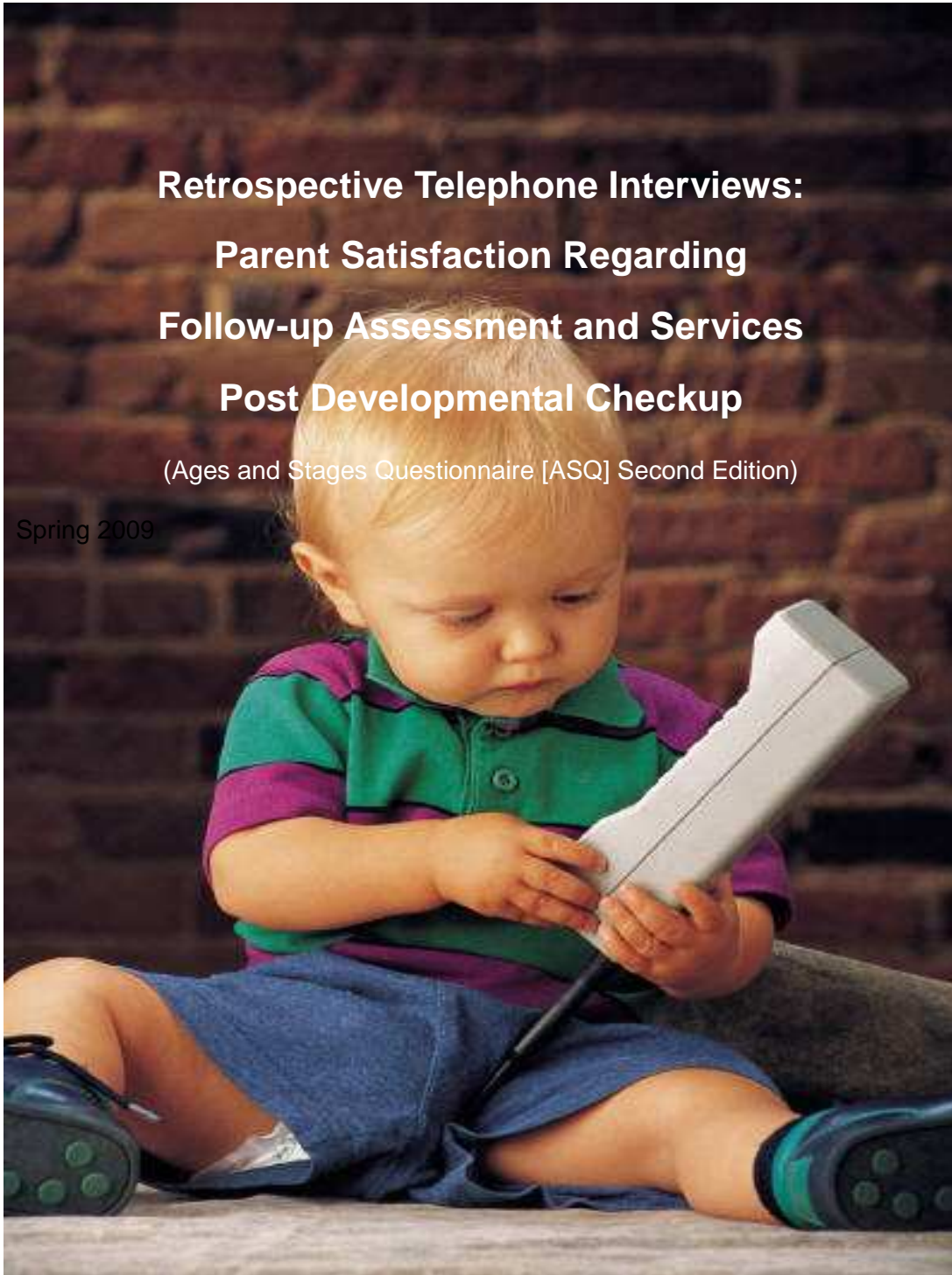


**Retrospective Telephone Interviews:
Parent Satisfaction Regarding
Follow-up Assessment and Services
Post Developmental Checkup**

(Ages and Stages Questionnaire [ASQ] Second Edition)

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Executive Summary

Purpose

The purpose of this qualitative study was to understand parents' experiences as they journeyed with their children from completion of developmental screening through to discharge from Children's C.A.R.E. services.

Methodology and Results

Eighteen interviews were conducted with parents of children who were referred to Children's C.A.R.E. services for further assessment following a developmental check-up (response rate was 69.23%; 18/26). Parents resided in Lethbridge (33.3%; 6/18) and surrounding smaller communities (66.67%; 12/18). More than half of the parents (55.56%; 10/18) had completed the ASQ at various community agencies. They were later contacted, by telephone, for further assessment and follow-up services as required. Some parents indicated that they appreciated the proximity of the services and they were aware of such services because of media advertising.

The time between completion of the ASQ and initial contact *for follow-up* ranged from a few weeks to 8-9 months. Half of the children (50%; 9/18) obtained further assessment and/or intervention within four months of completing the ASQ. A smaller percentage of parents waited 4 to 6 months (16.67%; 3/18). Two parents waited longer than 6 months between the ASQ assessment and referral to clinical services. Most parents (72.22%; 13/18) viewed the wait time as reasonable; five participants reported that the wait time was not reasonable.

The majority of children (88.89%; 16/18) were referred for follow up (assessment and/or services) with a speech language pathologist (SLP). *Of this number, 12 were male (66.67%) and 4 were female (22.22%). One male received multiple services, including SLP and physiotherapy. Another male received only physiotherapy.* It is interesting to note that just over one-third of the children who were referred did not require further services or interventions (33.33%; 6/18). With respect to these children, parents perceived suggestions and/or educational material received in conjunction with the assessment as valuable

For the children referred for treatment (66.67%; 12/18), treatment time ranged from 6 weeks to 3 months. Three of the eighteen children (all males) continued to receive ongoing support and services at the time of the interview. The majority of parents were satisfied with the assessment process and the services they received (89.89%; 16/18).

Conclusion

Overall, the majority of parents expressed positive feelings towards the ASQ, and for follow-up provided by Children's CARE Services; notably, they felt empowered with respect to their child's growth and development and valued the additional assessment and treatment. The vast majority of parents learned something new about early childhood development and the developmental check-up as a result of their experience.



Retrospective Telephone Interviews: Parent Satisfaction Regarding Follow-up Assessment and Services Post Developmental Check-up

(Ages and Stages Questionnaire [ASQ] Second Edition)

Introduction and Methodology

During April and May 2009 telephone interviews were attempted with 26 Southern Alberta parents who had completed an Ages and Stages Questionnaire for their child with a need for further assessment. The parents had completed these ASQ's between the months of February 2008 to December 2008 and were randomly selected from a larger pool of parents whose children received services.

Permission and written consent were obtained from the parents prior to the interview (see Appendix A, Consent for Telephone Interview) and confirmed by verbal consent at the beginning of the interview. Parents were advised that their comments would be used for research and for program planning and quality improvement purposes (see Appendix B, Telephone interview script).

All interviews were conducted and recorded by a single interviewer. Handwritten responses were typed immediately following the interview.

The following semi structured interview guide was used to engage participants in dialogue and discussion (see Appendix C):

1. Can you please tell me what happened with you and your child from the point of completing the Ages and Stages Questionnaire through to the follow-up you received as a result of completing this questionnaire?
2. Do you have any questions about the Ages and Stages Questionnaire, assessment, follow-up services or discharge services?
3. Did you learn anything new about early childhood development/ developmental check-up as a result of your experiences?
4. Is there anything else you would like to share?

These questions and probes serve as the organizing "framework" for the findings.

Results

Three attempts (at various times throughout the day) to contact each participant were made within a one month timeframe. Of the 26 prospective participants, four telephone numbers were out of order; four parents did not respond to the phone messages left by the interviewer. All of the parents who were eventually contacted agreed to participate in the study (response rate 69.23%, 18/26). Interviews lasted approximately 10 to 15 minutes.

Demographics

The majority of respondents (66.67%; 12/18) resided in rural Southern Alberta communities; 33.33% in Lethbridge (6/18). The breakdown of the interviews by location is presented in Table 1.

Table 1 Respondent residence

Location	Interviews
Lethbridge	6
Cardston	2
Coaldale	2
Raymond	2
Stirling	2
Coleman	1
Purple Springs	1
Vauxhall	1
Welling	1
Total	18

All of the respondents were female (18/18). Of the children who received services, one third (33.33%; 6/18) was female and the other two thirds were male (66.67%, 12/18). The majority of children referred for services (88.89%; 16/18) received speech language pathology (SLP) services (females, 100%, 6/6; males 83.3%, 10/12). One male received multiple services, SLP and physiotherapy. Another male was referred for physiotherapy services. . One-quarter of the males (25%; 3/12) required ongoing multiple services and support which were still in effect at the time of the phone interview.

Several parents indicated they were familiar with the ASQ from previous exposure with their other children.



Agency Administering the ASQ

The agencies responsible for administration and completion of the ASQ and the number of parents referred were as follows:

Agency	Parents
Community Based Screening	10
Children’s CARE Services	4
Parent’s As Teachers	2
Parent Link Centre	2

In this sample, community-based screening (check up blitz within specific communities) was responsible for the majority of the parents whose children were referred for additional assessment and services (55.55%; 10/18).

Community Program Participation

Respondents and their children had previously participated in or were actively participating in the following community programs:

Table 2 Participation in Community Programs

Community Program	Parent/Child Participation
Children’s CARE	
SLP	17
Physiotherapy	2
GAWM – Educational Initiatives	
You Make A Difference	1
It Takes Two	2
Parenting a Strong-Willed Child	1
Stay and Play	2
Community Agencies	
Parent Link	3
Parents As Teachers	1
Other	
Pass Program	1
Preschool	1
First Steps	1

Note: The total is more than n=18 as parents/children concurrently participated in more than one program.



ASQ-based Referral to Children's CARE: Initial Contact with Parents

The time between completion of the ASQ and initial contact *for follow-up* ranged from a few weeks to 8-9 months. Half of the children (50%; 9/18) obtained further assessment and/or intervention within four months of completing the ASQ. A smaller percentage of parents waited 4 to 6 months (16.67%; 3/18). Two parents waited longer than 6 months between the ASQ assessment and referral to clinical services. Most parents (72.22%; 13/18) viewed the wait time as reasonable; five participants reported that the wait time was not reasonable.

Over ¼ of the respondents (27.78%, 5/18) reported that no treatment services were received (based upon the START assessment). Parents were provided with pamphlets, other educational material and/or suggestions for working toward developmental milestones with their children.

Treatment/Intervention Duration

For children referred for treatment, parents reported that the treatment duration ranged from six weeks to more than three months.

Table 3 Treatment Duration.

Duration of Treatment Percentage and Number of Children

6-8 Weeks	11.11%; 2/18
2 Months	22.22%; 4/18
3 Months	5.55%; 1/18
Ongoing Treatment	16.66%; 3/18
No Services Required	16.66%; 3/18
Uncertainty/ Length Treatment	27.77%; 5/18
	n =18

Telephone Interviews

1. Can you please tell me what happened with you and your child from the point of completing the Ages and Stages Questionnaire through to the follow-up you received as a result of completing this questionnaire?

Probe #1: What was your experience with the assessment?

With the exception of one parent, all other participants (94.44%; 17/18) voiced very positive comments with regard to the ASQ and their child's developmental check up.

"As a result of the Ages and Stages Questionnaire I was able to help him along."

"It helped me to know where my child is."



"I've learned a lot every time I do the ages and stages questionnaire. I learned where they should be at those months."

"It was actually really good- speech assessed and fine motor skills, it was good."

"It was good. It happened quickly and it was something I wanted them to look at."

"It was really fun and I had a good time, really good."

"No we got a speech assessment done because of it. He was fine."

"They did a complete assessment. Then [care provider] and another lady came and went through motor skills and stuff."

One parent had wanted take the questionnaire home to "try it out" with her child:

"I thought it should have been taken home with me, things I would have to do to get proper answer like the cheerio in the bottle, only part of the questionnaire I thought bothered me."

Two parents believed their children were too young to be properly assessed. Their children were uncomfortable with a) assessors (as they were not known to them), and b) the location where the assessment was conducted.

Probe #2: What kind of experience did you have with the follow-up you received? What services were offered?

Overall, most of the respondents' children received some form of treatment.

"They had called me and my son for an evaluation and to see a speech pathologist. She evaluated certain things, where he was vocally, and we saw her for about three months. We did that and after three months he just started talking."

"Actually I wasn't offered too many services. The evaluation put him right where he was supposed to be and they offered suggestions not services cause he didn't need it."

"Yeah, we had really good follow-up. There were some concerns with the speech aspect. They had no problem accommodating the transfer. I had to move and this didn't throw them, it was thorough and I was satisfied with it. It was fun."

"She was referred to a speech pathologist. Follow-up from that was good. I feel there was follow-up where there needed to be."



One parent who felt that the assessment did not address her concerns hired a privately-funded agency for a reassessment.

“Assessed his speech and motor skills within the realm of normal and closed the file. I privately hired a speech pathologist and he referred me back and they lost my forms that have been the difficulty. Now I am waiting to hear back.”

Probe #3: Did you encounter any barriers to receiving services?

Two-thirds of the respondents reported that they did not experience any barriers to receiving services (66.66%; 12/18). For parents who did report barriers to receiving service (22.2%, 4/18), these included: loss/ misplacement of the ASQ (n=2), delayed referral for follow up (i.e., more than 6 months) following the completion of the ASQ (n=2), and lack of confidence in assessment findings (n=2).

“The first questionnaire I filled out was lost so it took a little longer until after the second one.”

“I filled out the ASQ one time and never heard back. I filled it out again, not thrilled with follow-up, filled another, and moved, they didn’t call even though a cell number was left.”

Two parents, did not encounter any barriers, but decided not to go through with the services that were offered to their children:

“I saw so much improvement I didn’t go there [service]. I went to Lethbridge to check his hearing and he’s doing great.”

Probe #4: Was the timing from referral to intervention reasonable/ acceptable / adequate? How long? Did you experience any delays in terms of accessing a service? If ‘yes’, please tell us about it?

Half of the children (50%%; 9/18) obtained interventions (further assessment/treatment) within four months of being referred. A smaller percentage of parents waited 4 to 6 months (16.67%; 3/18). Two parents waited more than 6 months (11.11%; 2/18) between referral and intervention. A couple of the parents experienced delays from the loss of their ASQ form and so they were unable to state the time from referral to intervention (11.11%; 2/18). Two parents experienced confusion as to whether their child received treatment from the referral of the ASQ or their family physician (11.11%; 2/18).

“They gave me [a] couple of handouts with games and tasks that was good”.

“ I think they did give me pamphlets and other things about what I could do at home with certain sounds like speaking slowly and enunciate”.



Table 4 Reported Wait Time: ASQ Completion and Referral for Assessment/Treatment

	Percentage of Parents
Few Weeks to Six Weeks	(27.77%; 5/16)
Two to Three Months	(16.66%; 4/18)
Four to Six Months	(16.67%; 3/18)
More than Six Months	(11.11%; 2/18)
Lost Questionnaires	(16.66%; 2/18)
Confusion over ASQ or Physician Referral	(11.11%; 2/18)

The majority of parents perceived this wait time as reasonable (72.22%; 13/18). The remainder reported that this length of time was unreasonable (27.77%; 5/18).

Probe #5: Were you satisfied with the service provided?

The vast majority of respondents (including the two participants whose ASQs were misplaced) were satisfied with the service provided (88.89%; 16/18).

"Absolutely."

"I was very satisfied with it."

"Yes she came to our home and spent 45 minutes with him, lots of time and asked me some questions."

"I was satisfied with the treatment."

Dissatisfied parents made the following observations:

"Not really, screening was good, not the follow-up, I don't think so."

"Still in process. I don't think 100% their fault, not the whole blame. I'm a little dissatisfied."

2. Do you have any questions about the Ages and Stages Questionnaire, assessment, follow-up services or discharge services?

None of the respondents (18/18) had further questions about the ASQ questionnaire, assessment, follow-up services or discharge services.

3. Did you learn anything new about early childhood development/developmental check-up as a result of your experiences?

Probe: Can you tell us about that?

The majority of parents (61.1%, 11/18) felt that they had learned something new about early childhood development and/or developmental check-ups as a result of their experiences.



“Yes, different words, more words and some ideas to get him talking more. Action words like push pull, two word sentences, two word combinations using action words.”

“Yes, where a child is supposed to be at a certain age.”

“I learned something new every time. Something particular didn’t stand out at any one time more than another. A lot of times I get ideas and where someone should be at a certain time.”

“Yeah I did actually. Where she should be at if she’s ahead. Makes you do things different.”

“Yes I do and yeah I use to ask and then they gave me a program what to do.”

“I would say so yep I didn’t realize how much your child should know up to pre-school. It’s a good point of reference that was really nice.”

Four parents (22.2%, 4/18) responded ‘no’ as they had previous early childhood development training or had other children who participated in an ASQ check-up.

“Um not too much. I’ve done an early intervention course and I’ve worked with young kids so there weren’t any surprises.”

“No not overall, they gave me couple hand outs with games and tasks that was good.”

“No I didn’t not here, but my second one I had “Families First” and I learned about the ages and stages. If it was my first then yeah.”

“Nope.”

For some parents (n=4), the experience reinforced their existing knowledge about early childhood development and the role they could play in promoting their child’s optimal development.

“I think it was reinforcing it might have clarified. It just reiterated where and what I am doing with alphabet and numbers. A good reminder.”

“Um I guess you could say I did but I can’t pinpoint specifically. I guess what is normal and not normal.”

“Not really, a few things. I should start doing with him with scissors and cutting some stuff.”

Overall, satisfaction with the Grow Along with Me staff was high as exemplified by the following comments:



“It was, well he didn’t participate much, he wasn’t talking, he was three. They asked him all kinds of questions. They were really patient. They helped me get him into a pre-school”.

“ People that were facilitating the screening did an excellent job”.

The promotion and availability of early childhood development check-ups were perceived positively by parents.

“ I was surprised it was well advertised. [The] only reason ...I went was because a notice was sent home with my other kids through the school Advertising was well done”.

“ I think it’s well advertised and easy to get to”.

4. Is there anything else you would like to share?

Probe: Ask parents if they would like to make comments about child developmental check-up, their experience(s), and/or their child’s experience(s) they did not mention earlier in the discussion.

Several parents indicated that the developmental check-up reinforced their personal sense of knowing:

“Trust your mother instinct.”

“It’s a good point of reference that was really nice.”

Two parents learned about the importance of hearing and its relation to speech development:

“Just the hearing thing there was a long waiting list. It was about four months from the time of referral to begin any program.”

“The speech issues and follow up I think hearing tests should be done to rule out any issues.”

Two parents felt their children were too young to assess and would normally develop on their own if given a bit more time.

“Met with us once of course. I thought it was difficult for them to do a speech assessment with kids that small as he was not comfortable. It was difficult for the ladies with us to assess his speech; I think it would have taken more sessions for him to feel comfortable.”

“Only concern was his speech. He was barely 18 months old at the time so not really talking all that much. He was with three other little boys. We did parent play, structured play, it was good, interactive, but didn’t really help with speech. They wanted parents to have goals but there was no direction how to



help him in speech. For me, I thought it almost made us worry about his speech too much, a little delay but normal by next screening. Maybe if they screened him three months later they maybe would not be concerned about his speech.”

Two parents also suggested that the completion of the ASQ and subsequent identification of potential delays resulted in their children being labelled. They perceived that this might bias future interactions in the school and/or medical setting.

“I really like this whole thing. My husband’s concern is he doesn’t like this information passed on, labelling and shared with the school just because it is now not that it is going to stay this way.”

“Um one thing I didn’t care for seems he got put with a label. Right now severe developmental delay, not anything else physically way ahead. My other son, they knew all about him, your older son had this or that, what they could offer.”

One parent mentioned the importance of community in their child’s development:

“I did find that the community actually can be involved. I didn’t have to get a doctor involved. I didn’t know there were services provided by community health. I would say it is very user friendly.”

Availability/proximity were important to some parents:

“ I appreciate that it’s available and close”

“After this class, which ends in June, the following September he will be in the “Pass Program” four times a week. Nice for him”.

Of the 18 participants contacted, three children continued to receive ongoing intervention and support (ten months to one year later). Each of the parents expressed positive support for the programs/interventions their child was receiving:

“The help he received has really helped him progress. He’s come a long way”.

“They’ve been really helpful getting me everything I need, definitively good. They keep helping and pushing me through with courses and classes”.

Limitations

This study was limited given that 18/26 parents participated in the survey. Contact with single parents or where the primary care-giver worked full or part-time outside of the home may have been systematically eliminated as the telephone interviews were restricted to daytime hours.



No pilot testing of the interview guide was conducted. The standardized questions may have been ambiguous or the distinction between questions unclear; on some occasions, parents appeared to be uncertain of what was being asked of them. For example, Question 1, probe 4, asks “Was the timing from referral to intervention reasonable/acceptable/adequate? More than one parent stated that this sounded all the same to them so did not really know how to respond. Specific questions about the type of intervention received, wait times, duration of the treatment would be helpful.

Another difficulty was the indicated date of ASQ completion. These dates did not accurately reflect the parents’ memory of their completion of the ASQ. Some of the dates provided were in fact the date the file was closed after service had been received, not the date they completed the ASQ. With other completion dates, the day and the month had been switched around and did not accurately reflect when the ASQ was completed.

Historical bias may have impacted parental recall as some of the interviews were completed more than a year after the parents completed the ASQ with their child. In other instances, parents had completed several ASQs with their child and were unsure of which experience to report on.

Conclusion

Overall the value of the ‘Grow Along With Me’ program, including the ASQ and the follow-up interventions appeared to be a worthwhile and positive experience for the clear majority of parents who participated in this retrospective telephone interview. Parents voiced support and encouragement for other parents to have their children undergo the ASQ check-up.



References

Squires, J., Potter, L. & Bricker, D. (1999). *The ASQ User's Guide for the Ages & Stages Questionnaires. A Parent-completed, Child Monitoring System* (2nd Ed.). Baltimore, MD: Paul H. Brookes Publishing Co.



Appendix A

Interview Questions (with Probes)

1. Can you please tell me what happened with you and your child from the point of completing the Ages and Stages Questionnaire through to the follow-up you received as a result of completing this questionnaire?

Probe #1: What was your experience with the assessment?

Probe #2: What kind of experience did you have with the follow-up you received? What services were offered?

Probe #3: Did you encounter any barriers to receiving services?

Probe #4: Was the timing from referral to intervention reasonable/ acceptable / adequate? How long? Did you experience any delays in terms of accessing a service? If 'yes', please tell us about it?

Probe #5: Were you satisfied with the service provided?

2. Do you have any questions about the Ages and Stages Questionnaire, assessment, follow-up services or discharge services?

3. Did you learn anything new about early childhood development/ developmental check-up as a result of your experiences?

Probe: Can you tell us about that?

4. Is there anything else you would like to share?

Probe: Ask parents if they would like to make comments about child developmental check-up, their experience(s), and/or their child's experience(s) they did not mention earlier in the discussion.



Appendix B

Telephone Interview Script

Hello. **I am calling on behalf of Chinook Health. Recently you brought your child to the health unit. At that time, a nurse** asked you to participate in a project called 'Grow Along With Me'. You **checked** off a box on the first page of the Ages and Stages Questionnaire **expressing** interest in participating in this project. That is why I am calling you today.

I am involved in the evaluation of the 'Grow Along With Me' project. I would like to ask you four questions about your experience with the Ages and Stages check-up you completed. There are no known risks associated with your participation. You may have some discomfort reflecting on and sharing your experiences; however, you may also feel better talking about what happened. Are you willing to be interviewed?

Interviewer Notes:

<input type="checkbox"/>	<p>If the respondent:</p> <ul style="list-style-type: none"> ■ Asks the length of time required to answer the four questions, state "approximately 15-20 minutes". If the respondent states she/he is not interested in being interviewed, thank her/him for their time and hang up the receiver. ■ States "yes", then proceed with the telephone interview. Inform the respondent that by saying "yes" they are providing you with verbal consent to participate in the telephone interview. If the respondent states "no", as him/her if they would like to rebook the telephone interview at a time that is more convenient for them. <p>Ask the respondent if he/she is 18 years of age or older. If "yes", continue with script and interview.</p> <p>If the respondent is under 18 y.o.a., state that this evaluation cannot include people under 18 y.o.a. Thank the respondent for her/his time and hang up the receiver.</p>
<input type="checkbox"/>	<p>If "no", thank the respondent for their time and hand up the receiver.</p>

This project has been approved by an ethics committee at the University of Lethbridge (i.e., the Human Subject Research Committee), as well as by the Chinook Health Region (i.e., the Research Committee). The results from this study will be documented in a final report that will be submitted to our funder (i.e., Alberta Health and Wellness). Our findings will also appear in Chinook Health newsletters (e.g., Interchange, The Compass), a Chinook Health hosted webpage (<http://www.growalongwithme.ca/>), local newspapers, etc. The results may also be presented in person at professional conferences or published in journals read by clinicians and researchers interested in **early childhood development**. At no time, however; will your name be used or any identifying information revealed.

I also want to remind you that all the information we collect from you today will be recorded and safely stored at the University of Lethbridge for seven years and then disposed of as confidential was as per University of Lethbridge standard practice. Furthermore, your participation in this telephone interview is completely voluntary and your decision about whether or not to participate will not affect the care you or your child (children) receives from the Chinook Health Region and their partners. You may refuse to answer any of the questions I ask by simply saying "next question please". You are also free to withdraw your statements at any time during or after this interview by simply saying "I don't want to be a part of this project".



Note there is no immediate benefit to you for participating in this interview other than the information you provide may help Chinook Health Region partners improve the programs and services they provide to children and their families. If you have any questions, concerns, or need additional information about the 'Grow Along With Me' project, you may contact the lead evaluator (Dr. David Gregory: (403) 329-2432) or the 'Grow Along With Me' project coordinator (Mark Moland: (403) 329-5255). **If you have any other questions regarding your rights as a participant in this research, you may also contact the Office of Research Services at the University of Lethbridge at (403) 329-2747.**



have any other questions regarding my rights as a participant in this project, that I may contact the Office of Research Services at the University of Lethbridge at (403) 329-2747. Finally, I understand that this information is collected under the authority of the *Health Information Act* and the *Freedom of Information and Protection of Privacy Act*.

Parent's/Legal Guardian's Signature

Today's Date (dd/mm/yyyy)