model, three additional themes were identified, limited emotional granularity, limited metacognition, and external emotion regulation. Overall, parents with autistic children provided more external attempts of emotion regulation support. This could be attributed to A-ID children and adolescents typically having a higher prevalence of emotion regulation difficulties (Bakken et al., 2010), thus requiring parents to provide increased support. The greatest support disparity was found within the situation selection and situation modification domains, which may reflect the sensory sensitivity of this population (American Psychiatric Association, 2022).

This study had four primary limitations. The interviews predominantly captured the maternal perspective, and agreement between parents was not determined. The cognitive change domain, and "rumination" and "worry" sub-themes were primarily evaluated using examples of speech-based communication. This limits insights into the emotion regulation processing of the non-speaking population. Although this study included one non-speech using participant, the findings require replication to evaluate this populations emotion

regulation experiences. A further limitation was the composition of the A-ID group, as only a portion were formally diagnosed with autism, whilst the rest were above threshold on the DBC-ASA and did not have a formal diagnosis. Whilst trends in parental perspective were observed between parents with A-ID children and parents with children with O-ID, these groups could have differed in other aspects, necessitating the need for further comprehensive evaluation. Lastly, the perspectives of children and adolescents with an intellectual disability remains unknown, and it is unclear if their perspectives would align with their parents.

Conclusion

To our knowledge, this research is the first we know of to investigate the views of parents on the emotion regulation experiences of children and adolescents with intellectual disabilities, through the process model framework (Gross, 2014). Overall, the findings indicate the process model is applicable to this population, however, the definition parameters of the situation modification domain require further investigation to comprehensively capture the emotion regulation experiences of children and adolescents with intellectual disabilities. Moving forward, focus should be placed on assessing the perspectives of children and adolescents with intellectual disabilities on their emotion regulation experiences. Effort should also be made to include children and adolescents that do not use speech and use communication devices. These findings should be compared with the parental perspectives acquired here, and those of educators in previous research (Girgis et al., 2024). Overarching themes could be used to develop an emotion regulation measure – inclusive of a self-report, parent, and teacher version – a much needed resource for this population (Girgis et al., 2021). The findings could also guide the development of strength-based therapies, as autistic and non-autistic children and adolescents with intellectual disabilities may need differing treatment bases, specifically the incorporation of sensory elements for autistics. This study highlights the applicability of the process model of emotion regulation to children and adolescents with intellectual disabilities, and has the potential to inform further emotion regulation research, notably the development of an emotion regulation measure.

Acknowledgements

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Appendix

The COnsolidated criteria for REporting Qualitative research Checklist (COREQ; Tong et al., 2007).

No.	Item	Description	Section #
Domain 1: Research team and reflexivity			
Personal characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Method
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	Method
3.	Occupation	What was their occupation at the time of the study?	Method
4.	Gender	Was the researcher male or female?	Method
5.	Experience and training	What experience or training did the researcher have?	Method
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Method
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? *E.g. Personal goals, reasons for oing the research*	Method
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *E.g. Bias, assumptions, reasons and interests in the research topic*	n/a
Domain 2: Study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? *E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Method
Participant selection			
10.	Sampling	How were participants selected? *E.g. purposive, convenience, consecutive, snowball*	Method
11.	Method of approach	How were participants approached? *E.g. face-to-face, telephone, mail, email*	Method
12.	Sample size	How many participants were in the study?	Method
13.	Non-participation	How many people refused to participate or dropped out? What were the reasons for this?	n/a
Setting			
14.	Setting of data collection	Where was the data collected? *E.g. home, clinic, workplace*	Method
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Method
16.	Description of sample	What are the important characteristics of the sample? *E.g. demographic data, date*	Method
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Method
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Method
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Method
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Method
21.	Duration	What was the duration of the interviews or focus group?	Method
22.	Data saturation	Was data saturation discussed?	n/a
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	n/a
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Method
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Results
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Method
27.	Software	What software, if applicable, was used to manage the data?	Method
28.	Participant checking	Did participants provide feedback on the findings?	n/a
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *E.g. Participant number*	Results
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Results
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Results
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Results

Chapter 9. Study 5: "Because It Helps My Brain To Calm Down": A Qualitative Study of the Emotion Regulation Experiences of Children and Adolescents with Intellectual Disabilities.

The following chapter has been accepted for publication:

Girgis, M., Paparo, J., & Kneebone, I. (2024). *"Because it helps my brain to calm down": A qualitative study of the emotion regulation experiences of children and adolescents with intellectual disabilities.* [Accepted for publication]. Discipline of Clinical Psychology, University of Technology Sydney & School of Psychological Sciences, Macquarie University.

Abstract

Background: Children and adolescents with intellectual disabilities are prone to developing emotion dysregulation difficulties. The process model of emotion regulation may offer a comprehensive structure by which to understand this phenomenon.

Method: Seventeen children and adolescents with intellectual disabilities participated in semi-structured interviews on their experience of emotion regulation. Reflexive thematic analysis was used to analyse the data obtained.

Results: The applicability of the process model of emotion regulation to children and adolescents with intellectual disabilities was confirmed. Additional themes and sub-themes relevant to the model were also identified. Discrepancies in emotion regulation experiences were noted between autistic and non-autistic children and adolescents with intellectual disabilities.

Conclusions: The process model was found to be relevant to children and adolescents with intellectual disabilities. The identified themes and sub-themes could guide the development of outcome measures founded on the model for this population.

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Emotion regulation difficulties are prevalent among children and adolescents with intellectual disabilities and often expressed as mental illnesses or behaviours of concern (BOC; Munir, 2016; Nicholls et al., 2022). BOC is defined as "behaviours that indicate a risk to the safety or wellbeing of the people who exhibit them or to others" (Chan et al., 2012, pg. 37). BOC primarily encompasses: self-harm, physical aggression, non-compliance, overactivity, property damage, running away, screaming, temper 'tantrums,' repetitive questions, stealing, stripping, smearing faeces, and sexualised behaviours (Emerson et al., 2001; Emerson & Einfeld, 2011). Mental illnesses and BOC have long term impacts on this population, such as reduced quality of life, belonging, emotional wellbeing, and employment acquisition (Munir, 2016; Svetlana et al., 2018).

Between 18 and 35% of children and adolescents with intellectual disabilities are diagnosed with autism spectrum disorder (Dunn et al., 2018; Maenner et al., 2020). Comparatively, individuals with a dual diagnosis of autism and intellectual disability, experience worsened quality of life, particularly in the areas of social inclusion, interpersonal relationships, and physical wellbeing (Arias et al., 2018); similar trends are also seen between autistic individuals without intellectual disabilities and typically developing peers (Skaletski et al., 2021). Autistic individuals with intellectual disabilities (A-ID) are 2.5 times more prone to developing emotion dysregulation, compared to their peers only diagnosed with an intellectual disability (O-ID; Bakken et al., 2010). This susceptibility may stem from traits associated with autism, such as, sensory sensitivity and rigid thoughts and behaviours, particularly when coupled with the use of maladaptive emotion suppression and avoidance strategies (American Psychiatric Association, 2022; Hollocks et al., 2022; Mazefsky et al., 2013; Samson et al., 2012). Given these complexities, it is important to consider co-occurring conditions, and use a widely accepted theoretical framework of emotion regulation, to comprehensively understand the emotion regulation experiences of individuals with O-ID.

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The process model of emotion regulation, is arguably the leading framework in the emotion regulation field (Cremades et al., 2022, Gross, 2014). It is well-suited to understanding the emotion regulation experiences of children and adolescents with intellectual disabilities, as the model focuses on expressions of emotion regulation and dysregulation, rather than on diagnoses (Gross, 2014). Consequently, the process model aligns with the suggested transdiagnostic approach for this population, which is advocated due to the high prevalence of co-occurring diagnoses (Astle et al., 2022; England-Mason, 2020). The process model consists of cyclic domains of emotion regulation: situation selection, situation modification, attentional deployment, cognitive change, and response modulation (Gross, 2014); see definitions in Table 1. These domains overlap and are cyclic in nature, as emotion regulation strategies can lead to the formation of new situations, which can trigger the need for further emotion regulation (Gross, 2014).

Although the process model is a prominent emotion regulation framework, efforts to apply the model to children and adolescents with intellectual disabilities have been limited to the perspectives of parents and teachers in two separate qualitative studies to date (Girgis, Paparo, & Kneebone, 2024; Girgis, Paparo, Roberts, et al., 2024). In these studies, teacher perspectives on the emotion regulation experiences of this population were gathered using focus groups, likewise parental insights were collected using semi-structured interviews. Both supported the suitability of the process model for this population and identified several adaptive and maladaptive strategies. This research also suggested differences between the perspectives of parents with A-ID children and parents with children with O-ID (Girgis, Paparo, & Kneebone, 2024). Comparatively, parents of A-ID children reported cognitive distortions more often, whilst parents with children with O-ID reported cognitive restructuring more frequently.

Table 1

Definitions and Examples of the Five Domains of the Process Model of Emotion Regulation as Based on Gross (1998, 2014)

Domain	Definition	Example
Situation Selection	An individual first becomes aware of an upcoming situation and the associated emotional reaction. This leads them to either initiate or avoid the situation.	A child avoiding bath time by hiding or a child requesting their birthday presents early.
Situation Modification	When a situation has commenced the individual can modify the environment to alter the emotional impact.	Using headphones to help with homework or chores completion.
Attentional Deployment	The ability to shift attentional focus. Redirecting attention can be grouped into three categories. <u>Distraction:</u> the ability to either redirect attention to non-emotional aspects of a situation or away from the situation entirely. <u>Concentration:</u> attention is sustained by the	Distraction: child averting their eye gaze and focusing on a toy rather than their parents arguing. Concentration: when a child is concentrating on a YouTube video.

Domain	Definition	Example
	engagement of tasks which occupy finite cognitive abilities. Rumination: directs attention to emotions and related consequences.	Rumination: when an adolescent worries about hypothetical threats.
Cognitive Change	The individual evaluates whether an event can be managed within the context of their goals.	Reframing is one strategy, wherein an adolescent engages in self talk about being excited instead of anxious when presenting a class speech.
Response Modulation	This domain occurs later in the emotion regulation process and focuses on changing the trajectory of behavioural, experiential, or physiological responses.	When an adolescent is behaving aggressively and then walks around their school to reduce this state.

The perspective of children and adolescents on emotion regulation, within the process model framework, is currently absent. This is unsurprising given there are inherent challenges to including individuals with intellectual disabilities in research, particularly, a lack of validated measures, appropriate theoretical models, and difficulties gathering informed consent (Maes et al., 2021). Despite these challenges, it remains important to include the "voice" of this population (Maes et al., 2021), as exclusion prevents the comprehensive capture of lived experience. Moreover, exclusion impacts outcome measure development and is related to lower content validity (Brooks & Davies, 2008; Patel et al., 2023).

The aim of the current study is to directly gather the perspectives of children and adolescents with intellectual disabilities regarding their emotion regulation experiences and investigate the relevance of the process model to this population. Consistent with prior studies, a qualitative approach will be utilised, as process model-based outcome measures have yet to be validated for this population (Girgis et al., 2021). Comparisons will also be made between A-ID and O-ID individuals, given there may be emotion regulation differences between these two groups (Girgis, Paparo, & Kneebone, 2024).

Method

Participants

Children and adolescents with intellectual disabilities ($N = 17$, *Female* = 6) participated in the study. Verification of an intellectual disability diagnosis was established through one of two methods. Participants were either required to be enrolled in a purpose-built school catering to students with an intellectual disability, which necessitates a diagnosis of intellectual disability, or accepted into the Australian National Disability Insurance Scheme (NDIS) with a diagnosis of intellectual disability. The severity of the intellectual disability ranged from mild to severe, as determined by assessment, parent, and school reports, see

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Table 2. Participant ages ranged from 8-22 ($M = 16.41$), and 11 participants were screened for autism using the developmental behaviour checklist-autism screening algorithm (DBC-ASA; Brereton et al., 2002).

Table 2

Demographic Data

Demographics	
Children and Adolescents	$N = 17$
Age	16.41(3.78)
Age range	8-22
Gender (F:M)	6:11
School Grade	$M = 8.4$, $SD = 2.88$, *range* = 3-12
Schooling type	Purpose built school (5)
	Home schooling (2)
	Mainstream school with support class (2)
	Finished school (8)
Ethnicity*	Aboriginal and/or Torres Strait Islander (3)
	Asian (3)
	Caucasian (9)
	European (2)
	Indian (1)
	Middle Eastern (1)

Demographics	
Diagnosis	Intellectual disability (13)
	Global developmental delay (2)
	Down syndrome (2)
Severity of intellectual disability	Mild (6)
	Moderate (10)
	Severe (1)
Co-occurring diagnosis*	Autism/Above DBC-ASA threshold (11)
	Anxiety (3)
	Oppositional defiant disorder (3)
	Attention-deficit/hyperactivity disorder (8)
	Obsessive compulsive disorder (1)
	Cerebral palsy (2)
	Depression (1)
	Post traumatic stress disorder (1)
	Sensory processing disorder (1)
Communication type	Speech-based communication (16)
	Non-speech using (1)

Note: *data overlapped

Procedure

This study was approved by the University of Technology Sydney Human Research Ethics Committee (approval number: ETH16-0925). Convenience sampling was used to recruit participants, specifically, purpose-built schools for students with intellectual disabilities and National Disability Insurance Scheme (NDIS) funded support coordinators of children and adolescents with intellectual disabilities were contacted by email. . Informed consent was gathered, specifically, parents were able to consent on behalf of the participant if they were younger than 18 years old. Participants over the age of 18 provided consent, in addition to parental consent. Informed consent consisted of easy read English consent forms with visual aids as needed, explanation of the consent forms using accessible language/communication, and parental support.

Participants were allocated an hour to complete the interview in their home. Parents were present during the interview and instructed not to offer responses but encouraged to interpret idiosyncratic language expression or vocalisations if requested by the interviewer. The interviews were conducted by the first author (MG), a female clinical psychologist and PhD candidate. The interviews were audio recorded and later transcribed. During the interviews field notes were taken. To mitigate the known challenges inherent to the inclusion of this population, individual modifications to interviews were made for each participant: these included the use of drawings, simplified language, parents offering alternative phrasings, and relating questions to a participant's interests.

A semi-structured interview format was used. First closed ended questions were used to determine the relevance of the question. If the participant indicated the question was relevant, the participant was then encouraged to provide examples to mitigate against agreeableness, see interview guide in supplementary file 1. The questions were centred on the general emotion regulation experiences of the participants, as well as their emotion regulation

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experiences within the context of the process model domains (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014). Participants received compensation for their involvement, which included a $20 (AUD) gift voucher and a brief reading and language comprehension assessment and report. The results from this assessment were not considered within the context of this current study. This procedure was assessed against the COnsolidated criteria for REporting Qualitative research Checklist (COREQ; Tong et al., 2007), see Appendix.

Measures

Demographic Information

The following participant demographics were collected: age, gender, diagnosis, intellectual disability severity, co-occurring diagnoses, and communication type.

Developmental Behaviour Checklist-Autism Screening Algorithm (DBC-ASA; Brereton et al., 2002)

The DBC-ASA is an informant-based autism spectrum disorder screener for children and adolescents with intellectual disabilities. The DBC-ASA was completed by the participant's parents. The DBC-ASA contains 29 items and has good internal consistency (α = .94), sensitivity (0.86), and specificity (0.69). The recommended threshold score is $\geq$ 17. The DBC-ASA was used to differentiate between the A-ID and O-ID groups. Participants above the threshold were considered part of the A-ID group ($N = 11$), and those below the threshold were considered part of the O-ID group ($N = 6$).

Analysis

The analysis utilised Braun and Clarke's (2006) reflexive deductive guide and considered the data through the process model domains (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross,

2014). Braun and Clarke (2019) recommend one coder, as such the thematic analysis was only completed by the lead author (MG). Braun and Clarke (2019) advise against reliability checks, emphasising that the analysis aims to thoughtfully consider the data and to synthesise themes directed by theoretical frameworks, rather than pursuing consensus. In line with this recommendation, a single coder has previously been used to evaluate the emotion regulation of children and adolescents with intellectual disabilities (Girgis, Paparo, Roberts, et al., 2024).

Transcripts were organised using the qualitative software NVivo 12 (QSR International Pty Ltd, 2019). Following Braun and Clarke's (2006) six steps, the transcripts were analysed thematically and were informed by field notes. Initially, first impressions were formed after reviewing the transcripts repeatedly. The data was categorised into codes and linked to the five process model domains (Gross, 2014). Additionally, recurrent codes distinct from the process model domains were documented. The codes were synthesised into themes and sub-themes, and cross checked across the transcripts. The themes and sub-themes were then refined, defined, and named; quotes were also selected to represent these themes.

Results

The 17 participants were between 8 and 22 years old. Eleven were above threshold on the DBC-ASA, see Table 2. As detailed below, overall, the results supported the applicability of the process model domains to this population (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014). In addition to these findings, further themes and sub-themes were also identified, see Table 3 and supplementary file 2. Throughout the results, demographic information is paired with quotes to provide context, this information is presented in the following order: age,

gender, severity of intellectual disability, and if the DBC-ASA results were above or below threshold (e.g., 17, female, moderate, above/below DBC-ASA threshold).

Table 3

Themes and Sub-Themes

Themes	Sub-themes
Situation selection	Managing Stimulation
	Selection Acceleration and Deceleration
Situation Modification	Incorporating or Removing Sensory Elements
	Security within Connection
Attentional Deployment	Distraction
	Concentration
	Rumination
	Worry
Cognitive Change	
Response Modulation	Suppression
External Emotion Regulation	
Limited Emotional Granularity	
Limited Somatic Insight	
Limited Metacognition	
Symbolic Play	

Situation Selection

Participant interviews supported the relevance of the situation selection domain for this population, as emotion regulation experiences were consistent with choices to either select or avoid specific situations. Furthermore, participants reported at times being incapable of selecting situations or made distressing selections. Additional sub-themes were also identified: Managing stimulation and selection acceleration and deceleration.

Managing Stimulation

All participants described seeking out preferred environments and stimuli, such as: iPad, TV, YouTube, games, video games, toys, favourite foods, sensory toys and lights, special interests, sports, shopping, alone time or quiet time, social connections with family and friends, and music, "… if it's… a sad video, like on YouTube, I… turn it to a different thing. Like watching… a happy video or I listen to some music, or drawing" (19, female, moderate, above DBC-ASA threshold).

Participants also described avoiding or withdrawing from known unpleasurable environments or stimuli, such as: Animals, insects, social media, chores, showering, certain individuals, school subjects (i.e., Math), crowds, and sensory textures. Participants also indicated they enforced their choices by recruiting family assistance, communicating their intent, and arguing in favour of their preference, "[I avoid] cleaning my room… Argue point till I don't do it" (13, male, mild, above DBC-ASA threshold). Transitions between situations could also be difficult, "… it takes me a bit to get away from what I'm doing. Because once I'm in that like area of doing stuff, I would like to finish some of it" (22, male, mild, above DBC-ASA threshold). Within the context of managing stimulation, participants also described physically moving locations. This was expressed as staying away from sharp objects (when self-injurious thoughts were present), taking a step back from a frightening

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object/animal, leaving classrooms, seeking out contact with parents, moving into another room to avoid a stimulus, or seeking out quiet or alone time, "go to the most quiet [place]" (22, male, mild, above DBC-ASA threshold).

Selection Acceleration and Deceleration

Some participants indicated they either sped up or slowed down the arrival of a situation. The initiation of a new situation was accelerated by encouraging others to move faster "… might push my dad to do stuff… I probably… say [hurry up] a thousand times" (17, male, moderate, below DBC-ASA threshold). Participants also said they would wait outside for family, completed chores quickly "I run when I do it" (13, male, mild, above DBC-ASA threshold), organised items to hasten leaving the house, and finished shopping quickly to avoid crowds.

Conversely, the arrival of situations was noted to be decelerated by walking slowly, asking for a minute before starting chores, dressing slowly for school, and starting and competing tasks slowly, "I don't like getting in [the shower], so I take my time" (18, male, moderate, above DBC-ASA threshold). This deceleration strategy also appeared to be utilised for situations with positive associations, "… if it's something that you're excited about, then you need to feel it" (13, male, mild, above DBC-ASA threshold).

Situation Modification

The data aligned with the situation modification domain, as all participants reported making modifications to their environment to accommodate emotion regulation. Two sub-themes were also identified: Incorporating or removing sensory elements and security within connection.

Incorporating or Removing Sensory Elements

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Most participants described modifying situations by adding elements to assist with self-soothing. With regard to sleep, participants co-slept, slept with toys, and slept with the light on. Whilst accessing the community, participants wore clothing with soothing textures, engaged in routine such as sitting in the same exact spot, and took toys with them in the car "[toy makes me feel] bit safe and protect[s] me" (18, male, mild, below DBC-ASA threshold). Whilst general modification strategies included: using mobile phone, music, headphones, fidget toys, using favourite items, eating, drawing, asking for help, asking for a big squeeze, talking to toys, and covering their eyes, mouth and ears. Likewise, they would also cover their parent's mouth. Participants would also remove themselves from rooms when strangers visited or would move away from arguments. This would also extend to hiding body parts when feeling insecure, such as covering perceived crooked teeth when speaking.

Security within Connection

Participants reported they were better able to cope with distressing situations when supported by their family or friends. This support was sought out and presented as cuddles, requesting company, asking for help, co-sleeping, and requesting parents accompany them. This security within social connection was also expressed as physical proximity to their parents, including holding hands, or family sitting either side of them in public to prevent distress, "at least I have my mum" (17, female, moderate, above DBC-ASA threshold).

During social interactions participants reported letting others lead conversations in socially confusing situations, asked for hugs when feeling alone, and whispered to maintain privacy "I would whisper to my mum… when I get my period" (17, female, moderate, above DBC-ASA threshold).

Attentional Deployment

The relevance of the attentional deployment domain was confirmed, with all but two participants endorsing emotion regulation strategies consistent with this domain. Participants reported the use of distraction, concentration, and rumination; and an additional sub-theme of worry was identified.

Distraction

Participants described the use of distraction to manage their emotions, "distract myself from stuff to make my feelings feel small" (17, male, moderate, below DBC-ASA threshold). Particularly they used: Drawing, eating, sensory items, mobile phone, video games, music, storytelling, iPad, crafting, TV, trampoline, going outside, talking to friends, drinking water, YouTube, singing, reading, writing, patting pets, and engaged in special interests. They also reported distraction was also achieved by shifting their eye gaze away from distressing stimuli. Participants were also able to distract others when others were dysregulated.

Concentration

Participants reported distractions could evolve into concentration, particularly when engaging in special interests, video games, crafting, YouTube, meditation, and watching TV, "listen and watch… TV. Relax" (18, male, mild, below DBC-ASA threshold). Participants reported they found it difficult to disengage when concentrating, and this was expressed as fixed eye gaze. Concentration was also engaged when arguments occurred, during which they found it difficult to avert their eye gaze, "Even if I do look away, I can't keep myself from looking away" (17, female, moderate, above DBC-ASA threshold).

Rumination

Participants disclosed the use of rumination, the process of focusing on past events, "… it's… stuck in my mind. I… try… to think about [a] new image, but that image was… still stuck" (13, male, mild, above DBC-ASA threshold). The content of the ruminations included: family deaths, bullying, past mistakes at school, and whether they made mistakes recently. Rumination was also expressed as repetitive conversations or statements.

Worry

Participants voiced their worries, the process of focusing on the future, "I think about life and…how [it] could go wrong and how [it] could go… good" (13, male, mild, above DBC-ASA threshold). Participants were particularly worried about: getting a job, wasting time, potentially not liking a choice they make, others judging them, going to camp, a new schoolteacher, going to school, the health of loved ones, new locations, or going to known distressing situations. Worry was also expressed as repetitive questions.

Cognitive Change

All but two participants reported the use of cognitive change to manage their emotions, which is suggestive of the applicability of the cognitive change domain to this population, "I was just trying [to] think about something else" (13, male, mild, above DBC-ASA threshold). Of particular note, various types of cognitive distortions were reported by the participants, which included: dichotomous/black and white thinking, catastrophising/fortune telling, personalisation and blame, and labelling: "I may be stupid at times…" (19, female, moderate, above DBC-ASA threshold). Conversely, several forms of cognitive restructuring were reported, such as: generate alternative/ reframing, perspective taking, problem solving, asking questions/seeking clarification, positivity reorientation, and positive affirmations or mantras. Specifically, a variety of mantras, were used such as: I can do this, calm yourself, doesn't matter, you're okay, I'm a good person/student, my parents

love me, practice makes perfect, and "Be not upset" (18, male, mild, below DBC-ASA threshold). Participants also gave themselves positive affirmations from the perspective of their favourite cartoon or video game character. Participants further expressed being able to assist others to use cognitive change, specifically they provided mantras and assisted in problem solving, "With my mum I'll probably solve it. Like I was trying to like help her in some way" (13, male, mild, above DBC-ASA threshold).

Response Modulation

The response modulation domain was associated with the largest volume of data. All participants disclosed the use of a variety of strategies, and emotion regulation experiences. Specifically, emotion dysregulation was expressed as self-harm, aggressive behaviours, non-compliance, escape based behaviours, and unpleasant physiological responses. Participants tended to regulate their emotions by meeting their sensory needs (i.e., having quiet/alone time, drinking water, sensory activities, using a punching bag, and going for walks etc). Participants also described using meditation by way of taking deep breaths, counting to 10, and practicing yoga, "Because it helps my brain to calm down" (14, female, moderate, above DBC-ASA threshold). Additionally, participants used communication to regulate their emotions, whether via speech with friends, family or favourite characters; or through other mediums such as journalling, "When I talk about my feelings, I guess it helps sometimes" (17, female, moderate, above DBC-ASA threshold). Medication was also reportedly used to regulate emotions, though participants had varying experiences; wherein, some disliked medication, others found the medication helpful but did not request it, while the third group requested the medication. Of particular note was the use of maladaptive emotion regulation strategies, as represented in the sub-theme of suppression.

Suppression

Participants voiced deliberate attempts to conceal their expressions. This was accomplished by refraining from communication, withdrawing, attempting to prevent facial expressions and hands from shaking, and attempting to supplant their emotions, "Make up my feelings" (14, female, moderate, above DBC-ASA threshold). If their emotions were questioned, they would deny their emotions. This typically occurred when participants were distressed in locations considered unsafe, such as when at funerals or school, "… tricking them… pretend to be happy… I don't trust them" (20, male, moderate, below DBC-ASA threshold). However, this strategy was not used when in safe environments. Participants reported expressive suppression was not always an effective emotion regulation strategy, "It doesn't stay that long" (17, female, moderate, above DBC-ASA threshold). Participants also described thought suppression, which at times could be paired with elements of distraction, "You just tell your brain to stop" (14, female, moderate, above DBC-ASA threshold), however, it was acknowledged that this strategy was not always successful, "... sometimes doesn't work" (17, male, moderate, below DBC-ASA threshold).

Additional Themes

Themes distinct from the process model domains were identified, specifically, external emotion regulation, limited emotional granularity, limited somatic insight, limited metacognition, and symbolic play.

External Emotion Regulation

Participants reported receiving support to regulate their emotions from their family, teachers, and friends. This support was externally provided across all five process model domains. These strategies included directing participants to soothing situations, modifying the situation, providing distractions, prompting cognitive restructuring, and providing sensory management such as providing hugs or alone time, and reminding them to take their

medication. These efforts were described as, "Help… calm myself down, if I… too upset" (19, male, moderate, above DBC-ASA threshold).

Limited Emotional Granularity

The participants' ability to describe their emotions was illustrated across three levels. The first level consisted of participants who could identify emotions and used limited descriptive terms (i.e., happy, angry, sad etc). The second level consisted of participants that used less nuanced descriptions such as "Bad day emotions" (22, male, mild, above DBC-ASA threshold), used adverbs to indicate heightened emotions (i.e., "very scared"), or used assistive technology (i.e., communication app; the participant's descriptive words only included: hungry, crazy, sad, happy, and mad). Likewise, one participant was taught to use the blue zone (low mood), green zone (positive emotions), yellow zone (heightened emotions) categories to identify emotions; the context of this skill is unknown. Additionally, this level included participants that mislabelled emotions, and described emotions using non-emotive words (i.e., curious, crying, sleepy etc). The last level included participants that displayed alexithymia, for instance reporting "[I feel] nothing" (13, male, mild, above DBC-ASA threshold), or responded with "I don't know" (20, female, mild, below DBC-ASA threshold) when asked about their emotional state; these responses were consistent even when comprehension was confirmed.

Limited Somatic Insight

Participants struggled to describe their somatic symptoms in relation to their emotion regulation experiences, their insight is summarised into four levels. The first level consisted of participants that were able to describe their somatic symptoms. The second level included participants able to identify the existence of a general somatic experience across the entirety of their body, but could not pinpoint the location. The third level included the ability to

identify the location but not the somatic sensation (i.e., angry face). Lastly, alexisomia was evident, as some participants were unable to identify the location or the somatic symptom.

Limited Metacognition

Metacognition is related to cognitive insight and impacts an individual's capacity to utilise cognitive change. Specifically, participants struggled with cognitive insight, and at times did not use cognitive change. Several participants were unaware of the content of their thoughts, but were able to identify the related emotion, "I don't know what I'm worried about" (20, male, moderate, below DBC-ASA threshold). Participants were able to increase their insight by discussing their concerns with their favourite characters. Reduced insight was also exacerbated when under stress, "I just get annoyed. Just stop thinking in my head" (13, male, mild, above DBC-ASA threshold).

Symbolic Play

Participants reportedly used video game or cartoon characters to engage in symbolic play, the process of speaking to the character about their emotions or thoughts. This process facilitated cognitive change, specifically the following cognitive restructuring sub-themes: "generate alternative/reframing," "problem solving," and "positive affirmations or mantras," "He'll [character] be like, don't talk shit about yourself. You are [a] beautiful woman" (19, female, moderate, above DBC-ASA threshold). Likewise, symbolic play also facilitated response modulation via the "communication" sub-theme, as this process assisted participants to externalise their internal processing, "I tell batman to help to make me calm down" (20, male, moderate, below DBC-ASA threshold). The participant's historical use of symbolic play is unknown.

Cross Comparisons

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Differences between participants above and below the DBC-ASA threshold were noted. Specifically, participants above the DBC-ASA threshold had a pattern of reporting: selection acceleration and deceleration, rumination, concentration, cognitive distortions, problem solving, positivity reorientation, perspective taking, aggressive behaviours and external attentional deployment. Whilst participants below the DBC-ASA threshold had a pattern of reporting: positive affirmations or mantras, generate alternative/reframing, and meditation. Of note, while participants above the DBC-ASA threshold tended to report cognitive distortions, both groups similarly reported cognitive restructuring. The remaining sub-themes were relatively comparable between both groups.

Discussion

This study is the first to evaluate the emotion regulation experiences of children and adolescents with intellectual disabilities, through the process model lens. Overall, the thematic analysis supported the relevance of all five domains of the process model (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014). In addition to this finding, additional themes distinct from the process model domains were detected, specifically, "external emotion regulation," "limited emotional granularity," "limited somatic insight," and "symbolic play."

Multiple themes and sub-themes intersected and supported the cyclical pattern outlined in the process model, demonstrating how emotion regulation experiences and strategies led to the emergence of new situations (Gross, 2015). Specifically, overlaps occurred between the situation selection and situation modification domains, as modifications could create new situations. Likewise, the situation selection theme and the attentional deployment sub-theme "rumination," overlapped as situation selection was influenced by rumination content. The "rumination" and "worry" sub-themes also overlapped with the

reports of cognitive distortions. Whilst the response modulation domain intersected with the situation selection and situation modification domains, as response modulation selections perpetuated and modified situations. The convergence of these themes emphasises the importance of context, as emotion regulation experiences and strategies are not inherently related to specific domains (Gross, 2014). Of note, participants reported using social connections to modify situations as seen in the "security within connection" sub-theme, which transcends the situation modification definition of "modifying external, physical environments" (Gross, 2014, p. 10). These findings are consistent with parent and teacher perspectives (Girgis, Paparo, & Kneebone, 2024; Girgis, Paparo, Roberts, et al., 2024) and suggests the scope of the situation modification domain warrants further investigation in order to adequately capture the emotion regulation experiences of children and adolescents with intellectual disabilities.

Themes discernible from the process model domains were identified, including: "external emotion regulation," "limited metacognition," "limited emotional granularity," "limited somatic insight," and "symbolic play." Within the theme of "limited emotional granularity" and "limited somatic insight," participants demonstrated several levels of emotional and somatic insight. This is expected, as individuals with intellectual disabilities typically encounter more challenges generating emotive words compared to non-emotive words (Mellor & Dagnan, 2005). Likewise, limited somatic insight is associated with children with intellectual disabilities (Emck et al., 2012). Symbolic play also aided participants in externalising their thoughts and emotions, a practice linked to increased occurrences of internal state language (Hashmi et al., 2022).

Participants above the DBC-ASA threshold were classified as A-ID, while those below were classified as O-ID. Emotion regulation experiences differed between children and

adolescents above and below the DBC-ASA threshold. Specifically, those above the threshold tended to report "concentration," which may be related to the propensity for autistic individuals to engage in special interests and related hyperfocus (American Psychiatric Association, 2022). Those above the DBC-ASA threshold also tended to report cognitive distortions. This may be related to the higher prevalence of emotion dysregulation in A-ID children and adolescents compared to those with O-ID (Bakken et al., 2010). Of note, in a prior study parents with A-ID children had a pattern of reporting expressive suppression— a pattern not observed by parents of children with O-ID (Girgis, Paparo, & Kneebone, 2024)— the current findings indicated the reporting pattern of expressive suppression was comparable between groups. Parents of A-ID children may not have recognised their child's attempt to suppress their emotions to the same degree as parents with children with O-ID. This may be due to miscommunications that commonly occur between autistic and non-autistic individuals (Mitchell et al., 2021). In this context, emotions may be suppressed and attract the negative effects of this strategy (Geraerts et al., 2006). Whilst simultaneously, the maladaptive strategy remains undetected, due to observers misinterpreting emotional expressions. These trends should be viewed with caution considering the small population size, and varying levels of metacognitive insight.

Overall, the results supported the applicability of all process model domains for children and adolescents with intellectual disabilities. However, this study has four key limitations. The DBC-ASA is not validated for individual's over 18 years old (Brereton et al., 2002), however, alternative valid autism screeners for older adolescents with intellectual disabilities have yet to be developed. Secondly, the perspectives were not corroborated with observations, and reporting may have been influenced by a desire to avoid social stigma. This is particularly relevant, as this group is likely to experience discrimination (Ali et al., 2015).

Likewise, communication difficulties may have affected the participant responses. This, in turn, could have influenced the interpretation of the limited somatic insight and limited metacognition themes. As such, these themes might represent expressive language challenges, rather than a lack of insight. Additionally, the relationship between age and emotion regulation could not be assessed due to the small sample size. Lastly, insight into the non-speech using population is limited as only one participant utilised a communication device. A strength of this study is the inclusion of the "voice" of children and adolescents with intellectual disabilities, which is a perspective often not captured. This was made possible due to the following accommodations: parental support, easy read English forms, visual aids, and simplified language. It is vital that future research consider the need for such accommodations in order to capture the lived experience of this population.

This study is the first we know of to directly explore the emotion regulation experiences of children and adolescents with intellectual disabilities, via the process model domains (Gross, 2014). Whilst the overall findings indicate that the process model of emotion regulation is applicable in this population, the situation modification domain parameters require further review in order to capture the breadth of experiences of children and adolescents with intellectual disabilities. Moving forward, attempts should be made to capture the emotion regulation experiences of children and adolescents who use communication devices. Comparisons should also be made between the perspectives of children and adolescents with intellectual disabilities, and parents and teachers (Girgis, Paparo, & Kneebone, 2024; Girgis, Paparo, Roberts, et al., 2024). The aggregated themes and sub-themes could serve as a foundation to develop a process model-based emotion regulation measure, encompassing a self-report, teacher, and parent version—as such measures are not currently available (Girgis et al., 2021). The current findings could also inform therapies for

this population, for example, therapies could incorporate language development elements, focus on enhancing somatic and metacognitive insight, and build on existing play therapies used in this population (Mora et al., 2018). These therapies could also incorporate the adaptive emotion regulation strategies already in use, whilst shifting away from known maladaptive strategies such as avoidance, and expressive and thought suppression (Campbell-Sills et al., 2014; Dekker & Koot, 2003; Rudaz et al., 2017).

Conclusion

Collectively, through direct participant perspectives, this study emphasises the suitability of the process model of emotion regulation to children and adolescents with intellectual disabilities. Further, the model facilitates a more comprehensive understanding of the emotion regulation experiences of this population. This study advances emotion regulation research pertaining to this population and offers insights that might guide the development of outcome measures and interventions, whilst amplifying the underrepresented "voice" of children and adolescents with intellectual disabilities.

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Appendix

The COnsolidated criteria for REporting Qualitative research Checklist (COREQ; Tong et al., 2007)

No.	Item	Description	Section #
Domain 1: Research team and reflexivity			
Personal characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Method
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	Method
3.	Occupation	What was their occupation at the time of the study?	Method
4.	Gender	Was the researcher male or female?	Method
5.	Experience and training	What experience or training did the researcher have?	Method
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Method
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? *E.g. Personal goals, reasons for doing the research*	Method
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? *E.g. Bias, assumptions, reasons and interests in the research topic*	n/a
Domain 2: Study design			
Theoretical framework			
9.	Methodological orientation and theory	What methodological orientation was stated to underpin the study? *E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Method
Participant selection			
10.	Sampling	How were participants selected? *E.g. purposive, convenience, consecutive, snowball*	Method
11.	Method of approach	How were participants approached? *E.g. face-to-face, telephone, mail, email*	Method
12.	Sample size	How many participants were in the study?	Method
13.	Non-participation	How many people refused to participate or dropped out? What were the reasons for this?	n/a
Setting			
14.	Setting of data collection	Where was the data collected? *E.g. home, clinic, workplace*	Method
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Method
16.	Description of sample	What are the important characteristics of the sample? *E.g. demographic data, date*	Method
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Method
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Method
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Method
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Method
21.	Duration	What was the duration of the interviews or focus group?	Method
22.	Data saturation	Was data saturation discussed?	n/a
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	n/a

No.	Item	Description	Section #
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	Method
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Results
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Method
27.	Software	What software, if applicable, was used to manage the data?	Method
28.	Participant checking	Did participants provide feedback on the findings?	n/a
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *E.g. Participant number*	Results
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Results
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Results
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Results

Supplementary File 1: Interviewer Guide

Note: Questions containing multiple emotions were asked one at a time. Prior to asking the questions below, the participants were asked whether the question applied to them, for example: "Do you worry?" If yes, then the following question was asked "How do you stop worrying." Participants were then asked to provide specific examples of when they used the reported strategy.

Domain	Questions
General emotion regulation	• What do you do when you are happy/sad/angry/scared? • When you are sad/angry/scared what do you do to feel better? • What are the names of some feelings?

Situation selection	• What is something you don't like to do?
	
	    o When you are going to [insert example], what do you do to feel better?
	
	• When do you avoid things?
	
	• What are some of your favourite things?
	
	    o How do you get them?
	
	    o How can you get your [insert example] faster?

Situation modification	• How do you make a situation [insert example] better? o How does mum/dad help you? • When do you get cuddles from mum or dad?

Attention deployment	• Distraction
	o How do you forget about sad/scary/angry things?
	o Where do you look when you are happy/sad/angry/scared?
	• Concentration
	o What's something you can concentrate/focus on?
	o Is it hard to stop what you are doing?
	• Rumination
	o What do you think a lot about?
	o What do you worry about?
Cognitive change	• How do you stop worrying?
	• How do you change what you are thinking?
	• What do mum and dad say to help you feel better?
Response modulation	o What do you do when you are happy/sad/angry/scared?
	▪ Where do you feel happy/sad/angry/scared in your body?
	o How do mum and dad help you feel better?
	o When do you hide your feelings?
	o When do you fake your feelings?
	o When do you talk about your feelings?

Supplementary File 2: Detailed Results, inclusive of all themes and sub-themes

The 17 participants were between 8 and 22 years old. Eleven were above threshold on the DBC-ASA, see Table 2. As detailed below, overall the results supported the applicability of the process model domains to this population (i.e., situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2014). In addition to these findings, further themes and sub-themes were also identified, see Table 3. Throughout the results, demographic information is paired with quotes to provide context, this information is presented in the following order: age, gender, severity of intellectual disability, and if the DBC-ASA results were above or below threshold (e.g., 17, female, moderate, above/below DBC-ASA threshold).

Situation selection

All participant interviews supported the relevance of the situation selection domain for this population, as emotion regulation experiences were consistent with choices to either select or avoid specific situations. Additional sub-themes were also identified: Managing stimulation, location shifts, selection acceleration and deceleration, selection incapable, and distressing selections.

Managing stimulation

All participants described seeking out preferred environments and stimuli, such as: iPad, TV, YouTube, games, video games, toys, favourite foods, sensory toys and lights, special interests, sports, shopping, alone time or quiet time, social connections with family and friends, and music, "… if it's… a sad video, like on YouTube, I… turn it to a different thing. Like watching… a happy video or I listen to some music, or drawing" (19, female, moderate, above DBC-ASA threshold).

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Participants also described avoiding or withdrawing from known unpleasurable environments or stimuli, such as: Animals, insects, social media, chores, showering, certain individuals, school subjects (i.e., Math), crowds, and sensory textures. Participants also indicated they enforced their choices by recruiting family assistance, communicating their intent, and arguing in favour of their preference, "[I avoid] cleaning my room… Argue point till I don't do it" (13, male, mild, above DBC-ASA threshold). Transitions between situations could also be difficult, "… it takes me a bit to get away from what I'm doing. Because once I'm in that like area of doing stuff, I would like to finish some of it" (22, male, mild, above DBC-ASA threshold).

Location Shifts. Within the context of managing stimulation, participants described physically moving locations. This was expressed as staying away from sharp objects (when self-injurious thoughts were present), taking a step back from a frightening object/animal, leaving classrooms, seeking out contact with parents, moving into another room to avoid a stimulus, or seeking out quiet or alone time, "go to the most quiet [place]" (22, male, mild, above DBC-ASA threshold).

Selection acceleration and deceleration

Some participants indicated they either sped up or slowed down the arrival of a situation. The initiation of a new situation was accelerated by encouraging others to move faster "… might push my dad to do stuff… I probably… say [hurry up] a thousand times" (17, male, moderate, below DBC-ASA threshold). Participants also said they would wait outside for family, completed chores quickly "I run when I do it" (13, male, mild, above DBC-ASA threshold), organised items to hasten leaving the house, and finished shopping quickly to avoid crowds.

Conversely, the arrival of situations was noted to be decelerated by walking slowly, asking for a minute before starting chores, dressing slowly for school, and starting and competing tasks slowly, "I don't like getting in [the shower], so I take my time" (18, male, moderate, above DBC-ASA threshold). This deceleration strategy also appeared to be utilised for situations with positive associations, "… if it's something that you're excited about, then you need to feel it" (13, male, mild, above DBC-ASA threshold).

Selection incapable

Participants indicated at times they were unable to select situations and would typically feel frozen, "I couldn't process" (19, female, moderate, above DBC-ASA threshold).

Distressing selections

Although participants typically expressed situation selection as seeking out pleasurable stimuli and avoiding distressing situations some also described seeking out known distressing situations such as sad music or frightening content online. This occurred when they were sad or already frightened, and overlapped with the rumination sub-theme.

Situation modification

The data aligned with the situation modification domain, as all participants reported making modifications to their environment to accommodate emotion regulation. Two sub-themes were also identified: Incorporating or removing sensory elements and security within connection.

Incorporating or removing sensory elements

Most participants described modifying situations by adding elements to assist with self-soothing. With regard to sleep, participants co-slept, slept with toys, and slept with the light on. Whilst accessing the community, participants wore clothing with soothing textures,

engaged in routine such as sitting in the same exact spot, and took toys with them in the car "[toy makes me feel] bit safe and protect[s] me" (18, male, mild, below DBC-ASA threshold). Whilst general modification strategies included: using mobile phone, music, headphones, fidget toys, using favourite items, eating, drawing, asking for help, asking for a big squeeze, talking to toys, and covering their eyes, mouth and ears. Likewise, they would also cover their parent's mouth. Participants would also remove themselves from rooms when strangers visited, or would move away from arguments. This would also extend to hiding body parts when feeling insecure.

Security within connection

Participants reported they were better able to cope with distressing situations when supported by their family or friends. This support was sought out and presented as cuddles, requesting company, asking for help, co-sleeping, and requesting parents accompany them. This security within social connection was also expressed as physical proximity to their parents, including holding hands, or family sitting either side of them in public to prevent distress, "at least I have my mom" (17, female, moderate, above DBC-ASA threshold).

During social interactions participants reported letting others lead conversations in socially confusing situations, asked for hugs when feeling alone, and whispered to maintain privacy "I would whisper to my mom… when I get my period" (17, female, moderate, above DBC-ASA threshold).

Attentional deployment

The relevance of the attentional deployment domain was confirmed, with all but two participants endorsing emotion regulation strategies consistent with this domain. Participants

reported the use of distraction, concentration, and rumination; and an additional sub-theme of worry was identified.

Distraction

Participants described the use of distraction to manage their emotions, "distract myself from stuff to make my feelings feel small" (17, male, moderate, below DBC-ASA threshold). Particularly they used: Drawing, eating, sensory items, mobile phone, video games, music, storytelling, iPad, crafting, TV, trampoline, going outside, talking to friends, drinking water, YouTube, singing, reading, writing, patting pets, and engaged in special interests. They also reported distraction was also achieved by shifting their eye gaze away from distressing stimuli. Participants were also able to distract others when others were dysregulated.

Concentration

Participants reported distractions could evolve into concentration, particularly when engaging in special interests, video games, crafting, YouTube, meditation, and watching TV, "listen and watch… TV. Relax" (18, male, mild, below DBC-ASA threshold). Participants reported they found it difficult to disengage when concentrating, and this was expressed as fixed eye gaze. Concentration was also engaged when arguments occurred, during which they found it difficult to avert their eye gaze, "Even if I do look away, I can't keep myself from looking away" (17, female, moderate, above DBC-ASA threshold).

Rumination

Participants disclosed the use of rumination, the process of focusing on past events, "… it's… stuck in my mind. I… try… to think about [a] new image, but that image was… still stuck" (13, male, mild, above DBC-ASA threshold). The content of the ruminations

included: family deaths, bullying, past mistakes at school, and whether they made mistakes recently. Rumination was also expressed as repetitive conversations or statements.

Worry

Participants voiced their worries, the process of focusing on the future, "I think about life and…how [it] could go wrong and how [it] could go… good" (13, male, mild, above DBC-ASA threshold). Participants were particularly worried about: getting a job, wasting time, potentially not liking a choice they make, others judging them, going to camp, a new school teacher, going to school, the health of loved ones, new locations, or going to known distressing situations. Worry was also expressed as repetitive questions.

Cognitive change

All but two participants reported the use of cognitive change to manage their emotions, affirming the suitability of the cognitive change domain to this population, "I was just trying [to] think about something else" (13, male, mild, above DBC-ASA threshold). The following sub-themes were also detected: Cognitive distortions, cognitive restructuring, and prompting cognitive change in others.

Cognitive distortions

The following cognitive distortions were reported:

Labelling. A participant called herself stupid, "I may be stupid at times…" (19, female, moderate, above DBC-ASA threshold).

Dichotomous/black and white thinking. One participant engaged in all or nothing thinking, and struggled to grasp that others disliked his special interest, "I just try and make them [friends] realise that Lego is actually pretty good" (18, male, moderate, above DBC-ASA threshold).

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Catastrophising/fortune telling. Another participant expressed catastrophising thought patterns in response to school disciplinary action, "… I'm scared, it's going to go on my report and [it] affects my future" (13, male, mild, above DBC-ASA threshold).

Personalisation and blame. Participants engaged in personalisation, wherein they held themselves accountable for bullying they had endured. They also engaged in blame, as they considered others rude when they were not heard, "Always think they're rude" (22, male, mild, above DBC-ASA threshold).

Cognitive restructuring

The following cognitive restructuring examples were reported:

Positive affirmations or mantras. Participants used a variety of mantras, such as: I can do this, calm yourself, doesn't matter, you're okay, I'm a good person/student, my parents love me, practice makes perfect, and "Be not upset" (18, male, mild, below DBC-ASA threshold). Participants also gave themselves positive affirmations from the perspective of their favourite cartoon or video game character.

Generate alternative/ reframing. Participants were able to generate alternatives "there's no point in thinking about… that, might not happen" (13, male, mild, above DBC-ASA threshold), and reframed situations, "... if… mum's heart gone bad. I try to look at [it] a different way… that mum soon get better" (19, male, moderate, above DBC-ASA threshold). Participants, also spoke to their favourite characters to engage in cognitive restructuring.

Perspective taking. Participants were able to consider various perspectives "I'm trying to see both sides" (19, female, moderate, above DBC-ASA threshold).

Problem solving. Participants engaged in independent problem solving "plan B or plan A, which one will be better" (19, female, moderate, above DBC-ASA threshold), and

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spoke to video game or cartoon characters to troubleshoot problems. Participants also recruited help from others, such as requesting mum to "give me [a] compliment" (18, male, mild, below DBC-ASA threshold).

Asking questions/seeking clarification. Participants were able to ask questions and seek clarification, "I would probably ask somebody and say, I'm not sure what's happening" (20, female, moderate, below DBC-ASA threshold). This process would often inform problem solving and perspective taking.

Positivity reorientation. Participants were able to focus on the positive elements, "I just think about happy things. Not sad things" (20, female, moderate, below DBC-ASA threshold).

Prompting Cognitive Change in Others

Participants expressed being able to assist others to use cognitive change, specifically they provided mantras and assisted in problem solving, "With my mom I'll probably solve it..." (13, male, mild, above DBC-ASA threshold).

Response modulation

The response modulation domain was associated with the largest volume of data. All participants disclosed the use of a variety of strategies, and emotion regulation experiences, which are summarised in the following sub-themes: meeting sensory needs, communication, meditation, medication, self-harm, aggressive behaviours, repetitive questions, non-compliance, physiological responses, escape, expressive suppression, and thought suppression.

Meeting sensory needs

Participants voiced meeting their sensory needs when distressed, this was achieved primarily by having quiet time or alone time, drinking water, sensory activities, hugs, patting pets, colouring in, sitting outside, journalling, gym, music, massages, using a punching bag, and going for walks, "I can't get rid [of the] feeling, it takes me a little while" (13, male, mild, above DBC-ASA threshold).

Communication

Communication was reported, whether via speech with friends, family or favourite characters; or through other mediums such as journalling, was used to express oneself when distressed, "When I talk about my feelings, I guess it helps sometimes" (17, female, moderate, above DBC-ASA threshold).

Meditation

Participants described meditation by way of taking deep breaths, counting to 10, and practicing yoga, "Because it helps my brain to calm down" (14, female, moderate, above DBC-ASA threshold). Typically, these strategies were used when they felt nervous, scared, or when completing something new. These strategies were also encouraged by their parents and teachers.

Medication

Medication was reportedly used to regulate emotions, participants had varying experiences, wherein, some disliked medication, others found the medication helpful but did not request it, while the third group requested the medication, "It does help me feel better" (17, male, moderate, below DBC-ASA threshold).

Self-Harm

When dysregulated, self-harm was disclosed such as: biting, hitting their head, or scratching themselves with a knife.

Aggressive behaviours

Dysregulation was described as aggression, including: yelling, swearing, stomping feet, shouting, property damage, threats, physical aggression, punching, throwing items, screaming, kicking, hitting, fighting, "sometimes I just feel out of control" (18, male, moderate, above DBC-ASA threshold).

At times yelling was used to enforce their opinion, and property damage could be deliberate, accidental, or adaptive by way of deliberately damaging inconsequential items such as, ripping up journals.

Repetitive questions

This sub-theme overlapped with the cognitive change sub-theme of asking questions/seeking clarification, as this process at times involved a self-reported high volume of questions, "…I do ask a lot of questions about [what's] about to happen" (18, male, moderate, above DBC-ASA threshold).

Non-compliance

Participants disclosed ignoring and refusal, particularly in relation to chores.

Physiological responses

Participants described the following physiological responses to emotion dysregulation: clenched fists, shaking, variations of overactivity, heavy breathing, tenseness, crying, palpitations, rumbling/spinning stomach, butterflies in stomach, sweating, feeling hot,

light-headedness, feeling sick, and freezing. As well as a tendency for sleeping or taking

naps.

Escape

Participants also described escape-based behaviours, such as walking or running away

from fears (i.e., needles, insects), or school bullies, "Just try to get away from it" (19, female,

moderate, above DBC-ASA threshold). They also reported a desire to be somewhere quiet

and also encouraged others to abscond.

Expressive suppression

Participants voiced deliberate attempts to conceal their expressions. This was

accomplished by refraining from communication, withdrawing, attempts to prevent facial

expressions and hands from shaking, and attempts to supplant their emotions, "Make up my

feelings" (14, female, moderate, above DBC-ASA threshold). If their emotions were

questioned, they would deny their emotions. This typically occurred when participants were

distressed in locations considered unsafe, such as when at funerals or school, "… tricking

them… pretend to be happy… I don't trust them" (20, male, moderate, below DBC-ASA

threshold). However, this strategy was not used when in safe environments. Participants

reported expressive suppression was not always an effective emotion regulation strategy, "It

doesn't stay that long" (17, female, moderate, above DBC-ASA threshold).

Thought suppression

Participants described thought suppression, which at times could be paired with

elements of distraction, "You just tell your brain to stop" (14, female, moderate, above DBC-

ASA threshold), however, it was acknowledged that this strategy was not always successful,

"... sometimes doesn't work" (17, male, moderate, below DBC-ASA threshold). Participants reported that thought suppression was at times recommended by their parents.

Additional themes

Themes distinct from the process model domains were identified, specifically, external emotion regulation, limited emotional granularity, limited somatic insight, limited metacognition, and symbolic play.

External emotion regulation

Participants reported receiving support to regulate their emotions from their family, teachers, and friends. This support was externally provided across all five process model domains.

External situation selection. Participants reported they were directed to soothing situations by their parents, and were assisted to move to these locations. Parents also interrupted distressing situations, by telling their child to stop watching horror movies, or by removing video games that caused anger, "My parents usually just take me off of it [video games]" (17, male, moderate, below DBC-ASA threshold).

External situation modification. Participants described seeking assistance from their parents or teachers by asking for help in difficult situations, "Adult…solve the problem" (18, male, mild, below DBC-ASA threshold).

External attentional deployment. Narrations included parents prompting participants to distract themselves, by saying "I could do something instead" (13, male, mild, above DBC-ASA threshold). Parents also interrupted focused concentration when their child was struggling to disengage.

External cognitive change. Descriptions included parents assisting with cognitive restructuring, and the provision of compliments, mantras, and reframing, "They would

probably say 'it's okay. There's nothing to be scared about'" (20, female, moderate, below DBC-ASA threshold). Parents also gave alternatives, "Everyone [makes] mistakes" (22, male, mild, above DBC-ASA threshold).

External response modulation. Participants disclosed parents reminded them to take deep breaths, provided sensory management such as providing hugs or alone time, and reminded them to take their medication. These efforts were described as, "Help… calm myself down, if I… too upset" (19, male, moderate, above DBC-ASA threshold).

Limited emotional granularity

The participant's ability to describe their emotions was illustrated across three levels:

- Participants were able to identify emotions and used the following limited descriptive terms: Happy, angry, shock, gross, bored, tired, really pissed off, mad, cheeky, cranky, disappointment, frustrated, excitement, stressed, worried, wrong, anxiety, annoyed, confused, surprised, sad, afraid, nervous, shy, sick, regret, jealous, fear, furious, moody, good, calm, proud, upset, relax[ed], grouchy, overwhelmed, out of control, terrified, mean, hatred, and angst.

- Participants used less nuanced descriptions such as "Bad day emotions" (22, male, mild, above DBC-ASA threshold), and used adverbs to indicate heightened emotions such as, "very scared." Likewise, one participant was taught to use the blue zone (low mood), green zone (positive emotions), yellow zone (heightened emotions) categories to identify emotions; the context of this skill is unknown. Additionally, participants also mislabelled emotions, and described emotions using the following non-emotive words: curious, crying, sleepy, laughing, chatty, hurt, angelic, selfish, and insight. Assistive technology (i.e., communication app) was also used, the descriptive words were limited to: hungry, crazy, sad, happy, and mad.

- Participant reports were indicative of alexithymia, "[I feel] nothing" (13, male, mild, above DBC-ASA threshold), or responded with "I don't know" (20, female, mild, below DBC-ASA threshold) when asked about their emotional state; this response was consistent even when comprehension was confirmed.

Limited somatic insight

Participants struggled to describe their somatic symptoms in relation to their emotion regulation experiences, their insight is summarised into four levels:

- Able to describe their somatic symptoms as seen in the physiological sub-theme
- Able to identify the existence of a general somatic experience across the entirety of their body, but cannot pinpoint the location, "... my body feels weird when I'm nervous" (22, male, mild, above DBC-ASA threshold).
- Able to identify the location but not the somatic sensation: described as angry hands, angry face, angry arms, emotion in heart, angry in brain, sad everywhere in body, feels sad in head, "feel angry in my head" (17, male, moderate, below DBC-ASA threshold).
- Alexisomia was evident as some participants were unable to identify the location or the somatic symptom.

Limited metacognition

Metacognition is related to cognitive insight, and impacts an individual's capacity to utilise cognitive change. Specifically, participants struggled with cognitive insight, and at times did not use cognitive change. Several participants were unaware of the content of their thoughts, but were able to identify the related emotion, "I don't know what I'm worried about" (20, male, moderate, below DBC-ASA threshold). Participants were able to increase

their insight by discussing their concerns with their favourite characters. Reduced insight was also exacerbated when under stress, "I just get annoyed. Just stop thinking in my head" (13, male, mild, above DBC-ASA threshold).

Symbolic play

Participants reportedly used video game or cartoon characters to engage in symbolic play; the process of speaking to the character about their emotions or thoughts. This process facilitated cognitive change, specifically the following cognitive restructuring sub-themes: "generate alternative/ reframing," "problem solving," and "positive affirmations or mantras," "He'll [character] be like, don't talk shit about yourself. You are [a] beautiful woman" (19, female, moderate, above DBC-ASA threshold). Likewise, symbolic play also facilitated response modulation via the "communication" sub-theme, as this process assisted participants to externalise their internal processing, "I tell batman to help to make me calm down" (20, male, moderate, below DBC-ASA threshold). The participant's historical use of symbolic play is unknown.

Cross comparisons

Differences between participants above and below the DBC-ASA threshold were noted. Specifically, participants above the DBC-ASA threshold had a pattern of reporting: selection acceleration and deceleration, rumination, concentration, cognitive distortions, problem solving, positivity reorientation, perspective taking, aggressive behaviours and external attentional deployment. Whilst participants below the DBC-ASA threshold had a pattern of reporting: positive affirmations or mantras, generate alternative/reframing, and meditation. Of note, while participants above the DBC-ASA threshold tended to report cognitive distortions, both groups similarly reported cognitive restructuring. The remaining sub-themes were relatively comparable between both groups.

Chapter 10: Discussion

Dissertation Overview

Children and adolescents with intellectual disabilities are at an increased risk of developing emotion regulation difficulties, when compared to their typically developing peers (Munir, 2016). These difficulties are often expressed as co-occurring mental illnesses or behaviours of concern (Munir, 2016; Nicholls et al., 2022). Despite this, the process model of emotion regulation, which is arguably the leading regulation framework, has not been comprehensively considered in the context of this demographic (Gross, 2024; Samson et al., 2022). The aim of this dissertation was to determine the applicability of the process model to children and adolescents with intellectual disabilities, whilst simultaneously laying the foundation for process model-based patient-reported outcome measures (PM-PROMs). This aim was achieved through the five studies presented in this dissertation.

First a systematic review was conducted (Chapter 3; Girgis et al., 2021). The review aimed to determine the relevance of the process model, by means of identifying PM-PROMs currently validated for use with children and adolescents with intellectual disabilities. Second, service providers were surveyed to determine the real-world utility and applicability of the process model to this demographic (Chapter 5; Girgis, Paparo, & Kneebone, 2024c). Third, the applicability of the process model was determined, utilising an approach that drew on multi-informant and stakeholder perspectives. Initially, educator perspectives regarding the emotion regulation experiences of children and adolescents with intellectual disabilities were sought (Chapter 7; Girgis, Paparo, Roberts, et al., 2024). Next, the perspectives of parents were collected (Chapter 8; Girgis, Paparo, & Kneebone, 2024b). Finally, the direct perspectives of children and adolescents with intellectual disabilities on their emotion regulation experiences were gathered (Chapter 9; Girgis, Paparo, & Kneebone, 2024a).

Collectively, these five studies provide initial support for the applicability of the process model to children and adolescents with intellectual disabilities, laying the foundation for the development of future PM-PROMs that capture all five domains (situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2024).

Study 1 – A Systematic Review of Emotion Regulation Measurement in Children and Adolescents Diagnosed with Intellectual Disabilities

The systematic review built on prior work that confirmed the absence of PM-PROMs validated for autistic individuals with intellectual disabilities (Girgis et al., 2021; Weiss et al., 2014). Study 1 aimed to determine whether the current emotion regulation measures used for children and adolescents with intellectual disabilities assessed all five domains of the process model (situation selection, situation modification, attentional deployment, cognitive change, and response modulation; Gross, 2024). Additionally, the COnsensus-based Standards for the selection of health status Measurement INstruments (COSMIN) risk of bias checklist was used to determine the quality of the measures, as well as the relevance of the process model domains (Mokkink et al., 2018). Specifically, the checklist requires the relevance of theoretical frameworks to be determined prior to finalising PROM development (Mokkink et al., 2018; Terwee et al., 2018). This process also mirrors the initial steps required to develop PM-PROMs (Swan et al., 2023).

The review indicated an absence of PM-PROMs validated for children and adolescents with intellectual disabilities, with most measures excluded, as this demographic was omitted during measure conceptualisation (Girgis et al., 2021). Furthermore, the identified measures primarily overlapped with the response modulation domain—only one measure overlapped with four domains. Grading by the COSMIN risk of bias checklist

showed these measures did not adequately confirm the relevance of the process model domains. This is unsurprising, as no measures were specifically designed to measure these constructs. Overall, the review highlighted that the process model had yet to be directly applied to children and adolescents with intellectual disabilities and identified a lack of PM-PROMs validated for this population.

Study 2 – Would an Emotion Regulation Outcome Measure be Helpful for Children and Adolescents with Intellectual Disabilities? A Survey of Service Providers

In order to determine the relevance of the process model for children and adolescents with intellectual disabilities, the real-world usefulness of the model needed to be evaluated (Mokkink et al., 2018). Accordingly, Study 2 aimed to determine whether service providers regarded the process model as relevant and useful, and whether PM-PROMs were needed for services delivered to children and adolescents with intellectual disabilities (Girgis, Paparo, & Kneebone, 2024c). The results indicated that providers informally assessed the five domains of the process model, via clinical interview. Most providers expressed a need for PM-PROMs, and a preference for measures they could use with teacher and parent informants. The expressed need for PM-PROMs was correlated with experience and confidence, with less experienced providers more likely to endorse a need for PM-PROMs. Providers also expressed a preference for measures specifically developed for children and adolescents with intellectual disabilities. Despite this, providers indicated a tendency to use measures designed for the typically developing population, which likely reflects a combination of the following factors: multiple easily accessible PROMs for the typically developing population, a general unawareness of the limited available PROMS for children and adolescents with intellectual disabilities, and an overall scarcity of PROMs for this population. Thus, the results supported

the relevance of the process model to children and adolescents with intellectual disabilities and highlighted the need for PM-PROMS.

Studies 1, 2, and 3 — Comparisons Between Teacher, Parent, and Child and Adolescent Perspectives

A direct evaluation of the relevance of the process model was necessary, given its real-world utility (Study 2; Girgis, Paparo, & Kneebone, 2024c). With a view to laying the foundation for PM-PROMs, with separate recruitment, Study 3, Study 4, and Study 5 of this thesis, aimed to directly evaluate the relevance of the process model to children and adolescents with intellectual disabilities, by means of gathering teacher, parent, and child and adolescent perspectives, (Girgis, Paparo, & Kneebone, 2024a, 2024b; Girgis, Paparo, Roberts, et al., 2024). Overall, all three classes of informants supported the relevance of the process model. While the majority of sub-themes aligned between informants, several discrepancies between perspectives were noted, with the teacher study yielding the least number of sub-themes.

Situation Selection

Overall, all informant perspectives overlapped. However, discrepancies were noted, particularly in relation to teacher perspectives. Teacher perspectives did not include reports of "selection acceleration and deceleration". Additionally, although teacher reports did include instances of "location shift", "selection incapable", and "distressing selections", these reports did not eventuate into sub-themes. Potentially, this could reflect student demographics; however, as student information was not collected, this association cannot be confirmed. Only the teacher perspective included a "routine" sub-theme, but this mapped to the parent sub-theme of "selection inflexibility". Likewise, child and adolescent reports included instances of "selection inflexibility", but these reports also did not reach the threshold for

sub-theme formation. This may suggest that enforced structure, which is common in school settings, could be perceived as "routine", while self-driven routine could be interpreted as inflexibility. These findings emphasise the value of combining therapies with routine; for example, behavioural activation, a common situation-selection intervention, could benefit from being paired with structure and consistency.

Situation Modification

All informant perspectives endorsed the "incorporating or removing sensory elements" sub-theme. However, only the parent, and child and adolescent informants, reported "security within connection"; for instance, seeking close proximity to their parent when distressed. Teachers reported a similar sub-theme of "changing the relationship dynamic", which included student attempts to recruit others to their cause. While both sub-themes included a social aspect, the variability could be attributed to setting differences. For instance, children and adolescents may prefer social connection with their parents, while classroom settings may produce collective emotion regulation, a phenomenon that occurs in response to interpersonal interactions within a shared situation (Goldenberg, 2024). In this sense, the interpretation of dynamic changes may reflect a group-based emotion regulation strategy.

Attentional Deployment

All classes of informants reported "distraction", "concentration" and "rumination" sub-themes. However, only parents, and children and adolescents, reported a sub-theme of "worry". Teachers infrequently reported worry, as such, the threshold for sub-theme formation was not met. Reports of rumination and worry are unsurprising, given the association of these sub-themes with depression and anxiety, prevalent in up to 44% and 73% of individuals with intellectual disabilities, respectively (Edwards et al., 2022; Scheirs et al., 2023; Watkins et al., 2005). These sub-themes support the importance of attentional

deployment strategies, such as, mindfulness-based interventions, grounding techniques, and sensory based therapies designed to draw the individual's attention. One such program has been piloted in this demographic and resulted in successful attention redirection when distressed (Heifetz & Dyson, 2017). Mindfulness programs should be further explored for their usefulness in the management of worry and rumination in children and adolescents with intellectual disabilities.

Cognitive Change

All informant perspectives supported the "cognitive distortions" and "cognitive restructuring" sub-themes. The parent, and child and adolescent reports, completely aligned within the "cognitive restructuring" sub-theme. However, within the "cognitive distortions" sub-theme, no children or adolescents reported "mental filter/selective abstraction", "overgeneralisation" or "emotional reasoning". Also, only the teacher informants reported the "mislabelling emotions" sub-theme. This related to students regulating their emotions by stating their desired emotion instead of stating their current emotion; for example, stating they are happy when they are crying. This could perhaps reflect a high proportion of autistic students within this sample, as this strategy aligns with autistic communication patterns (American Psychiatric Association, 2022).

Teacher reports pertaining to "cognitive distortions" and "cognitive restructuring" were the least nuanced. The lack of reporting detail could be attributed to the teachers' predominant exposure to students who have moderate or severe intellectual disability. This is a cohort associated with considerable expressive language difficulties (American Psychiatric Association, 2022). The collective reporting of "cognitive distortions" and "cognitive restructuring" is congruent with research successfully applying cognitive behaviour therapy (CBT) to this demographic, as these themes are a core feature of CBT (Hronis et al., 2019, 2022). Of particular interest, cognitive change strategies were typically used during

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occurrences of low-intensity dysregulation. This aligns with current research findings, that reappraisal is a "costly" resource that is potentially inaccessible during episodes of high intensity dysregulation (Sheppes et al., 2011).

Response Modulation

The response modulation domain largely overlapped between all perspectives, with few discrepancies. Only teachers reported "stripping (non-sexual) and playing with bodily fluids". This may reflect the intellectual disability severity of their student cohort, as severe intellectual disabilities are more often associated with these behaviours (Emerson & Einfeld, 2011). Alternatively, parents, and children and adolescents, may not have reported this sub-theme due to embarrassment, as this demographic is often subject to discrimination (Ali et al., 2015).

Of particular interest, only parents, and children and adolescents, reported "expressive suppression," and only children and adolescents reported "thought suppression". These findings highlight the importance of capturing the voices of children and adolescents with intellectual disabilities, as suppression is an internal maladaptive strategy associated with psychopathology maintenance (Cavicchioli et al., 2023). This finding is of particular importance, as parents may be unaware that their children are suppressing their thoughts, or that they are experiencing the negative consequences of this strategy.

Additional Distinct Themes

With regard to additional themes, distinct from the process model domains, all informants reported some degree of "limited metacognition", and "limited emotional granularity". These results are unsurprising considering individuals with intellectual disabilities tend to experience difficulties with metacognition and emotive word generation (Igier & Valérie, 2022; Mellor & Dagnan, 2005). Limited insight also appears to correspond with the identification and selection stage of emotion regulation (Preece & Sikka, 2024). For

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instance, alexithymia can influence the activation of these stages, and impact the implementation of strategies, leading to emotion dysregulation (Preece & Sikka, 2024).

All informants reported external regulation, a sub-theme that is typically the focus of emotion regulation research concerning children (Gross, 2014). Within this context, the sub-themes associated with external regulation reflect emotion regulation goals; specifically, the goal is either other-focused non-social regulation (e.g., parent regulates child using parental resources), or self-focused social regulation (e.g., child or adolescent regulates their own emotions using parental resources).

However, only children and adolescents reported "limited somatic insight" and "symbolic play". This discrepancy is understandable, as somatic insight and symbolic play require knowledge of internal states and intention. The use of symbolic play to externalise cognition also aligns with a previous study, which found that this strategy is linked to more frequent use of internal state language (Hashmi et al., 2022). Additionally, the "limited metacognition" and 'limited somatic insight' sub-themes also indicate a degree of self-awareness, related to the emotion regulation monitoring stage.

Comparisons between Autistic Children and Adolescents with a Co-occurring Intellectual Disability and Children and Adolescents Only Diagnosed with an Intellectual Disability

The Developmental Behaviour Checklist-autism screening algorithm (DBC-ASA) was used to differentiate between autistic children and adolescents with a co-occurring intellectual disability (A-ID) and children and adolescents only diagnosed with an intellectual disability (O-ID). Discrepancies between the A-ID and O-ID groups were noted, but should be interpreted with caution, considering the small sample size and qualitative nature of the studies.

The A-ID group across both parent, and child and adolescent informants, reported the following sub-themes more often: "rumination", "concentration", "aggressive behaviours",

and "cognitive distortions". This is consistent with the literature, as A-ID are prone to hyperfocus, and are 2.5 times more likely to develop emotion dysregulation by way of mental illness than O-ID (American Psychiatric Association, 2022; Bakken et al., 2010).

Additionally, the A-ID group across both parent, and child and adolescent perspectives, more often reported "cognitive distortions", while parents more often reported the O-ID group used "cognitive restructuring". However, the child and adolescent informants reported comparable "cognitive restructuring", specifically, the A-ID group more often reported, problem solving, positivity reorientation, and perspective taking, while the O-ID group more often reported positive affirmations/mantras and generate alternative/reframing. These discrepancies align with findings suggesting maladaptive strategies (i.e., cognitive distortions) are greater predictors of psychopathology than adaptive strategies (i.e., cognitive restructuring; Aldao & Nolen-Hoeksema, 2012; Conklin et al., 2015). This is especially relevant when considering the higher incidence of mental illness in A-ID compared to O-ID (Bakken et al., 2010).

Of interest, the A-ID parent group more often reported "expressive suppression", while children and adolescents reported comparable frequency across both A-ID and O-ID groups. Whilst "thought suppression" was only reported by children and adolescents, with reporting comparable between A-ID and O-ID. Collectively, this could indicate that suppression strategies are partially undetectable to parents. This is problematic, as suppression is a maladaptive strategy (Geraerts et al., 2006). Overall, the similarities between these perspectives provides support for the relevance of the process model, while also highlighting internal emotion regulation experiences and use of different strategies across settings.

Research Implications

Collectively, the results of the service provider survey and the three perspectives (i.e., teacher, parent, and child/adolescent), support the relevance of all process model domains, and emotion regulation stages, to children and adolescents with intellectual disabilities. The findings also confirm that certain domains overlap. In particular, the situation selection and modification domains were interconnected, while attentional deployment predominately overlapped with cognitive change, and response modulation prompted the creation of new situations.

Although the situation modification domain was also relevant, the findings transcended its established definition of "modifying external, physical environments" (Gross, 2014, p. 10). Specifically, this population utilised social dynamics and connection, in addition to physical changes, to modify situations for the purpose of emotion regulation. These findings can be interpreted in two ways: either the data is reflective of emotion regulation goals, or the domain definition is missing a social element.

The use of social elements could reflect emotion regulation goals. Specifically, emotion regulation goals can be achieved via social or non-social means, or in other words from the resources of others or from an individual's own resources (Gross, 2024). In this context, there may be a dynamic interplay of emotion regulation goals between parents and their children. Using the example of hand holding, the child has a self-focused goal to modify a situation and uses non-social means to reach out and hold their parent's hand. Whilst the parent has an other-focused emotion regulation goal and uses social means to hold their child's hand. In this sense, "physical environments" could arguably include spatial positioning relative to others.

Alternatively, the findings suggest the situation modification parameters may potentially encompass social connection and dynamics beyond spatial positioning. In this sense, this domain could also represent internal modifications. This contradicts Gross's (2014) definition of this domain, which states that internal modifications only pertain to the cognitive change domain. However, the current findings suggest social dynamics and connection are separate from the cognitive change sub-themes and are better captured within the situation modification domain. A possible theoretical justification exists for incorporating internal modification within the situation modification domain. Specifically, situation modification is a representation of the emotion regulation strategies targeting the "situation" component of the emotion generation valuation system. The "situation" component refers to both internal and external situations (i.e., cognitions or physical environments), suggesting regulation strategies that map to this emotion generative point should also target internal mechanisms. Returning to the hand holding example, the question remains: Is the modifier the physical proximity or the social connection achieved via hand holding? Considering these findings and unanswered questions, the situation modification domain parameters should be further explored and clarified within the context of children and adolescents with intellectual disabilities.

Collectively, this body of work highlighted the emotion regulation experiences of children and adolescents with intellectual disabilities and supports the relevance of the process model to this demographic. It also noted the differing perspectives, particularly the variations in emotion regulation between A-ID and O-ID. This was only achievable with the input of three key groups of stakeholders: educators, parents, and children and adolescents. Particularly notable was the consideration of the direct perspectives of children and adolescents with intellectual disabilities. The inclusion of this population was made possible due to the following accommodations: informed consent was gathered with the assistance of

parents, easy-read consent forms, visual aids, and appropriate language considerations. Capturing the voice of this population enabled a comprehensive overview of the process model relevance, and highlighted discrepancies in the situation modification domain. Considering the value of these contributions, future emotion regulation research should endeavour to directly include the perceptions of children and adolescents with intellectual disabilities.

Limitations

These studies need to be considered within the context of several limitations. The systematic review only used a single coder to determine whether PROMs aligned with the five process model domains (Girgis et al., 2021). As such, coding reliability was not confirmed; however, coding was consistent with similar reviews (Weiss et al., 2014). Additionally, measures were excluded if the conceptualisation phase of development included autistic individuals. On reflection, measures should have been excluded only if the conceptualisation phase overlooked emotion regulation differences between autistic and non-autistic individuals with intellectual disabilities. While this amended criterion better adheres to the transdiagnostic framework (Astle et al., 2022), practically, it is unlikely the findings would have differed, given prior reviews conducted in this area failed to identify PM-PROMs validated for autistic individuals with intellectual disabilities (Weiss et al., 2014). This finding is further reflected in recent emotion regulation studies, which continue to note the lack of PM-PROMs for individuals with intellectual disabilities (Samson et al., 2022).

Regarding Study 2, the service provider survey was purposefully designed for the current research and was not validated, due to the absence of similar measures (Girgis, Paparo, & Kneebone, 2024c). Further, the survey largely reflected the opinions of female identifying providers, specifically, psychologists and behaviour therapists. It is unclear

whether other allied health professionals, or males, require PM-PROMs to the same degree. The survey was also limited to providers delivering services to children and adolescents aged 18 years and under. However, adolescence arguably ends at age 24 (Sawyer et al., 2018), meaning that the need for PM-PROMs for adolescents aged 19 to 24 years old remains unknown. Whilst this age group was better reflected in studies 3 to 5, it does not negate that PM-PROMs are needed for individuals aged up to 18 years old.

Concerning the qualitative studies, the themes were developed by a single coder, which aligns with the reflexive deductive guide and is adequate for determining the relevance of the process model (Braun & Clarke, 2006, 2019). However, according to the COSMIN guidelines, a PROM can only achieve the highest quality grade if two independent coders develop the themes (Mokkink et al., 2018; Swan et al., 2023; Terwee et al., 2018). To meet this provision, a second coder could review the raw qualitative data prior to PM-PROM item development. Additionally, all three studies examining educator, parent, and child and adolescent perspectives, minimally captured the experiences of individuals who do not use speech, which is a population regularly under-researched. This was due to difficulties recruiting non-speaking individuals, a common challenge concerning this population (Maes et al., 2021).

In terms of the teacher perspective (Study 3), this study yielded the least comprehensive sub-themes, especially within the cognitive change domain (Girgis, Paparo, Roberts, et al., 2024). This could be attributed to the use of focus groups, instead of interviews, as seen in studies 4 and 5. However, the consistency of the themes that emerged, across all informants, confirms that saturation was likely achieved[1]. This suggests theme

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[1] It should be noted, that whilst data saturation is not required when using the reflexive deductive analysis approach, saturation was sought in order to comply with the COSMIN-based PROM development process (Braun & Clarke, 2022; Mokkink et al., 2018; Swan et al., 2023; Terwee et al., 2018)

discrepancies may reflect setting differences and sample demographics rather than data collection methodology. Also, this study did not identify emotion regulation differences between A-ID and O-ID. Differentiation was not possible, as the aim of the focus group was to discuss the collective knowledge base of educators. Given this aim, informants were not prompted to specify student demographics when describing emotion regulation, and it is also unclear if educators were aware of the specific diagnoses of their students.

Studies 4 and 5 attempted to evaluate the differences between A-ID and O-ID (Girgis, Paparo, & Kneebone, 2024a, 2024b). Differentiating between these two groups was challenging, as only a fraction of participants had previously undergone formal autism assessments. As such, the DBC-ASA was used (Brereton et al., 2002). However, the DBC-ASA is not validated for adolescents over the age of 18 and an alternative measure has yet to be developed to include this group. Therefore, sub-theme differences at best reflect the possible presence or absence of autistic traits, as evaluated by the DBC-ASA threshold. Likewise, it remains unclear if sub-theme differences between studies 4 and 5 are due to participant demographics or genuine perspective differences (i.e., parent vs child/adolescent perspectives). This could be further explored in the future using dyad or triad studies, which would involve comparing a child's perspective with their parent's insights and/or their teacher's observations.

Future Research Directions

Future research should build on the qualitative studies in this body of work and pursue the development of PM-PROMs validated for children and adolescents with intellectual disabilities. In line with international standards, COSMIN should guide the development of such a measure (Swan et al., 2023). Specifically, the remaining PROM development steps should be completed, as previously outlined in Table 2.1. This would first involve a second

coder reviewing the interview and focus group transcripts, which would facilitate item generation. Subsequent steps would involve development of the response scale, expert review, piloting and refinement, and validation in a large sample. Additionally, emotion regulation differences between A-ID and O-ID should be considered during development. Potentially, this consideration could lead to either additional sub-scales or separate measures. Likewise, any measure should also account for the reported social element within the situation modification domain.

Study 5 extended prior research by directly capturing the voices of children and adolescents, a perspective often neglected. These direct accounts were possible due to the use of several accommodations, which should be integrated into future research to ensure the continued capture of these perspectives. Future PM-PROMs should also incorporate accommodations to facilitate the inclusion of non-speaking individuals, such as dynamic visuals (e.g., videos), easy-read language, text to speech, accessible fonts, and large text size (Maes et al., 2021; Mcclure et al., 2009; McDonald et al., 2022). Finalised PM-PROMs should also include self-report and proxy options, such as, teacher and parent informant versions. This aligns with best practice standards for emotion regulation assessment of children and adolescents, which recommend multimodal approaches, such as clinical interviews and multi-informant PROMs (De Los Reyes & Makol, 2019).

The lack of a validated PM-PROM has resulted in mixed results regarding the transdiagnostic classification of emotion regulation strategies (Compas et al., 2017). The validation of a PM-PROM could facilitate the investigation of transdiagnostic strategies, and potential causal relationships between strategies and mental illnesses, and subsequent therapeutic implications. Additionally, PM-PROMs could facilitate the exploration of perspective differences between parents and their children in dyad studies, as well as emotion regulation differences between A-ID and O-ID. This could also extend to exploring emotion

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regulation differences between various syndromes associated with intellectual disability, while also cross-comparing severity levels (i.e., mild, moderate, severe, and profound). Likewise, exploring emotion regulation changes across age groups would be useful, as between the ages of 10 and 12, emotion regulation skills tend to decrease (Moltrecht et al., 2021). Furthermore, the relationship between the emotion regulation domains and emotion intensity should be further explored; for instance, previous research showed that low emotion intensity is related to cognitive change, while high emotion intensity is related to attentional deployment (Sheppes et al., 2011). Lastly, PM-PROMs could be used to investigate the parameters of the situation modification domain.

Conclusion

To the author's knowledge, this body of research is the first to directly support the relevance of the process model of emotion regulation to children and adolescents with intellectual disabilities. Collectively, these findings advance emotion regulation research by highlighting the possibility that the situation modification domain may include a social element, with respect to this population. Additionally, this research has laid the foundation for the development of PM-PROMs for this demographic, a much-needed resource in this field (Samson et al., 2022). Most importantly, this research included the often-overlooked voices of children and adolescents with intellectual disabilities, thus revealing their unique lived experiences and internal worlds. In line with global advocacy for the full participation and equalisation of opportunities for people living with disabilities (Koontz et al., 2022), future research should encourage the active involvement of this demographic in decisions that impact them.

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Appendices

Appendix A: Ethical Approval for Studies

Subject: HREC Approval Granted - ETH16-0925

Date: Wednesday, 19 April 2017 at 10:45:20 am Australian Eastern Standard Time

From: Research.Ethics@uts.edu.au

To: Lynette Roberts, Mary Girgis, Research Ethics

Dear Applicant

Thank you for your response to the Committee's comments for your project titled, "The development of an emotion regulation scale for individuals with an intellectual disability". Your response satisfactorily addresses the concerns and questions raised by the Committee who agreed that the application now meets the requirements of the NHMRC National Statement on Ethical Conduct in Human Research (2007). I am pleased to inform you that ethics approval is now granted.

Your approval number is UTS HREC REF NO. ETH16-0925.

Approval will be for a period of five (5) years from the date of this correspondence subject to the provision of annual reports.

Your approval number must be included in all participant material and advertisements. Any advertisements on the UTS Staff Connect without an approval number will be removed.

Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually from the date of approval, and at the end of the project (if it takes more than a year). The Ethics Secretariat will contact you when it is time to complete your first report.

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

You should consider this your official letter of approval. If you require a hardcopy please contact Research.Ethics@uts.edu.au.

To access this application, please follow the URLs below:
* if accessing within the UTS network: https://rm.uts.edu.au
* if accessing outside of UTS network: https://vpn.uts.edu.au , and click on " RM6 – Production " after logging in.

We value your feedback on the online ethics process. If you would like to provide feedback please go to: http://surveys.uts.edu.au/surveys/onlineethics/index.cfm

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact Research.Ethics@uts.edu.au.

Yours sincerely,

Associate Professor Beata Bajorek

14 December 2021

Dear Professor Ian Kneebone,

Re: UTS HREC REF NO. ETH21-6627 – Do Health Professionals Require an Emotion Regulation Measure for Children and Adolescents with an Intellectual Disability?

Thank you for submitting your research project ethics application and the additional information for consideration by the GSH Local Research Office Ethics Panel which has delegated approval by the UTS Human Research Ethics Review Committee to review low risk research within the Graduate School of Health.

The Panel has considered the application and the additional information, and I am pleased to advise that the application has been approved.

Your approval number is UTS HREC REF NO. ETH21-6627.

Please note that the ethical conduct of research is an on-going process. The National Statement on Ethical Conduct in Research Involving Humans requires us to obtain a report about the progress of the research, and in particular about any changes to the research which may have ethical implications. This report form must be completed at least annually, and at the end of the project (if it takes more than a year).

I also refer you to the AVCC guidelines relating to the storage of data, which require that data be kept for a minimum of 5 years after publication of research. However, in NSW, longer retention requirements are required for research on human subjects with potential long-term effects, research with long-term environmental effects, or research considered of national or international significance, importance, or controversy. If the data from this research project falls into one of these categories, contact University Records for advice on long-term retention.

   To access this application, please follow the URLs below:
   * if accessing within the UTS network: https://rm.uts.edu.au
   * if accessing outside of UTS network: https://vpn.uts.edu.au

If you have any queries about your ethics approval, or require any amendments to your research in the future, please do not hesitate to contact me.

Yours sincerely,

Production Note:
Signature removed prior to publication.

Eddy Dharmadji
GSH Local Research Office
University of Technology Sydney

Appendix B: Qualtrics Survey Study 2

Introduction

At present there are not many questionnaires available to assess emotion regulation in children and adolescents (0 to 18 years old) diagnosed with Intellectual Disabilities (ID). This survey aims to determine if professionals working within the intellectual disability sector need such questionnaires and what might be included in them.

Screener

7. What is your profession?
   - ABA therapist
   - Behaviour therapist
   - Counsellor
   - Occupational therapist
   - Psychiatrist
   - Psychologist
   - School counsellor
   - Speech therapist
   - Other (please type response)

8. Are you currently working with children and adolescents (0 to 18 years old) diagnosed with ID? **Yes/No**
9. Please indicate which level of ID severity you work with? (Choose as many as apply)
   - Mild
   - Moderate
   - Severe
   - Profound
   - Unknown
10. How many years of experience do you have working with children and adolescents with ID, excluding breaks? (criteria is 12 months)
11. How many years total have you been working in your profession?
12. What percentage of your time/caseload do you spend working with children and adolescents with ID? (criteria 20% or more)

Demographics

- 7. What is your age?

- 8. What gender do you identify with?
    - Female
    - Male
    - Non-binary/third gender
    - Prefer not to say
    - Prefer to self-describe/other (please specify)

- 9. What is your ethnicity (Choose as many as apply)?
    - Indigenous Australian or Torres Strait Islander
    - Caucasian
    - Middle Eastern
    - Asian
    - African
    - North American
    - South American
    - New Zealander
    - Indian
    - European
    - Other (please specify)

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The following questions refer to your child and adolescent clients <u>with</u> Intellectual Disabilities (ID):

<u>Likert scale</u>

- Always
- Often
- Sometimes
- Rarely
- Never

10. How often do you use:

- d) Questionnaires in your practice?
- e) Questionnaires in your practice before you start treatment (tracking baseline)?
- f) Questionnaires in your practice after you start treatment (tracking progression)?

11. Do you use any of the following screener questionnaire(s)? Choose as many as apply.

- Depression Anxiety and Stress Scale (DASS)

- Spencer Children Anxiety Scale
- Strengths and Difficulties Questionnaire (SDQ)
- Beck Youth Inventory
- Developmental Behaviour Checklist
- Anxiety, Depression and Mood Scale (ADAMS)
- Kessler Psychological Distress Scale (K-10)
- Emotion Regulation Questionnaire (ERQ)
- Difficulties in Emotion Regulation Scale (DERS)
- The Mood and Feelings Questionnaire (MFQ)
- Screen for Child Anxiety Related Disorders (SCARED)
- Perth Emotion Regulation Competency Inventory (PERCI)
- Not Applicable
- Other (type response)

The following questions refer to your child and adolescent clients <u>without</u> Intellectual

Disabilities (ID):

<u>Likert scale</u>

- Always
- Often
- Sometimes
- Rarely
- Never

12. How often do you use:

d) Questionnaires in your practice?
e) Questionnaires in your practice before you start treatment (tracking baseline)?
f) Questionnaires in your practice after you start treatment (tracking progression)?

13. Do you use any of the following screener questionnaire(s)? Choose as many as apply.

- Depression Anxiety and Stress Scale (DASS)
- Spencer Children Anxiety Scale
- Strengths and Difficulties Questionnaire (SDQ)
- Beck Youth Inventory
- Developmental Behaviour Checklist
- Anxiety, Depression and Mood Scale (ADAMS)
- Kessler Psychological Distress Scale (K-10)
- Emotion Regulation Questionnaire (ERQ)
- Difficulties in Emotion Regulation Scale (DERS)

- The Mood and Feelings Questionnaire (MFQ)
- Screen for Child Anxiety Related Disorders (SCARED)
- Perth Emotion Regulation Competency Inventory (PERCI)
- Not Applicable
- Other (type response)

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14. Do you assess the following emotion regulation factors when working with children and adolescents with intellectual disabilities (ID)?

Likert scale

- Always
- Often
- Sometimes
- Rarely
- Never

h) Their ability to seek out positive or negative situations?
i) Their ability to modify situations to lessen the emotional impact e.g., <u>Choosing</u> to wear headphones or using sensory items when in stressful situations?
j) Their ability to use distraction as a strategy?
k) Their ability to shift their attention?
l) Their tendency to ruminate?
m) Their ability to change the way they are thinking, whether positively or negatively?
n) Their physiological or somatic experiences?

15. How do you assess the following emotion regulation factors when working with children and adolescents with Intellectual Disabilities (ID)?

Multiple choice. Choose as many as apply.

- Assessed using Clinical Interview
- Assessed using Questionnaires
- Assessed using Standardised Assessments
- Is Not Assessed (if chosen cannot choose other items)

h) Their ability to seek out positive or negative situations?
i) Their ability to modify situations to lessen the emotional impact e.g., <u>Choosing</u> to wear headphones or using sensory items when in stressful situations?
j) Their ability to use distraction as a strategy?
k) Their ability to shift their attention?
l) Their tendency to ruminate?
m) Their ability to change the way they are thinking, whether positively or negatively?
n) Their physiological or somatic experiences?

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<u>Likert scale</u>

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

16. Please indicate your preference regarding emotion regulation questionnaires for

children and adolescents with Intellectual Disabilities.

e) Would you prefer questionnaires that more broadly identify emotion regulation difficulties over diagnostic specific questionnaires?
f) Would you prefer diagnostic specific questionnaires over questionnaires that more broadly identify emotion regulation difficulties?
g) Do you need more resources to better identify emotion regulation difficulties?
h) Would you use an emotion regulation questionnaire specifically developed for children and adolescents with ID, over a questionnaire developed for the general population?

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These questions aim to determine which aspects of questionnaires would be helpful in

your current work with children and adolescents with Intellectual Disabilities.

<u>Likert scale</u>

- Very Helpful
- Somewhat Helpful
- Neither Helpful nor Unhelpful
- Not Very Helpful

- Not At All Helpful

17. In your practice, how helpful would the following be for your work with children and adolescents with Intellectual Disabilities?

f) Self-report emotion regulation questionnaires?
g) Parent-report emotion regulation questionnaires?
h) Teacher-report emotion regulation questionnaires?
i) School observations for identifying emotion regulation difficulties?
j) Questionnaires that assist with developing your case formulation (i.e., Identifying the cause of symptoms and maintaining factors?)

18. How helpful are questionnaires identifying the following for children and adolescents with Intellectual Disabilities?

o) Emotion regulation difficulties in school-based settings?
p) Emotion regulation difficulties in home-based settings?
q) Antecedent based strategies?
r) Where a break down occurs in the emotion regulation process?
s) Preventative strategies for emotion regulation difficulties?
t) Responses to environments and subsequent emotion regulation difficulties?
u) The usefulness of distraction for emotion regulation difficulties?
v) The relationship between concentration and emotion regulation?
w) The presence of rumination?
x) The ability to cognitively reframe situations?
y) The themes of successful emotion regulation?
z) Physiological or somatic experiences?
aa) The preferred environmental modifications needed to assist with emotion regulation?
bb) The function of behaviour?

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19. What are some barriers to using emotion regulation questionnaires for children and adolescents with intellectual disabilities?

Likert scale

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

s)   Your client's parents/supports have difficulties with reading?
t)   Your clients have difficulties with reading?
u)   Your clients are unable to comprehend the questions?
v)   The cost of the available questionnaires?
w)   It is difficult to acquire the questionnaires?
x)   The limited availability of reliable and valid questionnaires for this population?
y)   The available questionnaires take too long to fill out?
z)   The available questionnaires take too long to score?
aa) The available questionnaires do not inform diagnostic assessments?
bb) The available questionnaires are not aligned with the DSM 5?
cc) The available questionnaires do not inform treatment planning?
dd) The available questionnaires do not capture the client's lived experience?
ee) The available questionnaires do not add anything extra to clinical assessments?
ff) The available questionnaires do not offer any real-world utility?
gg) I am not trained in how to use the available questionnaires?
hh) The use of available questionnaires impacts rapport?
ii) The available questionnaires do not have non-English translations?
jj) The available questionnaires do not have Easy-English translations?

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One of the most used emotion regulation frameworks is the process model of emotion regulation (Gross, 1998, 2014). Below is a description of the process model. Please answer the following questions regarding the emotion regulation of children and adolescents with intellectual disabilities (ID) with this framework in mind.

 The process model of emotion regulation has 5 domains:

- **Situation Selection**
- **Situation Modification**
- **Attention Deployment**
- **Cognitive Control**
- **Response Modulation**

Below are the associated definition

Domain	Definition	Example
Situation Selection	Avoiding or seeking out situations	A child avoiding bath time by hiding or a child requesting their birthday presents early.
Situation Modification	Modifying the environment to alter the emotional impact.	Using headphones to help with homework
Attention Deployment	Redirecting attention: this can be grouped into three categories. Distraction Concentration Rumination	Distraction: child averting their eye gaze and focusing on a toy rather than their parents arguing.
Cognitive Change	Changing their thinking	Using self-talk to say your excited instead of anxious when presenting a class speech
Response Modulation	Changing behavioural, experiential, or physiological responses.	Using deep breaths to feel calmer

Please consider these definitions when answering the questions below.

20. Have you heard of the following elements of the process model?

Yes/No

    g) The process model of emotion regulation?
    h) The domain situation selection?
    i) The domain situation modification?
    j) The domain attention deployment?
    k) The domain cognitive change?
    l) The domain response modulation?

21. These questions aim to determine if the above framework is used in your practice.

<u>Likert scale</u>

    - Strongly Agree
    - Agree
    - Neither Agree nor Disagree
    - Disagree
    - Strongly Disagree

    h) Is the process model the dominate framework used with children and adolescents with ID in your field?
    i) Is your practice informed by this framework when working with children and adolescents with ID?
    j) Do you use questionnaires based on this framework?
    k) Should a questionnaire be developed using this framework for children and adolescents with ID?
    l) Would you use a self-report questionnaire based on this framework for children and adolescents with ID?
    m) Would you use a parent-report questionnaire based on this framework for children and adolescents with ID?
    n) Would you use a teacher-report questionnaire based on this framework for children and adolescents with ID?

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Therapy Confidence Scale—Intellectual Disabilities (TCS-ID; Dagnan et al., 2015)

These questions aim to determine how confident you are at each stage of the therapeutic relationship development when working with children and adolescents with Intellectual Disabilities.

<u>Likert scale</u>

- Highly Confident
- Confident
- Moderately Confident
- Slightly Confident
- Not Confident

22. How confident are you that you can:

p) Identifying where in the emotion regulation process a break down occurs for children and adolescents with an intellectual disability?
q) Listen carefully to concerns presented by a client with an intellectual disability?
r) Be empathetic towards a client with an intellectual disability?
s) Understand special issues related to having an intellectual disability and their impact on a person's life?
t) Communicate with a client who has an intellectual disability?
u) Develop a therapeutic relationship with a client who has an intellectual disability?
v) Gather information from a client with an intellectual disability so that their difficulties can be better understood?
w) Use assessments in a way that a client with an intellectual disability will understand?
x) Explain results of an assessment process to a client with an intellectual disability?
y) Use knowledge about mental health issues in formulating the problems of a client with an intellectual disability?
z) Help a client with an intellectual disability to identify issues that need to be considered in sessions?
aa) Use knowledge of mental health interventions to work effectively with a client who has an intellectual disability?
bb) Identify therapeutic approaches that will be effective for a client with intellectual disability?
cc) Work with care-givers and other important people in the lives of people with an intellectual disability?
dd) End intervention with a client who has an intellectual disability in an effective manner?

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End of Survey

We thank you for your time spent taking this survey. Your response has been recorded.

Please see below for relevant references:

Dagnan, D., Masson, J., Cavagin, A., Thwaites, R., & Hatton, C. (2015). The Development of a Questionnaires of Confidence in Delivering Therapy to People with Intellectual Disabilities. *Clinical Psychology & Psychotherapy*, *22*(5), 392–398. https://doi.org/10.1002/cpp.1898

Gross, J. J. (1998). The emerging field of emotion regulation: An integrative review. *Review of General Psychology*, *2*(3), 271–299. https://doi.org/10.1037/1089-2680.2.3.271

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Appendix C: Easy English Consent Form

PARTICIPANT INFORMATION STATEMENT

Dr Ian Kneebone   Mary Girgis

We are a research team. Mary is the person doing most of the research.
Ian helps when needed.

We want to know what you do to feel calm when you are feeling upset or angry

You will be in a group 1.5 hours or you can talk to Mary on the phone or at school. Mary will record you. Everything said on the recording will be written down. I will ask you if you can understand some questions. You will tell us how to change the questions to make them sound easier.

All the information will be kept in a locked cupboard or on a computer with a secret password. Only the people on the research team will look at the information. We will tell other people about the study and how it went, but we won't use your name.

We won't tell other people your name or what you tell us, unless it's to keep you safe, or as required by the law.

You can say yes or no to consent in the study.
You can say yes, but then change your mind.
If you do change your mind, everybody will still be happy with you.

You can ring Mary, at the University of Technology Sydney on 04xxxxxxxx for help about the study.

If you ever want to complain about the research you can ring a manager at the University of Technology Sydney on 9514 9772.

You can keep this information

Appendix D: Educator and Parent Interview Schedule

- General emotion regulation
  - How does your child/students regulate their emotions?
  - What triggers emotion regulation or dysregulation?
- Situation selection
  - How does your child/students choose and avoid situations?
- Situation modification
  - What strategies does your child/students use to manage their environment?
  - How is the physical environment changed?
- Attention deployment
  - How does your child/students redirect their attention?
  - Distraction
    - How does your child/students use distraction to manage their emotions?
  - Concentration
    - How does your child/students use concentration to manage their emotions?
  - Rumination
    - What does your child/students worry about?
- Cognitive change
  - How does your child/students change their thoughts?
- Response modulation
  - What strategies does your child/students use to manage emotions in the moment?

Appendix E: Child and Adolescent Interview Schedule

Note: Questions containing multiple emotions were asked one at a time. Prior to asking the questions below, the participants were asked whether the question applied to them, for example: "Do you worry?" If yes, then the following question was asked "how do you stop worrying." Participants were then asked to provide specific examples of when they used the reported strategy.

- General emotion regulation
  - What do you do when you are happy/sad/angry/scared?
  - When you are sad/angry/scared what do you do to feel better?
  - What are the names of some feelings?
- Situation selection
  - What is something you don't like to do?
    - When you are going to [insert example], what do you do to feel better?
  - When do you avoid things?
  - What are some of your favourite things?
    - How do you get them?
    - How can you get your [insert example] faster?
- Situation modification
  - How do you make a situation [insert example] better?
    - How does mum/dad help you?
  - When do you get cuddles from mum or dad?
- Attention deployment
  - Distraction
    - How do you forget about sad/scary/angry things?
    - Where do you look when you are happy/sad/angry/scared?
  - Concentration
    - What's something you can concentrate/focus on?
    - Is it hard to stop what you are doing?
  - Rumination
    - What do you think a lot about?
    - What do you worry about?
- Cognitive change
  - How do you stop worrying?
  - How do you change what you are thinking?
  - What do mum and dad say to help you feel better?
- Response modulation
  - What do you do when you are happy/sad/angry/scared?
    - Where do you feel happy/sad/angry/scared in your body?
  - How do mum and dad help you feel better?
  - When do you hide your feeling?
  - When do you fake your feelings?
  - When do you talk about your feelings?