#### interRAI 0-3 Assessment Pilot Study: Qualitative Report

### **Executive Summary**

This report is an external evaluation of the utility of the interRAI 0-3 assessment tool that was constructed and piloted since 2014. The interRAI 0-3 assessment tool was created to address concerns (e.g., developmental, medical, emotional, social, etc.) in very young children 0-47 months-old as well as their primary caregivers. The tool was piloted with community-based health professionals to ensure its utility in clinical settings. For the purpose of this external evaluation, ten assessors agreed to be interviewed to discuss their experiences, in addition to three site-coordinators who assisted in implementation of the tool at the agencies. The evaluation methods have been described in section 1.0 and data collection tools have been included in section 3.0 (Appendix A).

Findings indicate that the interRAI 0-3 assessment has great potential to deliver the following:

- 1) early identification (e.g., of developmental concerns in vulnerable populations)
- 2) case management (e.g., increase communication, influence referrals, etc.)
- 3) family considerations (e.g., caregiver distress, quality of life, etc.)
- 4) future considerations (e.g., educational readiness and family poverty).

The above deliverables have been discussed briefly in section 2.0 and in detail with supporting quotes in section 4.0 (Appendix B). The numerical headings in section 2.0 correspond to those in section 4.0. Assessors and site-coordinators listed several suggestions to improve the assessment to better serve families and their very young children. The logistical information (i.e., practical notes for tool implementation) has been provided in a full report to the interRAI 0-3 team.

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#### Key terms

- Assessor: nurse, clinician, therapist, etc. who utilized the assessment for the pilot project
- <u>Client</u>: one of the children or families on which the interRAI 0-3 assessment was applied
- <u>Logistical information</u>: comments on practical implementation on the interRAI 0-3, such as advice for future assessors, missing information, software feedback, etc.
- <u>Participant</u>: one of the assessors or site coordinators who was interviewed for this study
- <u>Site coordinator</u>: program managers/directors who agreed to have their staff volunteer for the interRAI 0-3 study and conduct assessments at the agency with their clients
- ...: missing information (i.e., quote taken from a larger piece of text)

#### interRAI 0-3 Components

- <u>Items</u>: individual questions on the assessment (e.g., biological sex, date of birth, etc.)
- <u>Collaborative Action Plans (CAPs)</u>: an outcome from the assessment that offers suggestions for evidence-informed decision making to address various issues "triggered" by the interRAI 0-3. Each CAP has a unique triggering algorithm based on a series of specific items that capture the area of need. CAPs can have two or three levels of triggers that can include triggers for immediate concern, level or risk, or prevention/reduction. The CAPs that have been triggered from the completion of the interRAI 0-3 assessment form may be used to support decision-making strategies to support the current needs of the child.
  - o Attachment CAP
  - o Caregiver Distress CAP
  - o Caregiver Informal Support CAP
  - Communication CAP
  - Gross and Fine Motor CAP
  - Dressing CAP
  - o Nutritional Intake CAP
  - Parenting CAP
  - Physical Activity CAP
  - Problematic Eating CAP
  - o Physical Activity CAP
  - Problematic Eating CAP
  - Sensory Issues CAP
  - o Sleep Management CAP
  - Social Engagement CAP
  - Emotional Regulation CAP
  - Toilet Training Readiness CAP
  - o Transitions Planning CAP
  - Traumatic Life Events CAP

## **1.0 Methods**

As part of the interRAI 0-3 pilot project, individuals who had completed the interRAI 0-3 training and assessments (i.e., assessors) were recruited to participate in focus groups about their experiences with the assessment tool. Together, the Wilfrid Laurier University (WLU) research team (authors on this report) and the Western research team (creators of interRAI 0-3) created a semi-structured focus group guide based on the pilot project deliverables (deliverables listed in Table 7). The protocol and focus group guide were approved by both the Western and WLU Research and Ethics Boards (REB).

#### **1.1 Protocol**

The project coordinator was responsible for contacting site coordinators of participating agencies with a list of assessors who could participate in the external evaluation focus groups. The interRAI 0-3 research team was responsible for ensuring that confidential information was not shared with the external evaluation team, as assessors did not provide consent for their contact information to be shared beyond the interRAI 0-3 research team. The site coordinator then contacted the assessors and asked if they were interested in participating in a focus group. If the assessors were interested, they were instructed to contact the principal investigator directly.

After two rounds of recruitment e-mails, there were too few assessors (n=4) to conduct focus groups and the protocol was changed to one-on-one interviews. The WLU research team felt that interviews afforded more detail from a smaller pool of participants while reducing the barriers associated with focus groups such as length of focus group (i.e., 2 hours), leaving the workplace, and speaking about personal opinions in front of peers. Further, site coordinators were included to provide additional perspectives on the utility of the interRAI 0-3 assessment from a managerial, agency-wide implication viewpoint. The coordinators may have attended the training but did not employ the interRAI 0-3 with families.

After attaining ethical approval from the WLU REB for the new interview protocol, the project coordinator conducted a third round of recruitment. Ten assessors and three site coordinators agreed to participate (i.e., participants) in one-on-one interviews with the principal investigator. The interviews were conducted on the phone at a time convenient to the participants in February and March 2019 (see Appendix A for interview guide). The interviews ranged from 25 minutes to 83 minutes in length, with the average of 45 minutes. Participants also completed a background questionnaire to provide demographic information and a summary of their experiences with the assessment (see Appendix A for the questionnaire). Each interview was audio-recorded, transcribed verbatim (i.e., typed word for word into a Word document) using DragonSpeak 15 transcription software, and supplemented with field notes such as emphasis, non-verbal data (e.g., pauses), interview length, and time and date of interview to create a complete transcript.

#### 1.2 Analysis

The principal investigator examined all thirteen transcripts in the form of a content analysis (see Bengtsson, 2016). In the content analysis, each interview was read several times to

understand what the participants were saying about the interRAI 0-3 assessment tool. The principal investigator made notes about each transcript to develop themes in which to organize the data. These themes were created with the deliverables in mind (see Table 7 for a list of deliverables). The transcripts were then imported into NVivo 12; a software to organize textual data in qualitative research.

The principal investigator used the previously determined themes to create "nodes" in NVivo and aggregated text from the transcripts into the appropriate theme (or node). In this way, all the quotes about a particular theme were listed together, but they were still connected to the full transcript, thus maintaining contextual information from the conversation. Therefore, no quotes were taken out of context from the participants' conversations. The principal investigator then read all the quotes within the nodes to create a summary of the data. These summaries have been organized into two overarching themes: deliverable information (section 2.0 and Appendix B) and logistic information (report provided to interRAI 0-3 team).

#### **1.3 Participants**

All participants self-identified as female; ten were assessors and three were site coordinators. Participants had been employed an average of 14.4 years at their current workplace and all had more than ten years of experience in their field. All participants have been assigned pseudonyms in this report to maintain confidentiality. Other demographic information has been aggregated in the tables below.

<i>Table 1: Participant age</i> (n=13):					
18-24 years old	n=0	45-54 years old	n=5		
25-34 years old	n=0	55-64 years old	n=2		
35-44 years old	n=6	65-74 years old	n=0		
2		5			
Table 2: Highest degree of	of education (n=13):				
Undergraduate	n=6	PhD	n=1		
Masters	n=4	Other	n=2		
Table 3: Professional bac	ekground (n=13):				
Social work	n=4	Nurse/registered nurse	n=4		
Occupational therapist	n=4	Speech-Language Patholog	ist n=1		
<i>Table 4: Number of completed assessments for the pilot project</i> (for n=10*):					
5 to 7	n=3	14 to 16	n=0		
8 to 10	n=1	17 to 19	n=2		
11 to 13	n=2	20+	n=2		
* assessors only, site coordinators did not complete assessments for the pilot project					
-	-	-	1 0		
<i>Table 5: Confidence in using the tool</i> (for n=10*):					
Not at all	n=0	Confident	n=4		
Somewhat	n=3	Very confident	n=3		

\* assessors only, site coordinators did not complete assessments for the pilot project

#### **1.4 Important Considerations**

The purpose of the interRAI 0-3 pilot was to evaluate the assessment tool. This external evaluation was one piece of the pilot project to gather feedback in order to finalize the assessment for improved clinical utility. Ten assessors and three site coordinators participated in interviews about their experiences with the interRAI 0-3 tool. All assessors attended the interRAI 0-3 training and implemented the assessment for the first time during the pilot project. Several deliverables were listed as important to this research; information about which can be found in sections 2.0 and 4.0 and Table 7. Participants were also asked to comment on the logistics of the tool (i.e., practical notes regarding tool implementation); responses summarized in the logistical report given to the interRAI 0-3 team.

Overall, the participants had many positive comments about the interRAI 0-3 tool, but they also questioned its practical implications. The most frequent words used to describe the tool were comprehensive, detailed, long, and intrusive (see Table 6). There were positive comments, such as thorough, helpful, holistic, and standardized, in addition to negative comments such as overwhelming, daunting, time-consuming, and irrelevant (see Table 6 at the end of this section for more detail). On the whole, participants felt the interRAI 0-3 could be useful at a variety of levels (e.g., with families, across agencies, government statistics, etc.) with some changes.

Three site coordinators were included in this external evaluation to gain an additional perspective into the use of interRAI 0-3 at an agency level. The purpose of including these individuals was to enrich the data, as their perspectives differed from those who actually applied the assessment with families. Upon analysis, it was noticed that the site coordinators had a more positive outlook on the interRAI 0-3 than the assessors. For instance, when asking about whether the tool meets the deliverables, the site coordinators typically answered yes or at least said the tool had potential, whereas the assessors were more diverse in their responses. Where possible, it has been highlighted if the site coordinators had differing opinions from the assessors to ensure an accurate picture of the practical use of the interRAI 0-3.

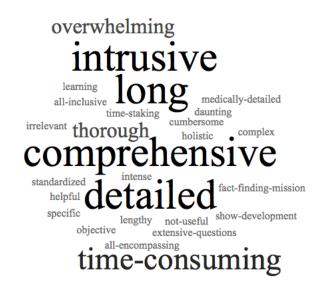
Before delving into the findings, it is important to note that the interRAI 0-3 CAPs were not yet published at the time of this pilot research, which affected assessors' interactions with the tool. Participants could access the CAPs on the interRAI 0-3 software, but otherwise had little insight for questions regarding the CAPs and their utility. Second, agencies were not implementing the interRAI 0-3 assessment as part of standard of care and agency protocols were likely adhered to while facilitating the interRAI 0-3 assessments. With the pilot nature and the professional designation of the assessor participants in the interRAI 0-3 pilot project, they were responsible for ensuring client needs. In this way, participants assisted with the validation of interRAI 0-3 assessment along with their agency standard protocol. In sum, due to the stage of development of this tool, the limited availability of CAPs, and the pilot nature of this project, the majority of participants did not use CAPs for client referrals. Some participants used the tool to validate the referrals they already made (i.e., to confirm a treatment plan), while others did not apply information from the CAPs at all.

The last consideration to note when reading this report is timeliness, as assessors completed their last assessment four to six months prior to their interviews. This could be attributed to a variety of factors, but primarily due to the staggered nature of the pilot research. For instance, agencies may have been trained as early as November 2016, but they did not do the interview until March 2019. Their use of the tool could have occurred at any point between training and the assessment completion date of January 31<sup>st</sup>, 2019. As a result, participants relied on distant memories when answering the questions. However, some participants asked to see the interview guide before doing interviews so they could review the questions and refresh their memories of the interRAI 0-3. Readers should keep these considerations mind when reading the following report.

#### Reference

Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, *2*, 8–14. DOI: 10.1016/j.npls.2016.01.001

*Table 6: Words to describe the interRAI 0-3.* Word frequency bubble (i.e., larger text signifies more frequent use of the word).



# 2.0 Summary of Deliverables

Many deliverables were highlighted as important to this pilot study, which were then used in the creation of a semi-structured interview guide. In the analysis, the deliverables have been organized into four themes: 1) early identification, 2) case management, 3) family considerations, and 4) future considerations. See Table 7 for details about whether the deliverables have been met and in which section they have been addressed. Also see Appendix B for the supporting quotes for these sub-themes.

*Table 7: interRAI 0-3 deliverables.* Deliverables coded as met or has potential (i.e., not met, but participants expressed potential for the interRAI 0-3 to meet the deliverable with the suggested changes in sections 2.0 and 4.0). Section 4.0 (Appendix B) has also been referenced with the table, as that is where supporting quotes have been listed for each deliverable.

	Met or Has	
Deliverable	Potential	Section
Improved identification of developmental, behavioral and socio-	Has potential	2.1.1, 4.1.1
emotional problems in young children		
Deliverable: Improved early identification of developmental,	Has potential	2.1.1, 4.1.1
behavioral and socio-emotional problems		
		2.1.1, 4.1.1
Intent: Increase the number of young children who are	Has potential	
identified with developmental/behavioral/emotional problems;		
Improve the assessment process to be more comprehensive		
Improved school readiness for these high-risk children	Has potential	2.4.1, 4.4.1
leading to improved likelihood of employment and improved		
financial outcomes in later life.		
Reduced suffering and poverty for these families as parents	Has potential	2.4.2, 4.4.2
will also receive supports to enhance outcomes and receive		
access to needed respite, food banks, informal and formal		
supports.		
<b>Deliverable:</b> Improvement in caregiver distress, social support,	Has potential	2.3, 4.3, 2.4,
school readiness, sleep, feeding, parenting, improved child and		4.4
family well-being.		
Intent: Early identification and intervention lead improved	Has potential	2.1.1, 4.1.1,
quality of life for families and their children, such as parental		2.3, 4.3
skills and child development immediately and in future.		
<b>Deliverable:</b> Improved care planning with the interRAI 0-3.	Has potential	2.2, 4.2
Intent: Increase the number of young children who receive	Has potential	2.1.2, 4.1.2
evidence-based treatment for services and best practice; Provide		
specific care planning needs for children of LBW		
<b>Deliverable:</b> Reduced problems with fine and gross motor	Has potential	2.1.1, 4.1.1
development, improved sensory integration, reduced mental		
health, behavioral, emotional and social issues, etc.		
		2.1.2, 4.1.2

Has potential	
Has potential	2.2.4, 4.2.4
Has potential	2.2.5, 4.2.5
Has potential	2.2.4, 4.2.4
Has potential	2.3.2, 4.3.2
Has potential	2.3.2, 4.3.2
Has potential	2.2.6, 4.2.6
Has potential	2.2.3, 4.2.3
Has potential	2.2.5, 4.2.5
Has potential	2.3.2, 4.3.2,
_	2.2.5, 4.2.5
Has potential	2.2.4, 4.2.4
	Has potential Has potential Has potential Has potential Has potential Has potential Has potential Has potential Has potential

#### 2.1 Early Identification

Across several deliverables, this pilot project sought to answer the question: can the interRAI 0-3 contribute to early identification of developmental issues, particularly for vulnerable children and families? To address this deliverable, transcript data were coded into two key sub-themes, which were increased identification of developmental issues and early identification of vulnerable populations.

Participants had different and sometimes conflicting opinions about the utility of the interRAI 0-3 for early identification. Reasoning for the polarity of responses was primarily due to the stage at which participants utilized the interRAI 0-3. The interRAI 0-3 was still in the developmental stage and components were changing as the pilot project went on. Therefore, the participants used this assessment tool in addition to their own assessments and simply validated whether or not the interRAI 0-3 highlighted the same concerns as they had already established.

Participants primarily conducted the assessment on current clients who had already been assessed due to the pilot nature of this project. In addition, it was mentioned that the interRAI 0-3 did not affect early identification because the young children have already been assessed by the time they have been referred to their services. Thus, if the clients' concerns were already

identified by the time they were referred to the assessor, the assessors could not have identified them any sooner. That said, the interRAI 0-3 did identify some concerns within the ages of 0 to 47 months of age, and in that way, it did contribute to early identification even if the child had been previously identified in the cases selected for the pilot project.

#### 2.1.1 Early Identification of Developmental Issues

When asked if the interRAI 0-3 could be used to identify developmental, behavioural, and/or socio-emotional problems in young children, six participants said yes (two SCs), five said no, and two were neutral (one site coordinator). The six participants who felt positively about the interRAI 0-3's ability to address concerns early in life felt that it was very detailed. In addition, the interRAI 0-3 would be particularly helpful for clinicians because it facilitated conversation about a variety developmental issues that may not fit within the scope of their expertise. Conversely, five participants felt that the interRAI 0-3 had limited capacity for identification of developmental issues as it was not sensitive enough to capture minor concerns in their clients. Further, they did not actually have the ability to use the interRAI 0-3 in this manner (i.e., for identifying concerns). Shorter screening tools were preferred in addition to tools that could identify smaller gaps in development in very young children.

#### 2.1.2 Early Identification of Vulnerable Populations

Another sub-theme across the deliverables was to identify concerns for vulnerable populations, such as children with low birth weight, traumatic experiences, neglect, and other factors that could contribute to vulnerability. Regarding whether or not the interRAI 0-3 could identify issues for vulnerable populations, seven participants said no, five said yes, and one had no comment because she *"did not come across that"* (Bailey). The context was similar to that described above: the interRAI 0-3 may not have been applied for this purpose in the pilot project, but had potential once implemented in its full form.

#### 2.1.3 Summary

There is potential for the interRAI 0-3 to influence early identification of developmental concerns in vulnerable populations; however, increased sensitivity is warranted to ensure children with less severe concerns can also be identified. Specific suggestions regarding which information should be added to the interRAI 0-3 has been provided in a report to the tool development team. Further, answering the question of who is going to use this assessment and when would also contribute to early identification, as many concerns were flagged before this tool was used in the first place.

#### 2.2 Case Management

Another goal of the interRAI 0-3 is to assist clinicians in managing clients, in which there are many factors, such as understanding client needs, communicating with others, and referring to other healthcare professionals. The theme of case management has been divided into six sub-themes discussed below. Note that many participants felt similarly about case management as they did regarding early identification: due to the pilot nature of this project, participants utilized

their pre-established methods for managing their caseloads meaning the interRAI 0-3 may not have been applied in practice.

#### 2.2.1 Comprehensiveness

The purpose of the interRAI 0-3 is comprehensiveness; touching on key areas of health that could be pertinent in infancy. Participants were asked which words came to mind when thinking of the interRAI 0-3, and four used the word comprehensive as a descriptor (see Table 6). When asked specifically if the interRAI 0-3 tool is comprehensive, seven participants said yes (one site coordinator) and four said *"it's getting there"* (Grace). One of the site coordinators felt she did not have enough first-hand experience with the interRAI 0-3 to comment on comprehensiveness. Interestingly, one assessor questioned the value of using a comprehensive tool as it will never meet all needs of every complex child she comes across.

#### 2.2.2 Tool Utility

In the interviews, participants were asked whether they have applied any information from the interRAI 0-3, specifically CAPs, to support their clients. As the CAPs were not fully available at this stage of this research (i.e., latest draft copies were available in the software, but nowhere else), participants reflected on their limited experiences with the outcomes. Further, participants did not use the tool on new families due to the pilot nature of this research. Eight participants said they did not see any completed CAPs. Further, CAP triggering may not have been sensitive enough to address minor concerns, such as small delays in development. That said, participants said the CAPs have potential to help clinicians validate their decisions for care. One assessor was unsure about practical application of the interRAI 0-3 CAPs due to the limited time frame of the pilot project. She would have liked follow-up with the families she piloted over time and also to work with the completed tool. Alternatively, a different assessor said that other tools could be just as effective and more user friendly than the interRAI 0-3 CAPs. It is possible that opinions on the CAPs were more negative because they were not published at the time of the pilot and sometimes did not trigger appropriately.

#### 2.2.3 Clinician Awareness

The interRAI 0-3 sought to improve healthcare providers understanding of the young children's needs, meaning that a clinician's awareness of early concerns may be enhanced after they employed the interRAI 0-3. The goal of improving clinical awareness is to ensure the child receives adequate care by improving communication between healthcare providers, increasing appropriate referrals, and reducing duplications. Participants discussed whether the interRAI 0-3 tool helped to raise their awareness of needed supports or perhaps other clinicians at their agency. Five participants felt they did not learn anything new from the interRAI 0-3 and four felt the interRAI 0-3 did not help to raise their awareness of clients' needs. However, four participants felt they learned about early development from using the interRAI 0-3 and four felt the interRAI 0-3 stimulated conversation between clinicians and families. Specifically, one assessor said the interRAI 0-3 did not affect her awareness overall, but prompted her to ask about potential issues earlier in time. Participants were also asked whether the interRAI 0-3 could help

to raise awareness of other clinicians at their agency, of which eight participants (three site coordinators) said yes and one said no.

#### 2.2.4 Referrals to Programming

Another deliverable from the interRAI 0-3 pilot project was to facilitate appropriate referral for children, in addition to assistance with triaging and prioritizing needs. There were mixed feelings on this particular topic with reference to the stage of research. Nine participants (one site coordinator) said that the interRAI 0-3 did not affect the number of referrals to care. Alternatively, five assessors and two site coordinators felt the interRAI 0-3 *could* affect referrals in the future (i.e., when CAPs are finalized, when the tool is used over time with families, etc.), three of which were part of the group listed above who said the interRAI 0-3 was not used for referrals.

#### 2.2.5 Reduced Duplication of Information Intake and Service Provision

To protect families from unnecessary expenses and stressors, it is important to reduce duplication of information intake (e.g., the amount of times a family must provide information to a clinician) and reduce duplication of services provided (e.g., ensure a family does not get referred to the same services by different clinicians). Seven participants said that the interRAI 0-3 did not play a role in reducing duplication of services at their agencies, five said that theoretically it could reduce duplication (three site coordinators), and one person answered no to reducing duplication, but yes to potentially filling that need in the future. There were some issues highlighted with respect to redundancy of information with families. Six participants (one site coordinator) said the interRAI 0-3 duplicates their current information collection system, so for the purpose of this pilot study they were recording family data twice. This was expected because the participants used the interRAI 0-3 in tandem with their current data collection procedures.

Another area of duplication pertained to families. While this is beyond the scope of the interRAI 0-3 pilot project and external evaluation, participants discussed the stressors experienced by families who repeatedly met with new clinicians. Accessing resources may be particularly draining for families as they are expected to repeat their "story" (i.e., their child's concerns and their experiences with healthcare professionals thus far) to every clinician they meet. The participants were aware of this issue and commented on privacy barriers (i.e., cannot share information between clinicians) and the additional work they do to compensate. Four participants (one site coordinator) felt that information sharing between agencies would mitigate this issue, but privacy regulations do not allow for this sharing. Five assessors reviewed existing client files to reduce the number of questions they needed to ask during the assessment, but three of these individuals also felt doing this preparation added significantly more work to their overburdened caseload.

#### 2.2.6 Communication of Needs

Complex children may have a variety of healthcare providers involved in early life and the interRAI 0-3 sought to improve communication between clinicians. More specifically, a goal of the interRAI 0-3 is to establish common language amongst the healthcare team. When asked if

the interRAI 0-3 contributed to common language, seven participants (three site coordinators) said yes, three said potentially, and three said no. Participants said the interRAI 0-3 could contribute to common language if used widely (i.e., across sectors) and if information was available to share between clinicians and agencies, but as it currently stands, the interRAI 0-3 has not yet contributed to common language. As mentioned above (2.2.5), information sharing is beyond the scope of this research, but it could contribute to common language between clinicians.

Looking at use of the interRAI 0-3 more broadly, participants were asked if information collected in this assessment could serve across sectors, potentially affecting communication at a higher level of service provision. Eight participants (two site coordinators) felt the interRAI 0-3 would be effective for serving across sectors, while five (one site coordinator) said it had great potential but needed "*to be massaged a bit*" (Wendy, site coordinator), meaning it needed adjustment before applying it in a clinical setting. That said, participants saw the value of using standardized assessments for comparing quality of care across sectors and directing government funding.

#### 2.2.7 Summary

Case management is a significant component of interRAI 0-3 utility. Participants felt the interRAI 0-3 was comprehensive or at least close to comprehensive, despite the fact that majority did not see the CAPs or apply them in practice. Further, the interRAI 0-3 contributed to clinician knowledge and could facilitate important conversations with families. The interRAI 0-3 did not contribute to increased referrals or reduced duplication as participants were using it in tandem to already established practices at their respective agencies. That said, participants felt the interRAI 0-3 had great potential for creating a common language between clinicians and could serve across sectors, particularly with respect to government level analyses of care quality. To improve the utility of the interRAI 0-3, agencies must reduce barriers – most notably information sharing barriers (i.e., privacy) – and enhance user convenience. This tool has the capacity to affect case management at a variety of levels, but several improvements are necessary before it could be utilized in practice, namely increased sensitivity while maintaining (or improving) brevity. Participants suggested improvements that are presented in the *Summary of Logistics*, sound in section 3.0.

#### 2.3 Family Considerations

With clinical use of the interRAI 0-3, concerns for children 0-47 months and their caregivers may be identified. The parents and guardians of vulnerable children undergo considerable stress that may contribute to caregiver distress, parenting, and overall quality of life. The interRAI 0-3 pilot explored the following deliverables: 1) improvement in caregiver distress, social support, parenting, and improved child and family well-being; 2) early identification and intervention leading to improved quality of life for families and their children, such as parental skills and child development immediately and in future; and 3) improved access to interventions and treatment with documented current receipt of psychological/psychiatric treatment, occupational therapy, infant therapists, speech and language, social work. These deliverables have been divided into five sub-themes below.

#### 2.3.1 Support Families

Participants were asked whether they believe the interRAI 0-3 could be used to support families, including the parents, children, and siblings. This question was asked hypothetically, as the interRAI 0-3 was in the pilot stage and participants did not actually use it in this way. Eight participants (three site coordinators) felt the interRAI 0-3 could be used to support families, but each presented a caveat about its utility, while five assessors said this tool would not be useful in family support.

While assessors acknowledged where the interRAI 0-3 would fill a need in supporting families, one of the caveats presented regarding caregiver support was limited access to CAPs and limited sensitivity for highlighting concerns in some cases. On the other hand, this tool could be just as effective, if not more so, than tools already being implemented at the agencies. Three assessors answered no when asked if the interRAI 0-3 could support families, but later in their interview discussed its utility in this area (therefore coded as yes). One assessor felt the interRAI 0-3 could help family members perhaps more than children due to their young age.

While the interRAI 0-3 could create a picture of a family's needs, it could be that not all participants would require all of the information in their practice. For instance, one participant gave the example that information about the maternal history is not necessary in the emergency room to help a child in crisis. She recognized this information would be important in time, but not within the time of her working with the family. Overall, participants felt the interRAI 0-3 could support parents and children, but less so with siblings. The lack of sibling information contributes to sensitivity issues with the interRAI 0-3 in accurately capturing a family's needs. That said, if a family has a concern with a sibling, another interRAI assessment could identify those concerns.

#### 2.3.2 Helping Families Gain Access to Resources

The interRAI 0-3 aims to help families' access interventions and treatment, to which five participants felt the interRAI 0-3 could indeed improve access to resources. That said, three participants (two site coordinators) highlighted it was not the use of the interRAI 0-3 that would increase access to resources, but the healthcare professional. Three participants said using the interRAI 0-3 would not improve access and one said she was not sure. Participants reasoned that many organizations already have procedures in place to ensure families have access to the resources they need, and therefore the interRAI 0-3 did not contribute to increased awareness.

When asked if the interRAI 0-3 could improve families' access to resources, one assessor said "... no, because it didn't list the resources." Therefore, if the interRAI 0-3 listed suggested resources (i.e., within the CAPs), it could be more effective in helping families gain access. The interRAI 0-3 can be used to prompt conversations, but the healthcare professional must know if the resources available in order to direct families. Once an issue has been highlighted on the interRAI 0-3, the healthcare professional could make referrals based on relevant information, such as the CAP and local resources available. It is important to note that participants responded hypothetically to this question as their clients have already been assessed and referred during

*this pilot study*. Similarly, if the final CAPs were published, those could be utilized as support for making referrals.

#### 2.3.3 Caregiver Distress

Caregiver distress is an important consideration when assessing the wellbeing of very young children, and therefore is a deliverable of the interRAI 0-3. Participants were asked if the interRAI 0-3 could identify or address caregiver distress. Seven participants (three site coordinators) felt the clinical utility of the interRAI 0-3 assisted with the facilitation of conversations between the professional and caregiver that stimulated the healthcare provider to suggest further resources. It could be that the interRAI 0-3 outcome may have triggered for concerns regarding caregiver distress, but the participants did not pilot the interRAI 0-3 on a family where that was a concern. Contrarily, six participants felt the interRAI 0-3 was not capturing the needs of parents with respect to caregiver distress. One assessor offered a unique perspective on the interRAI 0-3 and said her experiences with caregiver distress varied (i.e., *"it worked some of the time"*).

With respect to suggestions for the interRAI 0-3, one assessor and one site coordinator (who had positive and negative responses to caregiver distress, respectively) both discussed the possibility of the interRAI 0-3 *causing* caregiver distress if not used appropriately. For instance, a parent could get distressed if they noticed their child was not meeting developmental milestones as a result of doing this assessment. It is noteworthy however, that this issue would result from clinical misuse of the interRAI 0-3. Clinicians are specifically trained to use the tool in a conversational manner and to use their clinical judgement to notice when a family may be in distress from their line of questioning.

#### 2.3.4 Parenting Skills

Similar to caregiver distress, a deliverable of the interRAI 0-3 tool pertained to the identification and enhancement of parenting skills for the primary caregivers of very young children. Participants may not have had access to the parenting skills CAP, and so they were asked if the interRAI 0-3 *could* address or identify parenting skills in families with whom they work. Five participants said yes (two site coordinators), but seven said no. For those who answered no, they listed some reasons as to why it was not useful. For example, parenting may not be an area of expertise for some of these pilot project participants. Additionally, participants may have the knowledge to identify parenting skills without the interRAI 0-3, but recognized that it would facilitate important conversations for less experienced professionals (i.e., someone who is working in clinical practice for the first time as compare to someone who has been in the field for many years).

Due to the lack of experience with the interRAI 0-3 and the parenting skills CAP, participants speculated whether it could be useful. The site coordinators felt positively about the interRAI 0-3's capacity for addressing parenting skills, but they did not have direct experiences with the assessment. The interRAI 0-3 may not address the complexities of parenting, such as financial instability, caregiver capacity, caregiver support networks, and other factors that could affect one's ability to be an effective caregiver. Further, there may be issues addressing parenting

skills due to the age of the children (e.g., disciplinary practices may not be applicable for an infant) and the self-report nature of the interRAI 0-3 (e.g., a caregiver may perceive their parenting capacity more highly or poorly than it actually is).

#### 2.3.5 Quality of Life

As the interRAI 0-3 highlights the importance of physical and psychological concerns in very young children and their caregivers, it also aims to address quality of life for the family. Quality of life is an important indicator of health that should be addressed early in life. Responses were divided as to whether or not the interRAI 0-3 could affect the quality of life for families. Six participants said potentially (one site coordinator), three said yes, two said unsure (one site coordinator), and one said no.

By nature, asking families about their experiences will uncover areas of need contributing to quality of life. However, quality of life may not be perceived as an important consideration for some care providers and therefore the interRAI 0-3 could facilitate conversations leading to enhanced quality of life for families. Overall, participants felt the interRAI 0-3 had potential for addressing quality of life, but it could be improved to better support families (see Appendix B).

#### 2.3.6 Summary

On the whole, participants felt that families were a necessary consideration when assessing children aged 0-47 months. While the interRAI 0-3 addressed many aspects of supporting families, helping them to access resources, identifying caregiver distress, addressing parenting skills, and enhancing quality of life, there were also missing pieces that should be considered moving forward (found on the tool logistics report provided to interRAI 0-3 team). Participants felt there is potential for the interRAI 0-3 to address all of these issues, but some work is needed. The issue of sensitivity was mentioned by three participants, but it is necessary to note the interRAI 0-3's intent, which is comprehensiveness, covering a broad scope of concerns rather than deep examination of more specific issues. Participants felt the interRAI 0-3 could stimulate conversations that may prompt a clinician to further examine many areas of family functioning.

#### 2.4 Future Considerations

Two deliverables focused on the long-term implications of using the interRAI 0-3 assessment on children and families, particularly increasing young children's educational readiness and reducing family poverty.

#### 2.4.1 Educational Readiness

One of the aims of the interRAI 0-3 assessment tool is to help improve school readiness for highrisk children leading to improved likelihood of employment and improved financial outcomes in later life. When asked if the interRAI 0-3 could contribute to school readiness, eight participants answered yes, three answered unsure, one answered no, and one answered potentially (if the interRAI 0-3 is improved, tool logistics report provided to interRAI 0-3 team). Of note, all three site coordinators answered yes, while the assessors were more divided. Two assessors said it is too early to tell as the children they work with are too young (i.e., less than two years of age) for them to speculate about education. Another assessor said the interRAI 0-3 is not a good tool in the version she used it (i.e., it was still under development), but there is potential for it to address a variety of issues, including school readiness, once the tool is finalized.

#### 2.4.2 Family Poverty

A second proposal about the future wellbeing of families revolved around poverty. Specifically, an interRAI 0-3 is to reduce suffering and poverty by prompting clinicians to help families gain supports. These supports could enhance outcomes and improve access to needed respite, food banks, informal and formal supports. Of all the deliverables, it was most difficult for participants to respond about family poverty because of the long-term nature of this outcome. When asked if the interRAI 0-3 could contribute to family poverty, five answered no, four answered potentially, four answered yes (three site coordinators), and one answered unsure. Overall the feeling was that an experienced clinician could identify whether a family is at risk of poverty and direct them to the appropriate services, with or without the interRAI 0-3. Two assessors said that socioeconomic issues become apparent without the use of a tool like the interRAI 0-3, another said it was not sensitive enough to identify low risk situations. Further, families may choose to withhold information from the clinician and/or refuse the services he/she suggests. That said, this tool may facilitate discussions around finances that may lead to the family receiving support.

#### 2.4.3 Summary

While there were many differing opinions about future considerations, the outcome remains the same: interRAI 0-3 has the potential to set young children on a trajectory for success later in life. Participants felt the interRAI 0-3 was better able to address education (n=8) than poverty (n=4) and some (n=2 and n=3 respectively) commented on the potential for the interRAI 0-3 to affect these two future considerations. With respect to education, the assessors who did not respond positively felt it was too early to know whether their services would affect the children in school.

Regarding poverty – an issue even further into the future – responses were even more varied. Of those who did not respond positively, most felt that the interRAI 0-3 is one of many ways to address this issue, as a seasoned clinician, a previous assessment, or a different assessment tool would all pick up financial concerns. Further, family capacity (e.g., parental financial knowledge, ability to maintain work, etc.) is a major determinant of poverty and parents/caregivers may choose to withhold information or refuse services. In these ways, the interRAI *may* help some assessors to discover that a family is at risk for poverty, but it is up to the family and the assessor to create an action plan to affect change.

#### 2.5 Deliverables Conclusion

To conclude, participants felt the interRAI 0-3 had potential to affect four key domains of healthcare for clinicians, which were early identification, case management, family considerations, and future considerations. There were key concerns highlighted by participants that should be addressed to enhance the interRAI 0-3 moving forward. These suggestions have been highlighted here and are supported with quotes in section 4.0 (Appendix B). The logistical

information has been provided in a report to the interRAI 0-3 team. The changes suggested in the said report could also contribute to success for users of the interRAI 0-3 assessment tool.

# **3.0 Appendix A: Data Collection Materials**

# Demographic Questionnaire for Interview Participants

Age: 18-24 years old 25-34 years old 35-44 years old	<ul> <li>□ 45-54 years old</li> <li>□ 55-64 years old</li> <li>□ 65-74 years old</li> </ul>			
With which gender do you identify?				
What is your professional background?				
How many years of experience have you had in your Less than 1 year 1 to 2 years 2 to 5 years	profession? □ 5 to 10 years □ More than 10 years			
How many years have you been employed at your <u>current</u> workplace?				
What is your highest degree of education earned? <ul> <li>Undergraduate</li> <li>Masters</li> </ul>	□ PhD □ Other			
How many interRAI 0-3 assessment have you comple 5 to 7 8 to 10 11 to 13	eted? 14 to 16 17 to 19 20+			
How confident are you using the interRAI 0-3 tool? <ul> <li>Not at all</li> <li>Somewhat</li> </ul>	<ul><li>Confident</li><li>Very confident</li></ul>			

Thank you for completing this questionnaire!

#### interRAI 0-3 Assessor Interview

[Participants will have read and signed the consent form and completed a background questionnaire before starting the interview.]

Hello and welcome to our session. Thank you for volunteering your time to talk about the interRAI 0-3 project. My name is Nicole Reinders and I'm the external evaluator from Wilfrid Laurier University.

You were invited to this interview because you have participated in the interRAI 0-3 pilot project, so you are familiar with the tool, manual, and online software. As we engage in our discussion about your views, utility, and effectiveness of the interRAI 0-3 assessment, keep in mind that I am equally interested in your suggestions about to how to improve the tool and your positive experiences with the tool. All of your feedback is helpful to finalizing the interRAI 0-3 tool and manual.

I am taping this interview because I don't want to miss any of your comments. People often say very helpful things in these discussions and I can't write fast enough to get them all down or remember everything. We'll be on first name basis today, but I won't use any names in the reports. You may be assured of complete confidentiality. The reports will go to the interRAI 0-3 team and the external evaluator to help finalize the interRAI 0-3 project.

Let's begin with some introductory questions.

- 1. When you think about the interRAI 0-3 tool, what are some words/catch phrases that come to mind?
- 2. Please describe your experience using the interRAI 0-3 tool.
  - a. If any, please describe any positive outcomes of the tool.
  - b. If any, please describe any negative outcomes or limitations of the tool?
  - c. Approximately how many assessments would it take before feeling comfortable completing an assessment with one of your families?
  - d. To what degree, if at all, have you applied information from the tool outcomes in the support of children and families?

Next, we will talk about your practical experiences with the assessment tool.

- 3. Has your utilization of the interRAI 0-3 tool helped you support families? If so, please provide specific examples demonstrating how information from the tool has been used to support families.
  - a. Consider the children, their siblings, their parents, etc. To what degree, if at all, do you use the tool for identification of developmental, behavioral and socioemotional problems in young children? Provide specific scenarios if applicable.
- 4. Did your use of the tool help raise your awareness of needed supports?
  - a. Did your use of the tool contribute to raising the awareness of other professionals at your agency about the needs of families?

5. Were there any obstacles or reasons you may be hesitant to use the interRAI 0-3 tool with your families? If so, please describe.

Next, we will talk about the influence of the interRAI 0-3 on service navigation.

- 6. To what degree, if at all, have you used the outcomes of the interRAI 0-3 assessment to identify concerns in early development? Please provide specific examples to illustrate identification of early concerns.
  - a. Please comment on the activity I previously e-mailed (e.g., did the interRAI 0-3 help you to address sensory integration, communication, gross and fine motor skills, etc.)
  - b. Please comment on identification of developmental, behavioural, and socioemotional problems in young children. [This question is not about the triggering of CAPs. If discussion goes directly to

[This question is not about the triggering of CAPs. If discussion goes directly to CAPs, steer away and talk about early identification]

- To what extent, if at all, do you feel that information collected from an interRAI 0-3 assessment could be utilized and contribute to a child's educational readiness? (e.g., were supports identified that would help the child prepare for school?)
- 8. Please describe whether or not the information gathered to complete the interRAI 0-3 assessment has played a role in the referral process at your agency. Provide examples if applicable.
  - a. How, if at all, have you used information obtained from the interRAI 0-3 assessment to refer clients to the most appropriate programs internal or external to the agency?
  - b. Has your use of the interRAI 0-3 reduced the duplication of services for young children at your agency? If yes, please explain.
  - c. Please describe whether you have noted a change in the number of referrals to specialists (e.g., OT, PT, SLP) based on the outcome information from the interRAI 0-3 tool.
  - d. To what extent, if at all, has your use of the interRAI 0-3 played a role in assisting with case management at your agency?
- 9. Determining appropriate support for a complex child often requires a team of health professionals. To what degree, if at all, did your use of information obtained from the interRAI 0-3 affect communication surrounding children's needs?
  - a. To what degree, if at all, did your use of information from the tool help to create common language amongst the support team?
  - a. If applicable, please describe a time when information was needed from other team members to complete the interRAI 0-3 assessment?
  - b. In situations where the intake team conducted the first interRAI 0-3 assessment, did having the information available to other team members help reduce redundancies in terms of collecting information from the family?

Let's talk about the use and effectiveness of the interRAI 0-3 tool and the CAPs.

- 10. Please describe your thoughts about the CAPs and their utility.
  - a. If CAPs were triggered, did you use this information to help support the prioritization of care for the child?
  - b. Do you think the number of children receiving services at your agency has been affected as a result of understanding specific needs of the family and/or child based on the triggered CAPs, followed by interventions that were put in place?
- 11. Have you used the CAPs to identify issues and/or reduce problems for vulnerable populations?
  - a. If so, please describe an example. For example, children with low birth weight, traumatic experiences, neglect, etc.
  - b. If not, are there any barriers to utilization of this information?
  - c. If not, are there any changes to the processes or procedures at the agency level that could support the use and utility of the instrument?
- 12. Do you feel that any particular information is missing from the tool?
  - a. When considering missing information on the tool, do you feel there are any missing items, scales, or CAPs that would have contributed to better care for children and families? Please describe.
- 13. Do you think your use of the interRAI 0-3 tool and information obtained from the assessments could serve across sectors?
  - a. Is the tool and information obtained from the assessments comprehensive? (e.g., does it identify concerns of family and children?)
  - b. Have you utilized findings from the tool to direct early intervention and/or treatment of young children with developmental, behaviour, emotional concerns? Why or why not?

# To end our discussion, let's talk about the big picture of utilizing the interRAI 0-3 for families in your agency.

- 14. Do you think your use of the interRAI 0-3 (assessment tool and information collected from tool) will affect the quality of life for families? If so, how?
  - a. To what degree, if at all, has it been used to identify or address parenting skills?
  - b. To what degree, if at all, has it been used to identify or address other areas of concern within the family unit? E.g. family, functioning, respite, financial trade-offs, etc.
  - c. How do you think the use of information obtained from the interRAI 0-3 might impact family poverty in the future?
  - d. Did you better help families gain access, or become aware of resources to further support their children after completing the assessments?
- 15. Considering what you know now about the interRAI 0-3 tool and manual, what advice would you give to a new assessor?
  - a. Is there anything that can make the interRAI 0-3 training better?
  - b. Have you learned anything over your time using the assessment tool? (e.g., information obtained from assessment, CAPs, how to support families, etc.)

- c. Is there anything that can make the interRAI 0-3 assessment better? (e.g., addition or removal of items). If so, what items would you suggest to add or delete?
- d. Is there anything that can make the interRAI 0-3 manual better?
- 16. Do you have anything else to add about your experiences with the interRAI 0-3 assessment?
- 17. Do you have anything to ask me before we conclude our interview today?

# 4.0 Appendix B: Deliverables Findings and Quotes

Several deliverables were highlighted as important to this pilot study, which were used in the creation of a semi-structured interview guide. The transcripts have been analyzed with respect to each deliverable, each listed below along with the corresponding participant responses. For simplification, the deliverables have been organized into four themes: 1) early identification, 2) case management, 3) family considerations, and 4) future considerations. See Table 7 for details about whether the deliverables have been met and in which section they have been addressed.

#### 4.1 Early Identification

Across several deliverables, this pilot project sought to answer the question: can the interRAI 0-3 contribute to early identification of developmental issues, particularly for vulnerable children and families? To address this deliverable, transcript data were coded into two key components, which were increased identification and vulnerable populations.

#### 4.1.1 Early Identification of Developmental Issues

When asked if the interRAI 0-3 could be used to identify developmental, behavioural, and/or socio-emotional problems in young children, five participants said yes (two site coordinators), four said no, and three were neutral (one site coordinator). Reasoning for the polarity of responses was primarily due to the stage at which participants utilized the interRAI 0-3. The interRAI 0-3 was still in the developmental stage and components were changing as the pilot project went on. Therefore, the participants used this assessment tool in addition to their own assessments and simply validated whether or not the interRAI 0-3 highlighted the same concerns as they had already established.

Interestingly, some participants only conducted the pilot testing on current clients who had already been assessed, while others selected new clients and used the interRAI 0-3 as their initial assessment. In addition to the pilot nature of this project, some participants mentioned that the interRAI 0-3 did not affect early identification because the young children have already been assessed by the time they have been referred to their services. Thus, if the clients' concerns were already identified, these participants could not have identified them any sooner.

- "But usually it's been identified before we even do this assessment because they are coming from somewhere. The referral is coming to us and most likely has that identified and that's why they need our services along with you now, they want an assessment done obviously. So this assessment just happened to be the timing so it's going to validate their needs and their diagnosis, etc." Wilma (site coordinator)
- Six participants felt positively about the interRAI 0-3's ability to address concerns early in life, specifically that it was very detailed
  - *"It would replace what we currently use. It's more defined. The one we have is more general"* Bailey
  - "...I do remember there being questions in that area. So I think, as long as it's got questions in that area I would assume...There was a lot of questions about

communication, like how many words, that kind of thing. It was very detailed, so I think it would probably give you a very good idea." – Donna

- "... when you are talking about the CAPs, from you know sleep management, you know eating habits, parenting, attachment. And again when it comes to [facility], attachment is a huge piece of our services here, security, child informed care, social emotional. So all those pieces, when it comes to interRAI 0-3 CAPs, it's a wonderful way to look at it. And I feel the picture is very close to being completed. From sleep, to eating, to physical activity, to dressing. Yeah, I'm very impressed with the work, to be honest with you." Holly (site coordinator)
- "But for somebody that is coming in new that wouldn't necessarily know what the [other] developmental screen is, and those tools that we have used. This is where the RAI is great because it gives you the question: okay are they doing this? Are they crawling? They aren't crawling, so you go to the next one and then yes, they are now standing unassisted, so that tells you they've reached that area of development, right?" Jenny
- "yeah for sure. I guess, like I said the motor skills, so really addressing those motor skills. Getting kids to meet their milestones, fine motor, gross motor. Kind of like you mentioned before, even like school readiness, so identifying some of those tasks that we can work on to kind of get them ready for school, just to be more independent and higher functioning." – Tina
- "So when they did this assessment it was definitely so much more comprehensive that they were picking up on sometimes different areas, so around, whether it was the detail around the you know, making sure the family was aware of where they were in terms of the language, in terms of, so it's very detailed." – Wilma
- Five participants felt negatively about the interRAI 0-3 as it was not sensitive enough to capture trace concerns in their clients
  - "No, most infants I see have been referred for a developmental concern. If not, I use other tools and screeners to identify developmental issues." Grace
  - "With our young young population we felt like, to trigger those caps there had to be a big big gap. And that, in our minds that, if you're looking by month actually, that would have to be fairly significant delay to trigger those CAPs. [laughs] Because we work in early intervention, we sort of felt like those CAPs should have been triggered a little bit more readily at times." – Dianne
  - "... I think there's other screening tools that are just as good that take way less time. Yeah, like the Ages and Stages is really good. And I know like even the Ages and Stages takes a bit of time. So then my question is who is going to use this tool because it takes a long time. So I'm thinking if it's meant for like a nurse in the doctor's office, they don't have time for that. If you've got a public health nurse in the home, you already know there's a problem, so they can do an Ages and Stages. So I found it pretty big and cumbersome for that." Mellissa
  - "I feel like it was no different [from the assessments I currently do], and to be honest not as, not sensitive enough for the kiddos that we work with." – Robin
  - "So my concern for gross motor and communication are identical. It would identify children who have like **glaring** [emphatic] delays in their motor skills or their language, but it's not picking up on subtle delays... Very few CAPs were

triggered, and I only used them on children that had very significant delays. So that's surprising right?" – Tara

- Three participants were neutral, saying they did not utilize the interRAI 0-3 for early identification and did not offer any positive or negative comments about its practical application.
  - "I would say consistently the gross motor fine motor is, it's very, like there's more detail in that section. It gives a lot of examples, so I feel like it you know, it kind of checks the boxes on everything, do you know what I mean. So those are the CAPs that will come out more consistent. As opposed to like the communication, not so much, feeding, nutritional intake, I don't remember coming up for anybody that I assessed for issues with feeding. Yeah, and some of them would be non-applicable for us. You know we don't go into attachment." Freya

#### 4.1.2 Early Identification of Vulnerable Populations

Another theme across the deliverables was to identify concerns for vulnerable populations, such as children with low birth weight, traumatic experiences, neglect, etc. Regarding whether or not the interRAI 0-3 could identify issues for vulnerable populations, seven participants said no, five said yes, and one had no comment because she *"did not come across that."* The context was similar as described above, that the interRAI 0-3 may not have been applied for this purpose in the pilot project, but theoretically could be useful in a clinical setting once it has been tweaked.

- Seven participants said the interRAI 0-3 did not identify issues in vulnerable populations
  - "I'm not sure if they could. Because of something that would, by the time they get here it's probably already been identified." Grace
  - "... majority of those kids that are coming on with those issues, we already know about it." Jenny
  - "I would say no. It didn't contain information that was new to me." Tara
  - "... I'm not sure if the CAPs would be any different for clients who are not in those [vulnerable] situations." Tina
- Five participants said the interRAI could be used to identify issues in vulnerable populations in certain situations
  - "You know, possibly. You know, it's asking lots of questions in that area actually, but you know it's somewhat dependent on the responses of, of the people being interviewed. Whether that be family or foster family." – Dianne
  - "For sure... I was going through the manual and learned more about the scales and how it provides information about you know, there's a problem, and how severe is it, and how we can you know help to monitor and change it over time." – Holly (site coordinator)
  - "I guess if you didn't have any other tool, that stuff would kind of pop out at you that the child could be at risk." Melissa
  - "Definitely. If the right approach is used to facilitate the assessment... there has to be, before you even go in to get the assessment, there has to be a rapport and a trust set up with the family. They need to be able to trust that person." Wilma (site coordinator)

#### 4.1.3 Summary

There is great potential for the interRAI 0-3 to influence early identification of developmental concerns in vulnerable populations; however, increased sensitivity is warranted to ensure children with less severe concerns are also identified. Further, the logistics as to who is going to use this assessment and when would also contribute to early identification, as many concerns were flagged before this tool was used in the first place.

#### 4.2 Case Management

A primary goal of the interRAI 0-3 is to assist clinicians in managing clients, in which there are many factors, such as communication and referrals. The theme of case management has been divided into the six subthemes discussed below. Note that many participants felt similarly about case management as they did about early identification: due to the pilot nature of this project, participants utilized their pre-established methods for managing their caseloads meaning the interRAI 0-3 may not have been applied in practice.

#### 4.2.1 Comprehensiveness

The purpose of the interRAI 0-3 is comprehensiveness; touching on all areas of health that could be pertinent in infancy. Participants were asked which words came to mind when thinking of the interRAI 0-3, and four used the word comprehensive as a descriptor (see Table 5 in section 1.0). When asked specifically if the interRAI 0-3 tool is comprehensive, seven participants said yes and four said *"it's getting there"* (Grace).

- One of the site coordinators felt she did not have enough first-hand experience with the interRAI 0-3 to comment on comprehensiveness
  - "I don't think there was anything missing, but I'd like, to be honest with you, I would have had to use the tool several times over to be confident in my answer."
    Wendy (site coordinator)
- Interestingly, one participant questioned the value of using a comprehensive tool, saying:
  - "I don't think there was anything missing. I don't think it's a good use of resources. It looks like it would be, but it's not. You can't, these kids are complex. It's hard to find a one-stop shop to pick every [emphatic] issue up." Melissa

#### 4.2.2 Tool Utility

Participants were asked whether they have applied any information from the interRAI 0-3, specifically CAPs, to support their clients. Unfortunately, the CAPs were not fully available at this stage of this research and therefore participants reflected on limited experiences with the outcomes. Further, participants did not use the tool on new families due to the pilot nature of this research.

- Eight participants did not see any CAPs, with the exception to the few participants who contributed to their development

- "the CAPs, when we were doing the pilot project, were still being developed. And we were helping to give information towards the CAPs, but some of the final versions actually we haven't even seen. So we weren't really using the tool in its entirety in order to be able to truly apply the information that we were collecting." – Robin
- CAPs have the potential to help clinicians validate their decisions for care
  - "The hard part is you didn't get your CAPs. And for me, when I worked in the community, the CAPs are what helped you develop your service plan... So then if your manager says "why did you authorize 60 hours of PSW support for this person?" You can say "well when I did the assessment, these CAPs were triggered"... I think it's a great tool to help support the care coordinator... in the community RAI, you would actually get a CAP triggered. That would give you that added reinforcement that you're on the right track." Jenny
  - "I like the fact that it generates CAPs. We had something kind of more concrete. The assessment tool that we use now is more sort of open-ended, which there is nothing wrong with, this is more like, we are actually using like standardized scales and tools and that kind of thing." – Tina
  - "When it comes to the social emotional, like all of those pieces in detail as I told you, to assess the needs of our children and their families, help to identify those needs, the planning, our client plan, in a way to address those needs. And then how we can follow up and look at the outcomes and how we can adjust the plan to address those things." – Holly (site coordinator)
- The CAPs may not be sensitive enough to address sensitive concerns
  - "Those triggers for the CAPs just aren't sensitive enough to pick up on mild delays." Tara
  - "...if the CAPs were more sensitive than I think it could be better, but I think right now that the CAPs aren't being triggered as often as our program was hoping for. And so, from there, I feel like it's not doing a good job of identifying kids. I feel like it has the potential to; it asked so many questions, it covers all the age groups. I just think that some of the CAPs need to be more sensitive in order to be triggered." – Robin
- Some clinicians relied on their own ability to create a care plan in addition to the CAPs
  - "Yes it did [help to direct referrals] but I, but I also have a lot of experience. So yes it did, [the interRAI 0-3 assessment outcomes] helped to define [client concerns] a little bit better." Bailey
- Jenny was unsure about practical application of the interRAI 0-3 due to the limited time frame of the pilot project
  - "I never got to do a follow-up, right? These were all initials. So the thing is, yeah you get your CAP that triggers, but how do I know whether the service plan from the RAI perspective, what changed, right? I never, because all of the three that I did were all new people. Because we were on a timeline, right? And we only do our follow-ups, only three or six months, right? So all those three kids were new initials, so I mean how can you evaluate that?" Jenny
- Other tools could be as effective and more user friendly than the CAPs
  - "So when the CAPs triggered properly, which they did some of the time, I think there were other developmental screening tools that would have looked at those

particular areas, those CAPs, and provided similar information about those particular areas much more quickly." – Tara

- The CAPs were not reliable at the time of the pilot as they did not trigger appropriately
  - "We were piloting, the CAPs had not been finished, they weren't being triggered at times when they thought they should have been, and then kind of what the CAPs were saying actually, when it did trigger was kind of questionable based on our years of experience kind of working in this realm." – Dianne

#### 4.2.3 Clinician Awareness

The interRAI 0-3 sought to improve healthcare providers' understanding of the young children's needs, meaning that a clinician's awareness of early concerns would be enhanced after they employed the interRAI 0-3. Participants discussed whether the interRAI 0-3 tool helped to raise their awareness of needed supports or perhaps others at their agency.

- Four participants felt they learned about early development from using the interRAI 0-3
  - "...it was a bit of learning in regards to certain aspects of development, which are not my area of expertise. So I found it went into fine motor and speech in a little bit more detailed than I would have normally done, so I've taken that and applied it to my practice when I'm assessing kids for service. And it helps to really define what the needs were for the kids." – Bailey
  - "Even some of the developmental levels, it kind of gave me a better idea like. I have a fairly good idea just because I work with a large age group, but I think it even honed it in even more. And then even just thinking about some of the, even some of the medical stuff to, I kind of learned a little bit about that. Because it's pretty expensive in that as well." – Donna
  - "I mean it did, it did help to give some theoretical context to the decisions that I made, from the service where a patient was at, so I thought that that was good." Freya
  - "I think, the only thing that I can say it helped me with is, the gross motor and fine motor stuff, it was really good to see the descriptors of the different age groups... I just like how the information, and laid it out right there." Jenny
- For Tina, it did not necessarily raise awareness, but provided evidence to support her knowledge
  - "I would say it does. I would say confirms it, definitely. Yeah, kind of confirms that this is why we're providing this service that we are, yeah. I think specifically even more the developmental scales kind of were very detailed." Tina
- The interRAI 0-3 did not affect Robin's awareness overall, but prompted her to ask about potential issues earlier in time
  - "...it asks more questions sort of about stress and trauma, the pregnancy history, and you know, it asks about supports right off the bat. And so I think that is helpful information to kind of learn where the parents are at. And that is information that I feel I eventually do learn... I don't know if it's anything new, but it may not be in the order of how I get to know families. Where I felt that the interRAI kind of forced me to do that first." – Robin

- Eight participants said the interRAI 0-3 could help raise the awareness of other clinicians with respect to information about early development in general, or specific concerns within a particular family
  - "Absolutely, so one of the things is that the care coordinators in my organization are all registered healthcare professionals. However, a registered healthcare professional has multi-disciplines. So I have nurses, I have social workers, I have occupational therapists, physiotherapists, speech therapists on my team. So varying experience... There was a lot of opportunity for the care coordinators to get some education that isn't as readily available... To me it was very valuable."
     Wendy (site coordinator)
  - "I think it particularly is helpful because it touches on pretty much every area. And if you are a novice, unfamiliar, it is a great guide for you to make sure you don't miss things. You know for example; you didn't know the baby was premature. You didn't know that the parents are legally separated, you know. You didn't know there was CAS involved, you know?" – Jenny
- The interRAI 0-3 also stimulated conversation between clinicians and families
  - "...one thing we find with all the RAI tools, when there is a spot for abuse, or there is a spot for different sensitive topics, that it actually helps to facilitate that conversation. Because it is a concrete piece that's being asked." – Wilma (site coordinator)
  - "... there was some interesting discussion amongst my peers about some of the questions that pertain to stress and trauma, like those stress trauma life events questions. I think it was, those questions were collectively the ones that kind of made us squirm a little bit. And they may have been the ones that would be beyond what we would have asked in the first interviews with families. So I suppose the tool kind of help raise our awareness about those issues and the importance of bringing them up in conversations with all families, not just the ones we're worried about." Tara
  - "I think for me the stress and trauma life events; I think it just made a bit more awareness of those issues and bringing them up in conversation a bit more." – Grace
- However, five participants felt they did not learn anything new from the interRAI 0-3 and four felt the interRAI 0-3 did not help to raise awareness of their clients' needs
  - "No... I feel like we already have a lot of good sort of validated kind of assessment tools actually, to cover the areas that are being covered by it." Dianne

#### 4.2.4 Referrals to Programming

A deliverable from the interRAI 0-3 pilot project was to facilitate appropriate referral for children, in addition to assistance with triaging and prioritizing needs. There were mixed feelings on this particular topic with reference to the stage of research.

Nine participants said that the interRAI 0-3 did not affect the number of referrals

- "I do not think that the tool itself minimized amount of service or increased service. I think it probably gave us a better perspective developmentally where children were at, but it didn't affect our service delivery." Wendy
- *"They already have. The referrals [have] already been placed where they need to be placed." Grace*
- "No, and I would really strongly discourage individuals using information from the interRAI as it is right now in making decisions at this time. Because I think it would miss a lot of kids." Tara
- Seven participants felt the interRAI 0-3 *could* affect referrals in the future (three of which were part of the group above who said the interRAI 0-3 was not used for referrals)
  - "I would assume that it would go up. Because you're kind of indicating, like because some things really kind of slip through the cracks until it's, especially until school I think, for children. And so I think it would actually probably up our referrals to different areas, to different people and different agencies, potentially." – Donna
  - "So this is where this tool will pick up on, yes there would technically potentially be more referrals... I don't want to say that you are going to miss everything, but I think there is opportunity here for more referrals to maybe address the whole holistic picture of the child." – Wilma
  - "I'm pretty sure I'm going to see more referrals tied to, and again every single organization, when it comes to assessment, we will be talking the same language." Holly

#### 4.2.5 Reduced Duplication of Information Intake and Service Provision

During the pilot, seven participants said that the interRAI 0-3 did not reduce duplication of interventions and treatment, five said that theoretically it *could* reduce duplication (three site coordinators), and one person answered no to reducing duplication, but yes to potentially filling that need in the future. There were some issues highlighted with respect to redundancy of information with families.

- Participants felt there were very few redundancies at their agencies in the first place
  - "...there is an intake, sort of an intake service that coordinates which service they go to. So we don't have that [service duplication]." Grace
- Six participants said the interRAI 0-3 duplicates their current information collection system
  - "I think that the completion of the tool is a redundancy. Like the problem is, see if I asked the family questions that are on the interRAI for example, I already have to document that in the client's chart, right? So every question I ask anyway I have to write in their charts and that information gets incorporated in community treatment forms of care, in my clinic notes, that kind of thing. So there never will be a day when something like a questionnaire can replace what I would document in the chart." – Tara

Another area of duplication pertained to families. Accessing resources may be particularly draining for families as they are expected to repeat their "story" (i.e., their child's concerns and

their experiences with healthcare professionals thus far) to every specialist and clinician they meet. The participants were aware of this issue and commented on privacy barriers and the additional work they do to compensate.

- "I know families, they hate telling their story over and over again. So I think if there was like a way of how you do it, but when they go to emerge and they have all these developmental issues with their kids. And every nurse they see and every doctor they see, they have to repeat the same story over and over again. So I think, I don't know how you would do it with privacy and all that because, but yeah that [information sharing] would be really good." – Melissa
- Four participants felt that information sharing between agencies would mitigate this issue, but privacy regulations do not allow for this sharing.
  - "I think these families are overloaded. I think that, you know, it would have to be a tool that is shared across agencies, and gosh with all of our privacy legislations these days, the reality of that being possible, I'm not sure. But yeah, if that were feasible I could see some value in that." – Dianne
- Five participants reviewed existing client files to reduce the number of questions they needed to ask during the assessment, but three of these individuals felt it was significantly more work
  - "This took a lot of time to prep and then do the visit and then score after. So I felt the time too was sort of a negative experience for me. Because it just meant really planning ahead and building that into my already crazy busy caseload... so I did a lot of, like a case history file review. So that I could hopefully get a lot of the information from birth history or birth records so that I wouldn't have to ask parents those, like all of those questions, to hopefully sort of ease the amount of questions that I had to ask parents. And then also if there was anything written, more about the trauma or if like, the social history of the family, I could sort of get those questions." Robin

#### 4.2.6 Communication of Needs

Complex children may have a variety of healthcare providers involved in early life and the interRAI 0-3 sought to improve communication between clinicians. More specifically, a goal of the interRAI 0-3 is to establish common language amongst the healthcare team. When asked if the interRAI 0-3 contributed to common language, seven participants (three site coordinators) said yes, three said potentially, and three said no.

- The interRAI 0-3 could contribute to common language if used widely
  - "I think that if it was a standardized universal tool then the same language would be used to describe the same things, whereas currently it's not being used in that way. So for instance if I look at the developmental sector versus the health sector, we're using words interchangeably that are not interchangeable. So I do think everyone was using it that would be a benefit." – Wendy (site coordinator)
  - "I definitely think so, depending on what, I mean what different people are working on. They can each make a common plan. That's what the OT is doing

there, the physiotherapist is doing this, and maybe you know, early intervention is doing that. Definitely it can all come together." – Tina

- "I definitely see the value of RAI's, and I think we need to have some kind of standardized tool so that we are all talking the same language, the same assessment. We are comparing apples to apples." Jenny
- There is potential for the interRAI 0-3 to affect language, but some changes are necessary
  - "Yes possibly [hesitant]. I guess if people believed in it and [were] more readily using it, and kind of aware of the terminology. But I stress all of those factors because yeah, I just think maybe there would need to be some work on the tool to get it to that level. – Dianne
  - "I think a tool like this has great potential to go between. Like, when I think of us being a community agency, we work a ton with the hospitals and then we also sometimes have to collaborate with community pediatricians. And then there is a whole array of community agencies that we also work closely with, and we'll do joint visits with. So I think to have one overarching tool to use between all of those service providers would be excellent so that you know, we can then say you know, when the interRAI has all the bugs worked out, it's working fine, you know depend on the stability of it. We can say, you now this kiddo, this is where they are at gross motor, this is what the CAP are showing, communication. And I think that would be great information to be able to quickly share between service providers. Robin
- However, the interRAI 0-3 has not yet contributed to common language
  - "I don't think that the interRAI affected communication about the kids' needs. I mean, we would routinely document screening and assessment results anyway, we would routinely communicate client needs with colleagues within that circle of care, we have joint consultations that we make on a regular basis anyway as a team. So it's kind of already part of our clinical practice. And I don't think the tool is yet ready by itself to be kind of providing that picture, that complex child and family." Tara
  - *"I don't think it captures a really good picture of a complex child or a really complex family." –* Grace

Looking at use of the interRAI 0-3 more broadly, participants were asked if information collected in this assessment could serve across sectors, potentially affecting communication at a higher level of service provision. Eight participants (two site coordinators) felt the interRAI 0-3 would be effective for serving across sectors, while five said it had great potential, but needed *"to be massaged a bit"* (Wendy, site coordinator).

- Participants saw the value of using standardized assessments for directing government funding and comparing care across sectors
  - "I think the RAI would be, is very valuable, I know for the community piece it's helping support your governmental metrics. At the government you've got to prove that what you're doing is making a difference, right? And if we're all using it provincially, the same tool then you can compare yourself against peers, people that work in other areas." Jenny

- "So if you are familiar with the interRAI tools, it provides that consistency across. And then what can happen is, it provides a profile of who we're serving and how, what their needs are, and then basically from there, all the, linking-in services and providing information to support them." – Wilma (site coordinator)
- "So if they're involved in developmental supports like OT, physiotherapy, speech, you know we all have the same snapshot of that child. And then as that child goes maybe to daycare, and they've got a special needs resource person at the daycare that person could say "oh yeah so-and-so is on you know, whatever. Here's their development, they're using a sippy cup, and they're using a walker, and point walker. And they had a seizure disorder, here's the seizure meds, blah blah blah". So I think if everybody had the same, that might be helpful... And then when you go to school, the kindergarten teacher could see it. That would be good." Melissa
- There is potential for the interRAI 0-3 to be used, but it needs work before it is ready
  - "I do think that there's potential there. So work still needs to be done to improve the sensitivity to make me more comfortable to actually use the information clinically. Like right now I would not be comfortable using it clinically. But once that is accomplished, you know if we can sidestep some privacy considerations, right? To sort out between agencies, because all agencies have their own processes and whatnot. I mean, I do think that there would be potential to use the information from assessments across sectors and between agencies. But I think there would be a lot of legwork that would need to be done." – Tara
  - "Yes, potentially. I think where I am struggling is that I would, like this is for 0-3, but our population doesn't stop at three. So there has to be some thought around how is this tool aligned with the other tools, right? The 4-18, the adult, like how do they align so we're not replicating the work and it's capturing all the information that's required?... we do need the support and we do need consistency, and an ability to be able to have something that is used by all partners. And so that is a discussion that we're actually having provincially around the tools that currently exist to support that decision-making." – Wendy

While the interRAI 0-3 could contribute to common language, some participants expressed barriers to its use at their agency. Further, participants were asked to suggest changes to processes or procedures at their agency to better support their use of the interRAI 0-3.

- Barriers exist at the agency level that may prevent its use across sectors
  - "I definitely see the value of it for sure, but it takes more time definitely than the template I was using. So obviously you're not necessarily able to do as many assessments as you would do, so you're not seeing as many people as you would, but you're probably getting a more thorough assessment." Jenny
  - "But how will you cross privacy issues?... I don't know how you would do it. Like that's, that's a big leap, to use that tool that way because of the sensitivity in a lot of that information." Melissa
- Four participants offered suggestions for changes at the agency level regarding the interRAI 0-3

- "I think that's part of the process. It's making sure that you don't do things too soon... it's part of the education." Wilma (site coordinator)
- "I don't have access to those medical health records, so we're just reliant on the referral information that we get from the LHIN that's sending us the referrals. And then if it's a community pediatrician, again it's usually pretty dismal information. Like not dismal, just very limited. So you are very reliant on asking the parents for a lot of that information unless you are able to get a hold of the pediatrician or specialist beforehand to you know, get additional information. So you know, I think it's partially, I know the government is looking at getting an e-health system that's going to be more comprehensive and you know, being able to access so parents aren't having to say their stories over and over again." Jenny
- "I think it would be a valuable tool to use at intake. Sort of the initial assessment. To be incorporated with our initial assessments or referrals that we get to maybe general care plans. Definitely I think that be a change in procedure or values or. And then also at certain intervals, maybe using it to see improvement. By looking at those scales. To see improvement, if our services are making a difference. So maybe incorporating using the tool at different intervals, maybe yearly for every six months, like that kind of thing." – Tina
- "It would be helpful to determine how often this tool should be administered during service delivery. E.g., Beginning and end of service; Beginning of service only? Agencies will have to consider the time that it takes therapists to complete the interRAI 0-3." – Robin (member check)

## 4.2.7 Summary

Case management is a significant component of interRAI 0-3 utility. Participants felt the interRAI 0-3 was comprehensive or at least close to comprehensive, despite the fact that majority did not see the CAPs or apply them in practice. Further, the interRAI 0-3 contributed to clinician knowledge and could facilitate important conversations with families. The interRAI 0-3 did not contribute to increased referrals or reduced duplication as participants were using it in tandem to already established practices at their respective agencies. Because of this, using the interRAI 0-3 was a duplication in data collection and yet another instance where families had to tell their story. That said, participants felt the interRAI 0-3 had great potential for creating a common language between clinicians and could serve across sectors, particularly with respect to government level analyses of needed supports. To improve the utility of the interRAI 0-3, agencies must reduce barriers – most notably information sharing barriers (e.g., privacy) – and enhance user convenience. This tool has the capacity to affect case management at a variety of levels, but several improvements are necessary before it could be utilized in practice, namely increased sensitivity while maintaining (or improving) brevity.

# 4.3 Family Considerations

Not only does the interRAI 0-3 seek to support children 0-3, but also their families. The parents and guardians of vulnerable children undergo a great deal of stress that may contribute to caregiver distress, parenting, and overall quality of life. The interRAI 0-3 pilot project explored

the following deliverables: 1) improvement in caregiver distress, social support, parenting, and improved child and family well-being; 2) early identification and intervention leading to improved quality of life for families and their children, such as parental skills and child development immediately and in future; and 3) improved access to interventions and treatment with documented current receipt of psychological/psychiatric treatment, occupational therapy, infant therapists, speech and language, social work. These deliverables have been divided into five sub-themes below.

# 4.3.1 Support Families

Participants were asked whether they believed the interRAI 0-3 could be used to support families, including the parents, children, and siblings. This question was asked hypothetically, as the interRAI 0-3 was in the pilot stage and participants did not actually use it in this way. Eight participants (three site coordinators) felt the interRAI 0-3 could be used to support families, but each presented a caveat about its utility, while five participants said this tool would not be useful in family support.

- One of the caveats was limited access to CAPs, although the participant could see where the completed assessment would fill a need in supporting families
  - "I think with further development. Like the hard part is you didn't get your CAPs. And for me, when I worked in the community, the CAPs is what helped you develop your service plan, right? So I would like you to send me back a RAI with the CAPs and let me go out and do some of those and then be able to let you know... I mean there are questions that we, that it asks that could relate to provision, putting in respite care services or accessing another resource to look at respite care resources. Looking at you know, maybe maximizing family and friends support." – Jenny
- On the other hand, the interRAI 0-3 may not be sensitive enough for some families even when it is completed
  - "...it's not giving us any different information than the tools that we are already using. I also think that we are working with such a specialized complex population, that it didn't help identify any other developmental needs that weren't already identified through other tools... So in the way that we were using it, I feel like it was no different, and to be honest not as, not sensitive enough for the kiddos that we work with." Melissa
- Alternatively, this tool could be just as effective, if not more so, than tools already being implemented at the agencies
  - "...well it would have been used along with our normal processes, so as things were identified on the assessment, they were able to address those areas of risk potentially and for need. So we already have obviously a non-standardized assessment. This [interRAI 0-3] covers all of that plus [more]." – Wilma (site coordinator)
- Three participants answered no when asked if the interRAI 0-3 could support families, but later in their interview discussed its utility in this area (therefore coded as yes)
  - "I think it could highlight it [needed family support], absolutely. Under, say the caregiver distress, and then like I already do it clinically, but if it were someone

else – to think about connecting them to other local resources. Say financial, like government financial assistance programs for children. Or like helping them with housing or respite or crisis or something like that. So I guess yeah." – Grace

- Tina felt the interRAI 0-3 could help families, perhaps more than the child due to their young age
  - "I would say the family more than the child. Because I think at that level, at three, yeah I don't know if children are really – what's the word I'm looking for – aware of what their gaps are... Like if we are doing this on a child who is two and not walking, it's more the family I think, is more concerned that the child is not walking as opposed to the child who is not walking." – Tina
- The interRAI 0-3 could create a picture of a family's needs, but some participants would not need that information in their practice
  - "It gives me a better view of the family, so that it is appreciated. And I think there is a potential may be to identify future risk, but based on what we do, unless we had significant concerns, I don't know what we would do with that information."
     Wendy (site coordinator)
- Overall, participants felt the interRAI 0-3 could support parents and children, but few discussed its utility with siblings.
  - *"I didn't have that experience, I wasn't really, I don't, we weren't really looking at the siblings." Tina*
- The lack of sibling information contributes to sensitivity issues with the interRAI 0-3 in accurately capturing a family's needs
  - "I don't see any question around siblings, if siblings are healthy. Because we do have families with multiple children with medical needs. So if they have more than one, then of course there should be like a million CAPs in terms of you know, family capacity, stress level, that kind of stuff, that you know you're going to want to look at... it doesn't give us a clear picture that the single mother only has one child to take care of when, meanwhile the single mother has two children that are exactly the same to take care of. That's a totally different picture..." Freya

# 4.3.2 Helping Families Gain Access to Resources

The interRAI 0-3 aims to improve families' access to interventions and treatment, to which five participants felt the interRAI 0-3 could meet that deliverable. That said, three participants highlighted it was not the interRAI 0-3 itself that would increase a family's access to resources, but the healthcare professional's knowledge of what is available. Three participants said the interRAI 0-3 would not improve access and one said she was not sure.

- Most organizations already have procedures in place to ensure families have access to the resources they need, and therefore the interRAI did not contribute to increased awareness
  - "well no. I, no, like and I hope that we are doing a good job with that now, right? Because everyone has access to, for example a program like ours no matter their financial income. And our referral process is set up that, like it doesn't even have to be a family physician or a medical doctor, right?" – Robin

- When asked if the interRAI 0-3 could improve families' access to resources, Bailey said "... *no, because it didn't list the resources.*" Therefore, if the interRAI 0-3 listed resources (e.g., in the CAPs), it could be more helpful in helping families gain access
- Similarly, if there were working CAPs, those could be utilized as support for making referrals
  - "Through our [facility] reach we have, they have parenting courses, public health has them for the early baby program. So yeah definitely, we, I would utilize it to access those sources." – Jenny
- The interRAI 0-3 can be used to prompt conversations, but the healthcare professional must know if the resources available in order to direct families
  - "I'm hesitant to say that the tool itself would do that, but I do think the tool allows for the opportunity to gather more information to support us making those referrals." – Wendy (site coordinator)
  - "Letting the family know to keep an eye on that and talk to the physician. And seeing what resources there are in terms of getting some more community assessments... So even though we might not address the issue directly, linking them to where that resource is." – Wilma (site coordinator)
  - "But I don't think that the tool would really tell you how to address them. Like I think you have to know what's available in your community, like you would have to know what local services exist here." Tara
  - "...it could [increase access]... if no one's ever asked them that, if someone is available, knowing what the local available resources are." Grace
- Once an issue has been highlighted on the interRAI 0-3, the healthcare professional could make referrals based on relevant information.
  - "I would say yes for sure. I would say for example if a child is, if a mother is worried about let's say the child's not tracking, or worried about vision, make a referral to the you know, the low-vision program. Blind low-vision program, like that kind of thing." – Tina
- However, the participants responded hypothetically to this question as their clients have already been assessed and referred
  - "I have, like in terms of making referrals to external organizations. But the thing is for us, you know we piloted it, our patients were already on for specific purposes. So, I guess you can say just kind of reconfirmed why they were on our program. Because it identified, you know some of the CAPs that maybe were generated did, I guess confirm that, "yes, this patient has areas of delay in gross motor or fine motor, ADLs" like that kind of thing. But because our patients are already on our program, they were already sort of identified for having a need, right?" Tina

# 4.3.3 Caregiver Distress

Caregiver distress is a significant concern when considering the wellbeing of very young children, making it an important component of the interRAI 0-3. The participants were asked if the interRAI 0-3 could identify or address caregiver distress. Seven participants (three site coordinators) felt the interRAI 0-3 could influence caregiver distress, six felt it could not influence distress, and one said it addressed distress some of the time.

- Of the positive responses, participants said the interRAI 0-3 facilitated conversations around caregiver distress and stimulated the healthcare provider to suggest further resources
  - "... just in regards to the resourcefulness or if there was a crisis, who would they turn to? And if they didn't have anyone, then they should make some kind of links for those. It prompted me to say "you should get da, da, da, da for you know, for later on because you may need... like, you should get a respite worker, invest the time now because this is something you will be using in the future" for certain children." Bailey
  - "I like the caregiver distress one... It looked at different areas and the stressors that they may have in order to contribute to that. And I think it had something maybe about the hospital stay. I thought that was good." – Grace
  - "... it lends itself to identifying who the primary caregiver is and the attachment that is occurring between primary caregiver and other parents or caregivers in the home with the child. I did like that, that seemed quite specific, which I think informs our ability to understand how a family works." – Wendy (site coordinator)
  - "Yes, the tool identifies caregiver distress and we would use it as an opportunity to discuss alternative formal and informal supports that the family can access." – Wilma (site coordinator)
- It could be that the interRAI 0-3 does highlight caregiver distress, but the participant did not pilot the interRAI 0-3 on a family where that was a concern
  - "... if there was any kind of caregiver distress or that kind of thing that maybe we hadn't talked about before. We can look to see if there are any other external organizations that we can refer to that might be able to support them... I can't say that really caregiver distress has come out of using this tool, like on the, the tools I did with clients. But it could, like it certainly could." – Tina
- However, several participants felt the interRAI 0-3 was not capturing the needs of parents with respect to caregiver distress
  - "... if I think about a more complex child, what are the child's needs, what supports already exist? I don't know if it really truly captures that. If a child requires around-the-clock surveillance and care, it wouldn't capture the amount of time. It says, "in the last three days did they have anything?" And it's either a yes or no, right? And then it doesn't ask the questions if the parents are managing or if they feel they have enough support..." Freya
- Tara offered a unique perspective on the interRAI 0-3 and said her experiences with caregiver distress varied. She also offered a suggestion to enhance the CAP
  - "I did feel that some of the questions related to caregiver distress worked well some of the time. And I think what I liked about it was that it took into consideration information across various areas of the tool. There are a couple things that I would like to add to that caregiver distress CAP to almost have another trigger to consider. So a lot of the babies that I work with were born prematurely and also had lengthy stays in the NICU and there's some recent literature that talks about how parents of babies that are born prematurely and have that long scary NICU stay are actually at much higher risk of developing

clinical PTSD. So I feel that some questions in that caregiver distress piece might want to be tweaked so that it also includes something about that, like length of the hospital stay or the degree of prematurity." – Tara

- With respect to suggestions for the interRAI 0-3, Holly (site coordinator) and Robin (who had positive and negative responses to caregiver distress, respectively) both discussed the possibility of the interRAI 0-3 *causing* caregiver distress if not used appropriately
  - "... it can bring difficult emotions to the surface, so what are we going to do with that? You know, like most of the people who are going to be using interRAI here, they are child and youth workers, we have some ECE's, sometimes you open this can of worms and you don't know how to put it together. We need to find, make it known when it comes to the training, how we can train our interviewers that they will be doing this and using interRAI in our agency to deal with these situations, and where to send our patients, our clients, and how to view the situation because it can do more harm than good if you don't know how to deal with it." Holly (site coordinator)
  - "when you're asking families, "does your child do A, does your child do B, does your child do C?" And they're saying "no, no, no."... it brings that worry or stress, and thinking "oh my gosh, is my child supposed to be doing all of this?"... the assessment is for the child, to get an idea of where the child was at, but you have a lot of those family questions asked upfront and then if your team, say it's like a daycare worker for example, and then you don't have somebody that could be able to give that family social work support, then what do you do with that? Or then, who can the daycare then refer the family onto to get them set up with the right support that they need? Because they're dealing with the posttraumatic stress of the birth and the trauma that they went through with their child... And as professionals, there is an obligation for us, if we are asking the questions and we are getting answers from them, then how are we going to help? And who can best do it? Because if it's not in our wheelhouse, who are we going to send that family on to?" Robin

## 4.3.4 Parenting Skills

Similarly to caregiver distress, a deliverable of the interRAI 0-3 tool pertained to the identification and enhancement of parenting skills for the primary caregivers of very young children. The majority of participants did not have access to the parenting skills CAP, and so they were asked if the interRAI 0-3 *could* address or identify parenting skills in families with whom they work. Five participants said yes (two site coordinators), but seven said no. Their reasoning has been presented below.

- Parenting may not be an area of expertise for people who use the interRAI 0-3
  - "No, I have not personally done that. Like I've you know, that would not fall under my kind of domain of expertise I would say. And I would refer onto kind of social work or psychology to kind of look at those areas more so." – Dianne
- Alternatively, participants may have the expertise to identify parenting skills without the interRAI 0-3 but recognized that it would facilitate important conversations for less experienced professionals

- "...as a well-seasoned nurse, registered nurse, I mean I can look at a parent and if their eyes are, if their pupils are dilated, if there twitching, do you know what I mean? Like those cues that I can look at that may heighten to me that you know, I would explore that questioning with them. Whereas the RAI tool, it's there, do you know what I mean?" – Jenny
- Due to the lack of experience with the interRAI 0-3 and the parenting skills CAP, participants speculated whether it could be useful
  - "Yeah I would think so. Just that yeah, as long as it had those questions pertaining, right?" Donna
  - "So the tool certainly ask questions about like, inadequate parenting, and I remember finding it, some of those questions a little bit difficult to answer when considering babies. Like there were questions about discipline and limit setting, we don't really have to discipline like a seven-month-old [laughs] or really even set limits to children who aren't yet mobile because they aren't getting into trouble. So I remember the questions being kind of tricky to answer. And I'm thinking with the pilot, like I don't think that I ever saw a CAP triggered that had some suggestions around parenting skills." Tara
- The site coordinators felt positively about the interRAI 0-3's capacity for addressing parenting skills, but they did not have direct experiences
  - "Absolutely [it can address parenting skills and caregiver distress]. Again, I heard second hand, when it comes to collaborative action plans, and how CAPs identified clients' needs." Holly (site coordinator)
- The interRAI 0-3 may not address the complexities of parenting, such as finances, number of caregivers, caregiver capacity, etc.
  - "I feel that it could be more if we're looking to cast the net for everybody. And the complex section you would look at capacity and how many parents are there. What about extended family that's outside? I don't think it captures the financial resources as well, in terms of funding. So within the child sector there [is] some funding, like disability tax credit, ACSE, so there's funding that families could access. So, which financial resources is also a help, right? So I don't recall it asking that, I didn't see that as an option." Freya
  - "I feel like with the parenting, she's either, it didn't allow for some of those grey areas where, you know mom's all, she's totally self-absorbed and all she talks about is herself. But I'm not there for you, I'm here because your child isn't walking [laughs] and sitting [laughs]. I get that you have issues... It was really hard to find a spot for that kind of stuff. And like she wasn't a really bad parent, but there was a lot of room for growth..." Melissa
- There could be issues in addressing parenting skills due to the age of the children and the self-report nature of the interRAI 0-3
  - "I don't know how it would do that. If it's coming from the perspective of the parent [laughs]. And I'm not sure what the questions, like for the questions for say, my, my population of children. I don't know how, yeah, it's just so specific for little, little little people. Perhaps older." Grace

## 4.3.5 Quality of Life

As the interRAI 0-3 highlights the importance of physical and psychological concerns in very young children and their caregivers, it also aims to address quality of life for the family. Quality of life is an important indicator of health that should be addressed early in life. Responses were divided of whether or not the interRAI 0-3 could affect the quality of life for families. Three participants said yes, five said potentially, two said unsure, and one said no. Some responses were simply "I'm not sure" and "no" – those responses will not be presented to maintain brevity.

- By nature, asking families about their experiences will uncover areas of potential need contributing to quality of life
  - "yeah... the clearer picture you have of someone's situation, family, dynamics, developments, I think the better that you can help them, and you can know exactly what to hone in on, right? So I think that that could really help. Because sometimes people don't even know when they come in, all of what they need. So I think you can kind of really narrow that stuff down really well." Donna
  - "... so it's challenging because we would do an assessment regardless of if we had this assessment or not, right? So in my eyes I would hope that any assessment that were doing would capture concerns and would be able to impact the family and we would be able to mitigate potential risks. However, if this tool was not to be replaced with another tool in an agency, then I do think that there is risk, and that this tool would absolutely support making a difference." Wendy (site coordinator)
- However, quality of life may not be an important consideration for some care providers
  - "Quality of life? No. Well it does ask if the house is in disrepair and if the child is in custody. Yeah, I guess it does. Yep it's just not information that we really capture. But yeah, yeah it does... I mean, I could observe if the house is in disrepair, right? But... those are like Children's Aid questions..." Freya
- The assessment could affect quality of life in a number of ways
  - "Yes, through the assessment process, [the care coordinator] can identify if a patient or family needs resources regarding programs that can improve quality of life, such as camps, respite care service, PT/OT to address developmental delays where recommendations/equipment needs identified that can improve quality of life. Also to link [them] to children's treatment centres." Jenny
  - "... for families it could, well I mean positively and negatively I guess validate their concerns around their child. Like both in a positive sense because maybe they can access more resources, but in a negative sense because you know, maybe part of the realization that it really is sort of an issue or concern. So maybe kind of bringing I don't know, like making it more apparent that their child is not meeting their milestones." – Tina
- Majority of participants felt the interRAI 0-3 had potential for addressing quality of life, but needs improvement to better support families
  - "I think if the tool was working the way it's supposed to, there is potential for the assessment to be done to identify the needs and the goals of the child and the family. And getting those early intervention supports. I think in terms of whoever is doing the assessment is really going to need to know the assessment

well, because I think in terms of quality of life for families could mean different things. Does quality-of-life mean getting out of the hospital? Does quality of life mean living in a safer neighbourhood? Does quality-of-life mean being able to pay your bills on time? You know? We get to see all of those aspects of families because we're doing visits to the home; we're intruding in on the real-life realtime happenings of families. Whereas when they are just going to an appointment or they are being dropped off at daycare, they may not get that full sense. So I hope that whoever's using the interRAI would be **really** [emphatic] well trained and know what all of the, like the value of all these questions and especially the ones that are intrusive. Because what do you do with the information when you've been given a horrible answer? Right? So, I think yeah, there is a potential to improve quality of life, but I think when you get those big answers to big questions you have to have ways of dealing with those. Right? Otherwise is just going to sit marked down on a piece of paper on someone's desk." – Robin

"So I mean I think if the tool was improved, there would be potential, right? That would be central for the assessment to identify needs, because right now it's not sensitive enough. But if that was fixed, there would be potential for the assessment to identify needs and connect families with early intervention supports. Potentially earlier than they might currently be able to access supports... I think if the CAPs are written in a really supportive way to a layperson, I also think there is potential for those people, I don't know who they would be, but those people are already in the child's life, to begin some therapeutic activities while they are on the waitlist for professional services. So I think for those two reasons, that can improve quality of life. Like families might feel less stressed knowing that we've identified an issue, but we're on it, we are getting help now, and we're on the waitlist to get help from speech or physio- or whatever is needed. So yeah, I think it would [help] in that sense." – Tara

#### 4.3.6 Summary

On the whole, participants felt that families were a necessary consideration when assessing children aged 0-3 years. While the interRAI 0-3 addressed some aspects of supporting families, helping access resources, identifying caregiver distress, addressing parenting skills, and enhancing quality of life, there were also missing pieces that should be considered moving forward. Participants felt there is potential for the interRAI 0-3 to address all of these issues, but work is needed, which Grace summarized nicely by saying, *"I think if it were cleaned up, I think you could have the potential to make sure that families can get services. And to know, that hopefully nobody is missed."* The issue of sensitivity was mentioned by three participants, but the interRAI 0-3 was created as a comprehensive tool covering a broad scope of concerns, rather than depth into few concerns. Participants felt the interRAI 0-3 could stimulate conversations that could prompt a care provider to further examine many areas of family functioning.

## 4.4 Future Considerations

Two deliverables focused on the long-term implications of the interRAI 0-3 assessment, particularly educational readiness and family poverty.

### 4.4.1 Educational Readiness

It was proposed that the interRAI 0-3 could contribute to improved school readiness for high-risk children leading to increased likelihood of employment and improved financial outcomes in later life. When asked if the interRAI 0-3 could contribute to school readiness, eight participants answered yes, three answered unsure, one answered no, and one answered potentially (if the interRAI 0-3 was improved). Of note, all three site coordinators answered yes, while the assessors were more divided.

- Eight participants (three site coordinators) felt the interRAI 0-3 could help children go to school someday
  - "Yes, because you're getting a really clear picture of all [emphatic] the development, all of their developmental levels. And if you have that you know exactly what they are, what you can tell their teacher, that the child is going to need support in this area. Yeah, I think it would be extremely helpful." Donna
  - "... it hasn't really happened for me, but definitely. Yeah, I think it definitely could pinpoint areas to work on to get the child ready for school. So let's say, like I don't know, if their fine motor skills were delayed and they were going into JK, they need to work on sort of fine motor skills: holding a crayon, that kind of thing. It's definitely something that we could identify and work on to get kids ready for school." Tina
  - "Yes, for the later age. I think as they, you know and too, you're seeing their progress towards you know age 4, you know you're seeing that progress. If it was done, let's say even it was done once a year, you had a thorough assessment, you would definitely see where there you know, their progression." Wilma (site coordinator)
- Of those who did not answer yes, their reasons varied.
  - "That's a tough one, like I don't think I can give you a great answer there. I work with children under two, right? So I don't have much experience assessing school readiness just because of the age range of the kids. So I'm not sure." – Tara
  - o "... the kids that I see are really [emphatic] young, so probably not, no." Grace
  - "I would say no, this is not a good tool to identify if kids are going to be successful in school or not. That being said, I feel like there is potential for it to happen." – Robin

## 4.4.2 Family Poverty

A second proposal about the future wellbeing of families revolved around poverty. Specifically, the interRAI 0-3 would reduce suffering and poverty for families as parents will receive supports to enhance outcomes and receive access to needed respite, food banks, informal and formal supports, etc. When asked if the interRAI 0-3 could contribute to family poverty, five answered no, four answered potentially, four answered yes (three site coordinators), and one answered unsure. Overall the feeling was that a good clinician will be able to identify whether a family is at risk of poverty and direct them to the appropriate services, with or without the interRAI. Further, families may choose to withhold information from the clinician and/or refuse the

services he/she suggests. That said, this tool may facilitate discussions around finances that may lead to a family receiving support.

- Of those who answered no, their reasoning differed
  - "... without that tool, that still becomes apparent through our service time, at times as well... when that does come out without the interRAI tool, it is the family choosing to kind of make us aware of their circumstance..." Dianne
  - "I think it's really geared to low socioeconomic, but it was like kind of all or nothing.... So there're some homes where you know they're experiencing poverty and their house is kind of cluttery and old. And you know that they're at risk, but the interRAI didn't allow for filling that out. Like that, it's got to be really [emphatic] filthy... There is no sort of, in between... They were in subsidized housing. Like it was clean and tidy but had the potential. [The mom] sort of lacked a lot of parenting skills, she talked about herself a lot in the visits. Sort of, like that couldn't get captured on the interRAI." Melissa
  - "well no… I hope that we are doing a good job with that now… I would hope that whoever is doing the interRAI would have their toolkit be able to forward them on to financial services and to get the family set up. Because that's a lot of what we do already right? Through our program… So if they don't have an agency already involved and the interRAI does pick that up, then yeah I would hope that the person doing the interRAI would then be able to help get that rolling." Robin
- There is potential for this tool to play a role in referrals or in long term family poverty
  - "... it's not always going to affect it only because it's the choice of the person that, you know do they want to accept help in this area or do they not? And also, that's going to obviously affect, in all areas of this. Because we've had parents you know, we tell them "hey, you know your child has some of these issues and this is what we can refer you to" and they never follow through, so you can only help so much." Donna
  - "...from a theoretical standpoint, it would be a good opportunity to kind of get that data and information regarding those certain populations and you know, what's needed program-wise. I know that the RAI, our adult RAI actually informs how we do things, you know what the adults, within a home care. So I don't know if individually that would, just doing this RAI would help somebody to understand that. I think, you know we are in their home, we're going to see [risk of poverty]..." Freya
  - "And I don't think completing the tool or not is really going to change the trajectory of that. But for some families you know, the ones that I don't see, I could see how there could be some families that may be just, need to be almost directed onto the right path. And with the right services they might you know, be able to tweak some things and then be more independent and function better as a family unit. Without the support of the system." Tara
- Yes, the interRAI could play a role in reducing family poverty
  - "...moving forward, I think that would be very helpful, especially when it comes to the CAPs and when we are talking about nutritional intake, so making, provide something that will, transportation, communication." – Holly (site coordinator)

- "... yeah. That definitely as well can identify that and then help you to look at, okay, like I said, do you meet the application for assistance for children with severe disabilities? So you look at you know, do they need help getting linked to an OW? You know those kinds of resources." Jenny
- "Yes definitely. This tool definitely covers, gets into all of that because you're getting into the hole, and we've heard some of that from the others, just in terms of, you know because you are picking up on so many areas that have a financial impact." Wilma (site coordinator)
- "...my care coordinators know that there is a handful of programs that we always review with the family, right? So we always do the assistance for children with severe disabilities, it's not through our ministry but we speak about it. We let them know when applications can be received, or we get them one. We advise, "you may not be eligible, it's not our ministry, but it doesn't hurt to apply, right?" So we do that piece, we talk about special services at home if we feel that the child has a developmental component or are aware of a diagnosis. Again, it's self-reporting from the family, but we initiate that piece..." Wendy (site coordinator)

### 4.4.3 Summary

While there were many differing opinions about future considerations, the outcome remains the same: interRAI 0-3 has potential to set young children on a trajectory for success later in life. Participants felt the interRAI 0-3 was better able to address education (n=8) than poverty (n=4); however, there were some (n=2 and n=3 respectively) who commented on the potential for the interRAI 0-3 to affect these two future considerations. With respect to education, the assessors who did not respond positively felt it was too early to know whether their services would affect the children in school.

Regarding poverty – an issue even further into the future – responses were even more varied. Of those who did not respond positively, most felt that the interRAI 0-3 is not unique in its ability to address this issue, as a seasoned clinician, a previous assessment, or a different assessment tool would all pick up financial concerns. Further, family capacity (e.g., parental financial knowledge, ability to maintain work, etc.) is a major determinant of poverty and parents/caregivers may choose to withhold information or refuse services. In these ways, the interRAI *may* help some assessors to discover that a family is at risk for poverty, but it is up to the family and the assessor to create an action plan to affect change.

## 4.5 Deliverables Conclusion

To conclude, participants felt the interRAI 0-3 had potential to affect four key domains of healthcare for clinicians, which were early identification, case management, family considerations, and future considerations. There were key concerns highlighted by participants that should be addressed to enhance the interRAI 0-3 moving forward. These suggestions have been highlighted here and are supported with quotes in section 4.0 (Appendix B). The logistical report presented to the interRAI 0-3 team further describes the participants experiences with the

interRAI 0-3. The changes suggested in the following section could also contribute to success for users of the interRAI 0-3 assessment tool.