

Children with Complex Communication Needs



Focus Groups – Final Report

June 26, 2015

Calgary and Area Regional Collaborative Service Delivery

Prepared by: Lisa Casselman MSW RSW

TABLE OF CONTENTS

1. Report Highlights	1
2. Introduction	2
3. Methodology	2
4. Findings	3
4.1 Successes, Champions and Challenges	3
4.2 Collaboration	7
4.3 Barriers and Enablers	9
4.4 Resources	11
4.5 Transitioning	13
5. Conclusions	14
6. Appendices	15

1. REPORT HIGHLIGHTS

- **13 people participated in the two focus groups**, including four in the focus group for parents and nine in the group for speech language pathologists (SLPs). Because of low response rates there were no focus groups with teachers but one teacher was interviewed.
- **Multidisciplinary teams (e.g., OT, PT, SLP) are valued** and contribute to increased collaboration and better transition planning. Some SLPs said these teams should be within one organization rather than dispersed by geography or program.
- **Both SLPs and parents experience confusion about key contacts, roles and responsibilities.** It can be challenging to locate the SLP working with a child, or assigned to a school. Relative roles of teachers, aides and SLPs are not clear in some areas such as programming. Changes in organizational structure or function compound the confusion.
- **Collaboration could be improved**, particularly from the perspective of parents who would like more opportunities for involvement and more contact with SLPs through meetings and training.
- **Family is the constant in the child's life** and needs to be involved when the child is being discussed. Some parents were concerned that they aren't invited to meetings and feel "out of the loop".
- **Working across contexts** (e.g., home, school) supports use of communications technology.
- **Transition planning could be improved** by a stronger team approach including more involvement of parents, teachers, aides, SLPs and other professionals; having children try schools in the spring; and by improving the referral process.
- **Communication technology poses challenges** including keeping up-to-date with new hardware and software, getting technical support, repairing devices, and keeping programming current.
- **Device support is important** and includes assistance with choosing, setting up, maintaining, and programming a device.
- **Mentoring, modelling, monitoring, one-on-one and hands-on support** are valued ways of supporting use of communication technology by parents, teachers, aides and SLPs.
- **There is variability between schools and districts in financial and human resource support for communication technology.** This results in inconsistencies between schools for both devices and support. Lack of familiarity with the technology and cost concerns may lead to reliance on iPads, which may not be the best choice for all children.
- **Camps, websites, specialized teams, conferences, hands-on-training, chat groups and support groups** are helpful resources.
- **Learning resources exist but there is limited awareness** about what is available; use of existing resources should be optimized. Suggested resources included a centre of excellence, parent support group, chat groups, bringing experts to Alberta and having a conference about AAC.

2. INTRODUCTION

The Calgary and Area Regional Collaborative Service Delivery (RCSD) is undertaking a project, funded by Alberta Education, to explore how to best support children and youth with complex communication needs (CCN), specifically those requiring the use of communication devices. The project has included a literature review; surveys of teachers, parents and SLPs; focus groups with parents and SLPs; and an interview with a teacher. Collectively, the interview, focus groups, survey and literature review will help guide the development of resources and training to best support children using communication devices.

The body of this report highlights the findings from the two focus groups. The notes from the teacher interview are included as Appendix One. The notes from the two focus groups are appended as Appendix Two and Appendix Three.

3. METHODOLOGY

In collaboration with the CCN Committee, the consultant contracted to undertake and report on the focus groups prepared a Moderator's Guide, (Appendix Four). This guide was developed to focus the discussions and help ensure consistency in approach between focus groups.

Participants who completed a survey were asked if they would be interested in participating in a focus group and those who replied affirmatively were invited to register for a group. The original intent was to have one focus group for parents, one for speech language pathologists and two for teachers. The focus groups for parents and SLPs were conducted as planned but there was very little response from teachers to participate in a focus group. Because a good number of teachers had expressed an interest in participating in a focus group when asked on the survey, several different days, times and locations for the focus groups were offered, but received little or no response. It is thought that the time of year (i.e. May to early June) may have been a prohibiting factor. As a result one teacher was interviewed and no focus groups were conducted with teachers. 13 people participated in the two focus groups, including four in the focus group for parents and nine in the group for SLPs. The SLPs who participated came from public schools, private schools and Alberta Health Services and included both generalist and specialist SLPs. Including the one interview, there were 14 participants (Table 1).

The consultant facilitated the focus groups and all were audio-recorded. Respondents had granted consent prior to the focus groups and were advised that audio files would only be used by the consultant and would be destroyed upon completion of the final report. Based on notes taken during the focus groups and review of the audio files, the consultant identified key themes, illustrative quotations, and prepared this report.

It is important to note the limitations of this study. First, focus group results cannot be generalized to a larger population. Secondly, the study reports on only 14 participants over half of which were SLPs. Teachers were minimally represented in this study.

Table 1 – Focus Group and Interview Locations and Composition

Segment	Location	Focus Groups/ Interviews	Number of Participants
Parents	Calgary – St. Leo Centre	1 focus group	4
Speech Language Pathologists	Calgary – St. Leo Centre	1 focus group	9
Teachers	Rocky View Education Centre	1 interview	1
Totals		3	14

4. FINDINGS

4.1 SUCCESSES, CHAMPIONS AND CHALLENGES

Questions asked during this introductory section explored participants’ thoughts about what is currently working well, people who are champions, and what is not working well or needs improvement.

SUCCESSES AND CHAMPIONS

Both groups talked about successful collaboration¹ and highlighted that technical support with communication technology contributes to success. The SLPs said successful collaboration occurred both within multidisciplinary teams and also between specialized teams such as the Augmentative Communication and Educational Technology Service (ACETS) and the Support Services Inclusive Learning (SSIL) team. Parents mentioned collaboration with teachers, parents, and SLPs, particularly in relation to use of a device. There were no commonalities between the groups in terms of champions identified.

SUCCESSES - SLPS

- **Multidisciplinary teams** – Teams that bring together all the professionals involved with the child (e.g. occupational Therapists, physical therapists, psychologists, SLPs and vision specialists) were cited as examples of success. SLPs emphasized that it is most helpful when multidisciplinary teams are located within one organization.
- **Collaboration** – Specific mention was made of positive collaboration with ACETS and SSIL.

¹ Collaboration is discussed in greater detail later in this report.

- **Working across contexts** – This was described as working with children in the schools, in their homes and at times in the community.
- **Use of technology at home** – When children use their communication devices at home it is seen as an indicator of success.
- **Designated specialists, specialized teams** – Staff who have specialized competencies in technology, assessment or child development contribute to success. Likewise, when SLPs are assigned to a specific school or schools, this was thought to be helpful. The assistive technology team at Renfrew was highlighted as one example of a specialized team that provides support with communication technology.
- **Specialized classrooms; well-trained educational staff; working alongside teachers** – Classrooms with a specialized focus on special needs, well-trained teachers and aides, and having SLPs work alongside teachers promote positive outcomes.
- **Tracking through the life span, transition planning** – Following a child from early childhood through to adult life was seen as a success, with the ACETS team being an example of this.
- **Clarity about roles and responsibilities, who to contact** – Support is enhanced if professionals are clear about their roles and responsibilities as well as those of other professionals. Knowing who to contact regarding a child is very important.
- **Involvement of parents and peers** – Participants emphasized the importance of parental involvement, particularly when there are meetings about a child.

Some classes are very strong. They have well-trained people working with the children.

SUCCESSES - PARENTS

- **Resource or classroom teachers' interest in the child and his/her communication device** – This interest involved finding applications, supporting the best utilization of the device including use at home, ensuring that the device is programmed to facilitate classroom participation, and willingness to have a SLP in the classroom.
- **SLP classroom consultations** – One parent said the classroom consultation with a Calgary Board of Education (CBE) SLP was helpful but thought this should occur more than twice a month. Another parent talked about the value of meeting with an SLP at Renfrew every two weeks as this helped her program the device to include what is needed at school.
- **Collaboration among SLPs, teachers and parents to choose, set up and maintain a device** – This helps ensure that the device meets the child's needs and is programmed to help maximize use.

We need a champion for the child in each context such as showing parents how a device can be used and having someone designated to make sure it has been charged. Lots of people want to help but they are stretched too thin.

- **Private SLP** – One parent hired a private SLP who provided coaching about communication and use of the device.

CHAMPIONS - SLPS

- **Community of Practice** – Alberta Education offers this.
- **Teachers** – Some teachers are well trained, enthusiastic and determined supporters of children in their classrooms or schools.
- **ACETS Team** – This team was noted for its commitment to consulting and providing support about appropriate devices and their use.
- **Alberta Aids to Daily Living** – This service helps ensure that children get access to communication technology through funding support.

CHAMPIONS - PARENTS

- **Camps** – Two of the four parents attended camps in Ontario (iCan Communicate 2: Camp Thrive,) and Idaho (Advancing Adventures in Communicating). The camp in Ontario provided “amazing support” both during and after the camp.
- **PREP Program** – One parent identified this program as a champion “in the speech area”.
- **PUF Program** – An aide at this program was highlighted for seeing a child’s potential and working to develop it.

Caroline Musselwhite, Gretchen Hanser and Erin Sheldon provided amazing support both at the camp and after. They provided information about apps you could use and how to use them.

CHALLENGES

Some of the successes identified above were also listed as challenges indicating there are still obstacles limiting success. For instance multidisciplinary teams were identified as a success but if the team is dispersed it presents a challenge. Both groups identified the need for professional development, increased classroom support, keeping the device up-to-date, and confusion about key roles and contacts.

CHALLENGES - SLPS

- **Multidisciplinary team dispersed** – These teams become less effective if they are dispersed by geography or program rather than having the team within one organization.
- **Working across the lifespan** - Not all teams follow children through to adulthood, which can negatively impact transitions.
- **Insufficient classroom support** – The lack of aides and the ratio of staff to students is an ongoing concern.

- **Waiting lists** – Wait times to access services at ACETS or SSIL delay support.
- **Technology** – There is a lack of trial devices; it is demanding to keep up with changes in both hardware and software.
- **Limited knowledge base at the community level** – Although schools may be supported in the use of communication technology, there is a lack of knowledge and support at the community level.
- **Fragmented transitioning** – Overall, there were concerns about transitioning² including challenges transitioning from an agency to CBE (device but no support), and having information follow the child, particularly during grades 7-12. Effectiveness appeared to vary between classes and from year to year.
- **Lack of professional development** – This is limited at front lines of service and impacts the support from those working directly with children.
- **Area strategist role lacking** – The loss of the CBE strategist role was thought to have created challenges with service planning.
- **Confusion about key contacts** – SLPs said they have problems identifying other SLPs at schools or within Alberta Health Services (AHS). They also said that families are uncertain about who is working with their children.
- **Gaps in communication between home and school** – Gaps in communication between the child’s school and home environments pose challenges for use of the device and for developing understanding about goals, problems and issues.

Generalists and teachers have a lot of other needs beyond AAC. They need someone who researches this for them and then presents it to them.*

* Augmentative and alternative communication

CHALLENGES - PARENTS

- **Insufficient collaboration** – Parents said there is not enough collaboration among teachers, aides, SLPs, and parents.
- **Keeping devices up-to-date and relevant to the child’s needs** – Parents talked about the challenges with keeping the programming up-to-date so that their children can fully participate in the

He has been hiding the device at school. He wants to say something but it (programming button) isn’t there. He can’t find it so he gets frustrated and puts it aside. I removed some things and added them slowly so it is less confusing. There is nobody there to support him.

² Transitioning is discussed in more detail later in this report.

classroom. Challenges included a lack of knowledge and uncertainty about the relative roles of parents and the school. Some parents said they want to be in control of programming and others said it is a school responsibility.

- **Professional development for teachers and aides** – Staff could be better educated about programming, the importance of modelling use and about ways to include and motivate children with complex communication needs.
- **School not able to provide support** – One parent was concerned that the specialized school attended by her daughter was not able to facilitate communication with the device, necessitating a move to another school.
- **Confusion about roles** – Parents said they don't understand the relative roles of teachers, aides, and SLPs in programming, modelling use, providing in-classroom support and consultation. Further, some parents said they feel overburdened by the number of roles they have or are expected to have.
- **Lowered expectations of child** – One parent was concerned that when her child did not meet the individualized program planning (IPP) goal for use of the device in the classroom, the goal was lowered. She thought there should have been more focus on how to achieve the goal.

4.2 COLLABORATION

This section explored participants' thoughts about the current state of collaboration in support of children with complex communication needs. Parents tended to be less satisfied with current collaboration than SLPs. One parent said she "has to push for it", while another said that "it depends on who the teacher and SLP are". A parent said that the IPP development and review is currently the main opportunity for collaboration. Both the parents and SLPs said that challenges to collaboration include lack of role clarity, not knowing key players, and being uncertain about how to navigate the system.

WHEN COLLABORATION IS MOST EFFECTIVE

Putting effort into functional goals supports collaboration.

SLPs

SLPs said the following factors contribute to effective collaboration:

- **Child-focused** – Collaboration is strengthened when all participants are focused on the child's best interests.
- **Knowledge about those involved in collaboration including role clarity** – When participants are familiar with those involved it strengthens collaboration. This includes knowing skill levels and understanding expectations.
- **Trust** - Trust enhances collaboration and it is strengthened when people work together over a period of time. There was concern that recent organizational changes might negatively impact trust.

PARENTS

The following factors were said to contribute to effective collaboration:

- **Involvement of key players** – Collaboration is enhanced when meetings include teachers, aides and SLPs who are working with the child.
- **Meetings other than for IPPs** – Although collaboration occurs at IPP meetings, parents thought that additional meetings need to be set up to facilitate discussion about the child’s needs, without a specific focus on IPP development or review.
- **Being available for impromptu conversations** – Dropping into the school once a week and having a casual conversation with the teacher helped enhance collaboration for one parent.
- **High ratio of staff to students** – One parent said collaboration with the teacher was good, noting that there are six children, a teacher and two aides in the classroom. The teacher has time to meet with the parent for up to half an hour per occasion.

My goal is to create a multidisciplinary team that has a teacher and maybe an aide floating in each year. On that team we need peers, family, grandparents, SLPs, OTs— anyone who works with my child. The initial collaboration should be for everyone.

CHALLENGES TO COLLABORATION

Themes common to both SLPs and parents included lack of knowledge about key players, confusion over roles and difficulties navigating the systems. These factors negatively impact development of constructive, collaborative relationships.

SLPs

- **Difficulty navigating the systems; challenges connecting with SLPs** - Changes in SLP school assignments from year to year can negatively impact collaboration as relationships need to be re-established. Since there may be two SLPs assigned per school there can be inconsistency in which SLP is involved with a child.
- **Organizational differences in roles; changes in organizational structure** - Some said that there are inconsistencies between organizations in how closely the SLPs work with occupational therapists and physical therapists. Closer working relationships between these professionals were seen as desirable. The change from REACH to SSIL, along with incorporation into the RCSD, has also resulted in some confusion about the existence and role of the service. As well the RCSD team is relatively new. Collectively these organizational changes were seen to negatively impact collaboration.

When I am going to SSIL I know who to call but I am not as clear about how to find a SLP in AHS who works in education.

PARENTS

- **Need to push for collaboration; IPP relied on for opportunities** – Some parents were concerned that collaboration about their child did not occur unless they pushed for it. The exception to this was the collaboration that happens during IPP preparation and review but parents said that three times a year is insufficient and that not all key players are involved with the IPPs.
- **Lack of knowledge of key players, confusion about roles; uncertainty about navigating the system** – As was the case with the SLPs, parents said that clarity about organizations including key contacts and roles negatively impacts collaboration. One suggestion was to have SLPs in schools full-time rather than “loaning” them from outside organizations.
- **Limited SLP resources** – One parent valued meeting with the SLP and having this person present at meetings but at the same time she didn’t want meeting time to reduce direct service.

4.3 BARRIERS AND ENABLERS

BARRIERS

This section explored barriers to supporting children with complex communication needs and the factors that enable or promote support. Most of the barriers identified by SLPs related to keeping up-to-date with technology; developing capacity to acquire, use and support devices; and ensuring ongoing access to technology. SLPs also spoke about barriers associated with differing priorities for resource allocations within school districts and between schools. Parents emphasized similar barriers including the lack of programming support, limited education and training of teachers and aides about devices, and school-level allocation of resources.

BARRIERS - SLPS

- **Keeping technology up-to-date** – This was a major barrier; specific examples included:
 - not being up-to-date regarding technological advances, programming and vocabulary
 - outdated devices
 - learning about new devices
- **Supporting use of devices** – Specific examples included:
 - functional goals for device use not sufficiently meaningful
 - insufficient numbers of front line staff to support devices
 - lack of clarity about who to call for device support
- **Accessing devices** – Specific examples included:
 - lack of clarity about referral criteria and responsibilities; pathways to access devices not clear

If teachers don't have access to the specialized services they had in the past, they move to iPads because these are more familiar. More education is needed for administration and teachers to understand low tech through to high tech. The iPad is not the solution for everyone.

- not being able to afford the cost of a device for at-home use
 - device unavailable due to lengthy repair times, particularly if repairs are occurring in the United States; lack of loaner devices
 - device not charged or left at home
- **Local decisions about resource allocations** - School administration and staff make decisions about financial and human resource allocations for communication technology. They may not be familiar with communication devices but they are in the position to make resource decisions. As well, inconsistency in support between schools and districts results in varying degrees of barriers to use of devices.

Some administrations find money for support and others don't. You wonder how it is possible that they are in the same school district.

BARRIERS - PARENTS

- **Lack of communication with SLP** – Parents have not met the SLP and/or don't know when s/he is visiting the school.
- **Meetings about a child without the parents** – Related to a lack of communication with SLPs is the concern that a child's team, or some members of it, are meeting without the parents' knowledge or presence.
- **Inappropriate use of school resources** – Decisions about resource allocation are made at the school level and resources may not be used appropriately (i.e., a child may not receive all the support for which s/he is funded).
- **SLPs, teachers and aides not trained in assistive technology** – SLPs may have commenced their careers before the communication technology was in use, or their training may not be up-to-date with current technology. Likewise, some teachers and aides are not sufficiently trained.
- **Lack of programming support for parents** – Some parents thought that they don't get enough programming support and that keeping programming up-to-date is overwhelming but without this the child's opportunities for participation are limited.

ENABLERS

Both parents and SLPs talked about bringing children and/or parents together to exchange information through user groups, chat groups or camps. Both groups agreed that modelling supports device use.

ENABLERS - SLPS

- **Training, mentoring, modelling, monitoring** – SLPs emphasized that these supportive actions – from teachers, aides, SLPs, parents or peers – enable the most effective use of communication technology. One example was the value of helping parents become familiar with a device before using it.

- **User groups for children using devices** – When children can use their devices to communicate with peers it helps “normalize” the use of communication technology and may help encourage device use. As well these groups provide an opportunity for parents to connect and share their experiences with communication technology.
- **AAC camps** – SLPs noted that camps encourage use by providing information and support, while also “normalizing” use.
- **ImPAACT Program** – This evidence-based protocol (learning road map) supports instruction.

It helps when we provide education about the easiest way to fit the device use into the day—to fit it into the routine at home. The service is designed to set the device up and then let go. We need ongoing mentoring.

ENABLERS - PARENTS

- **More one on one time** – Parents said that one-on-one time with teachers or SLPs was very helpful.
- **Teachers modelling use of a device** – Some parents said that this is a critical action to encourage children’s use of technology in the classroom.
- **Collaboration with SLPs** - Parents appreciate being contacted by the SLP to initiate communication and discuss proposed work with the child.
- **Ongoing communication with those supporting the child** – Some parents acknowledged that it is challenging to set up meetings and indicated that quick meetings with teachers or SLPs (e.g., after school when picking up child) or emails can be helpful to inform parents about device use, applications etc.
- **Chat groups (parents, children)** – These facilitate information exchange and file sharing; schools can help create awareness of these through a poster or mention in the newsletter.
- **Support in choosing devices** – Suggestions included a decision-making tree about choosing a device, a universal plan to help make an informed decision, and equipment trials.

4.4 RESOURCES

Resources were identified throughout focus groups sessions as examples of successes and enablers. Parents and SLPs agreed that there are many resources available but it is challenging to locate them, particularly those that are appropriate to a specific developmental level. Parents and SLPs identified many of the same resources including the internet, camps, workshops, conferences, and group support. They both emphasized the importance of hands-on experience with technology.

GAPS - SLPS

- **Lack of SLPs trained in assistive technology** or SLPs needing more training to be up-to-date.
- **Need for training to help administration and teachers understand the range of technology** from low tech to high tech (not just iPads).

HELPFUL RESOURCES - SLPS

- **Specialized teams such as ACETS and SSIL** are a very helpful resource and can do assessments.
- **Manufacturers and vendors** - Their websites, helplines, tutorials, and webinars are good resources.
- **YouTube** – Presentations are available online, including from AAC experts.
- **Provincial or national association resources** – Articles or other resources from these organizations can be helpful to share with parents.
- **Other websites** - Websites mentioned were www.setbc.org and www.praacticalaac.org.
- **Conferences** - Some provide hands-on opportunities to use devices, which is very helpful to those who are not familiar with the technology or want to keep up-to-date.
- **Community of Practice** - Alberta Education offers this resource opportunity.

HELPFUL RESOURCES - PARENTS

- **ACETS and PUF SLPs** – Parents said SLPs were good resources and specifically mentioned positive experiences with those from ACETS and PUF.
- **Camps** – Camps in Idaho and Ontario were good resources for two parents.
- **Internet and online support including manufacturers' websites** – Specific mention included Autism Speaks' 100-day kit.
- **Hands-on training/workshops** – Parents emphasized the value of resources that provide hands-on experience with communication technology.
- **Exchanges with other parents** – Other parents are a good source of information and support.

SUGGESTED RESOURCES – PARENTS

- **Centre of excellence** - The Bridges School in California was cited as a good example. A centre would be a resource hub for parents, teachers, aides, SLPs and other professionals. Children could get special attention at the centre for days or weeks, as required.
- **Parent support group** for parents whose children are using communication technology
- **Chat group** facilitated by parents. One parent had been involved in a group through ACETS—for the child using the device.
- **Hands-on workshop** about using a device for parents and teachers

- **Parents' conference** with a special focus on communication needs for Alberta
- **Bring experts to Calgary** - Some of the experts such as those met at camps could be brought to Calgary to present information and provide advice.

4.5 TRANSITIONING

Although there are some very successful transitions, SLPs said that overall, transition support is lacking and considered “poor”. They noted that inadequate transition planning can have serious consequences and result in service gaps for a child. Parents also talked about challenges with transitioning and corresponding gaps in service. Both groups said that multidisciplinary teams and trial periods before a transition support successful transitions.

- *Transition planning doesn't happen because we don't know that the child exists. The next agency needs to be alerted about the child's needs.*
- *There can be a six month service gap if there is no transition planning.*

SUCCESSFUL TRANSITION PLANNING - SLPs

Factors in successful transition planning included:

- **Multidisciplinary transition planning** - The involvement of all disciplines engaged with the child strengthens transition planning.
- **“All About Me”** – These teachers' reports pass helpful information about the child on to the next teacher.
- **Family-centred planning** – The family is the constant in the child's life and provides critical input and support for planning and executing transitions.
- **Transitioning between specialized schools/programs** – These transitions were thought to work quite well but transitions were seen as less effective when children are moving from a specialized school/program to a non-specialized one.

Areas where improvement is needed included:

- **Transition planning between agencies** – This is compromised by a lack of multidisciplinary teams, therapists moving between schools, and not knowing about budgets for the upcoming year.
- **Consistent and appropriate referrals** - Some children “fall through the cracks” if a referral is not made. For instance this could happen if a school does not make a referral to SSIL.
- **Earlier transition planning** - Commence planning in the spring before the transition and have trials of the new service to identify needs and make changes if necessary.
- **Equipment transitions** – The communication devices don't necessarily transfer between schools or agencies, particularly the low-tech devices.

SUCCESSFUL TRANSITION PLANNING - PARENTS

Factors in successful transition planning included:

- **Bridge person** – This person provides continuity between the old and new settings.
- **Parent involvement** – Parents need to be involved before, during and after transition.
- **Multidisciplinary team** – Transition planning is strengthened when all disciplines are actively involved.
- **Trial periods** – These are needed before finalizing placements in classrooms.

Schools don't offer ways of easing transition and we don't know what it is appropriate to ask for. It would be good to have a general practice of trialing transitions for two to five days in June.

Areas where improvement is needed included:

- **More involvement of parents** – This is particularly important during transition planning and soon after placement, not just at IPP review.
- **More support before placement is finalized** – This includes pre-placement orientation and trial periods.

5. CONCLUSIONS

There were common themes between the parents and the SLPs groups, with both mentioning resource allocation, technical and programming support, confusion about key contacts, roles and responsibilities, lack of collaboration and insufficient transition planning. Comments ranged from high level concerns about organizational structure to issues about front-line staff's involvement in programming devices and modelling behaviour.

Although one of the intents of this study was to get more information about desired resources, both parents and SLPs said there are enough resources but insufficient awareness of these. A possible next step is a scan, inventory or annotated bibliography of existing resources.

Other concerns and suggestions pertain to operational issues and resource allocation and may be given further consideration by the CCN Committee and partner organizations.

6. APPENDICES

Appendix One – Notes from Interview with Teacher

Appendix Two – Notes from Focus Group with Parents

Appendix Three – Notes from Focus Group with Speech Language Pathologists

Appendix Four – Moderator’s Guide

APPENDIX ONE - NOTES FROM INTERVIEW WITH TEACHER (SPECIAL EDUCATION COORDINATOR)

Date and Time: 4:30-5:30 pm, June 2

Number of Attendees: 1

Location: Rocky View Education Centre

Note: The teacher interviewed is a special education coordinator for a K-4 school. iPads were introduced in late 2014 and are used by three students as a form of communication technology. The iPads in use are paid for by the family.

1. SUCCESSES AND CHALLENGES

- This is the first year with devices in the school. One of the biggest challenges was the licensing of the applications for the iPads because a licence is needed for every device the application is on. A license costs \$350 but we can only use it on one device. We have lots of technology available in our building but it is the licensing that is the challenge.
- If the school pays for the device it stays with the school so when child moves on the device doesn't. Parents are encouraged to buy the iPad and the application. The financial burden is a factor.
- Staff were trained in the technology by another school's staff.
- There are three children using these iPads now and next year there will be five. We started the first child in December and the third child a few weeks ago.
- The children caught on to the iPads within a day. Prior to iPads they had a binder with photos. We could upload the same photos they used in the binder. It was an easy transition and it "speaks" for them. We had to use the same consistency in how we implemented the iPads as we did with the binders. We had to be diligent in telling the children to go to the device and tell us what they want.
- We have three orientation meetings with the family. At the first meeting we present the idea. At the second meeting we load the applications and then we present it to the family at the third meeting. We work on it for a month before we demonstrate it to the parents. We make "Coles notes" to tell them how to add or subtract from the device. Everyone is on board. We got the buy-in because the family bought the iPad.
- All of our families love the idea that their child can get a need or want met in the community. We have to get the device all set up and then we show them how to add to it. We get the family to take the photos so it is personalized for the student. Some parents want them to repeat orally or use the device as a secondary tool so it may be used more at school than at home.
- There is an assistant who does the adding or subtracting of information on the device. It is hard to maintain the knowledge since it is used every day.
- Each of the three children has an assistant. The assistant is the primary person who uses the device.

- The children are learning that they get something from it – their needs and wants are met. It has helped them to have a voice in the day; it gives them more choice and more power.
- Parents like having a say in which buttons are activated. There is more consistency between home and school with the iPads. The old system (Peck binders) stayed at school.

- Generally, the devices are not used as much at home because they have their own language. Some families want the child to be verbal first. Some homes may be rather complex and involve messages and communication with siblings.

2. COLLABORATION

- We have consultation through the SSIL team. Rocky View also has speech therapists who deal primarily with mild and moderate cases. After kindergarten all complex speech goes to SSIL. SSIL comes out every couple of months but I can get them sooner as needed. We have one SSIL SP for all my children at this school.
- It would be great to have a full time SLP in the school. It is hard to know what is worth contacting the SLP over and what isn't.
- The OT needs to know what the SLP and PT are working on. Speech is involved in everything. The SSIL team comes out as a group. The assistants can't necessarily meet with SSIL team but the special education coordinator can. It is a disservice not having the assistants at the meeting. The SSIL team will try to go in the classroom. The special education teacher shares the solutions with the parents.

3. BARRIERS AND ENABLERS

- If we had open licensing that would make it easier and would help get the devices (owned by the school) going home and from building to building.
- Families would be nervous if they didn't own the device. If a family buys the app they can load it onto five devices but if we purchase it the licence limits it to only one device. We would have to buy five licences, which is expensive and then the device doesn't leave our school. How would we transfer a licence to next school?
- Implementation is not far enough on to get the devices set up for community.
- We don't know how it is being implemented at home. The students are pretty resilient to figure out how it works at home and at school. We are not sure how it is used with respite workers. Now we are doing programming, but we are developing "Coles notes" to help them.
- A strong enabler is one-on-one support with the same people – the classroom assistants.

4. RESOURCES

- "Coles notes" are being developed to help parents when they get a device.
- Another school provided initial training for school staff.
- It would be good to have someone to trouble shoot.
- It would be helpful to have more sharing of resources or a central location where we can get them. SLPs should be able to offer a toolbox for the device and help trouble shoot. We need to be able to call someone who knows how to use it.

5. TRANSITIONING

- We haven't had to transition yet but we have the solution in terms of equipment because the family owns the device. We want the app, the toolbox and the device go to the next school. We do orientations at the next school in the spring or in September if they need more support.
- If parents needed help using it in the community they would talk to the special education coordinator.

6. FINAL COMMENTS

- It is a challenge to get the parents to look at how to get their child communicating 10 years out.
- We have agreed that the parents are the hub officially because they own it – back it up etc. In terms of setting it up, it is a collaboration. We meet a few times a year to add things that can wait, otherwise they can call me to get a change.
- It would be hard to plan far enough ahead to get every curriculum point in the device. Our three students are very complex and not up to curriculum – more dealing with basic communication needs.

APPENDIX TWO - NOTES FROM FOCUS GROUP WITH PARENTS

Date and Time: 9-11 am, May 13

Number of Attendees: 4

Location: St. Leo Centre

1. SUCCESSES AND CHAMPIONS

- Christine Meikle – The resource teacher has taken an interest in my daughter and is looking for apps for my daughter to use, ways can we best utilize my daughter’s device (uses vmax, also apps on iPad). Resource teacher is sharing information so we can support that use at home.
- Pay for services SPL – This person was hired privately. She provides advice about exercises used in speech and coaching about device use.
- The SLP uses the device and tells me what I can add to the device so he can use it more effectively in class. The teacher doesn’t always tell me in advance what they will be working on; this makes it harder to make the connection between school and home.
- My child is in a class without children using devices but the teacher meets with me to talk about the device. FSCD, classroom teacher, SSIL and the parent collaborate to create a device that works well. We brought together a SLP from FSCD, and from SSIL, and classroom teacher together with parent and then they set the device up so it would include what she needed in class.
- We have a meeting with SLP (ACETS) every two weeks to go through my child’s iPad. The SLP helps me program what she needs at school. Facilitating it out into the classrooms has been challenging.
- Christine Meikle has a communications classroom; my daughter is in another classroom. The teacher has been excited to learn about communications devices and is willing to have our SLP come in.
- SLP from CBE comes to see him in classroom twice a month; she helped him use the device in the class. We need more classroom support; two times a month is not enough. This person is getting moved and now there will be a communications specialist who will see him once a month but I have not heard from this person.

2. CHALLENGES

- The teacher doesn’t know about device; she needs to ask us to do programming or add something into the device. They can’t program or add something quickly.

- It is good to have one programmer put this information into the device and it is the parent. It is important to have one programmer for one device. If the device went to school and the SLP programmed it, the home would be confused.
- There needs to be some collaboration with parents and teachers—more meeting of SLP and teachers and parents.
- The child’s needs and interests change as they age; teenagers have different communication needs. I would like a centre of excellence where there is a team at a resource centre where kids can come.
- The teachers don’t know how to best include and motivate our children. Our private SLP taught us how to motivate my child to use the device.
- We need clarity with the teacher, SLP and parent about what roles each will take on. Now we (parents) are taking on every role.
- He has been hiding the device at school. He wants to say something and it isn’t there. He can’t find it so he gets frustrated and puts it aside. I removed some things and added them slowly so it was less confusing. There is nobody there to support him. The SLP came twice a month but now a SSIL is supposed to come once a month. The SPL from CBE called a meeting with SSIL but now SP and SSIL cannot be together servicing one child.
- The teacher needs Nova Chat too; the teacher has to speak his language. The teacher needs to learn the device but doesn’t have time.
- There is an issue keeping the device up to date with curriculum so he can stay engaged; he needs someone to support him in his language.
- My child is disengaged if he doesn’t have what is needed.
- Whoever is working with the child needs to make sure the relevant language is on his/her device to support engagement. Child doesn’t talk because it is harder and gets away with not engaging because the material is not there.
- To keep it up to date, parents need to know what to add.
- Each child is so different – all of our kids have different skills. Programming needs to be so specific to their skills.
- Even if they don’t use full language they learn that letters mean something.
- Alberta Education has to step in if they want inclusion—give them the supports so that they can have meaningful purposeful education.

Champions

- Our private SLP (There was controversy about whether or not private SLPs can treat at a school.)
- Camp with SLP – in Ontario
- AAC camp in Idaho—the person who runs it is our champion.
- We are trying to set a camp in Alberta with Alberta and Saskatchewan SLPs.
- PREP program – they give me information to take to the school but I feel the school just puts it in the file.
- Aid with PUFF program saw daughter’s potential; she did things daughters said she would never do.

3. COLLABORATION

- There were glitches with the device. The SLP said maybe there is something else we can use and put a referral to ACETS in the fall. They sent it to SSIL, but we haven't heard about it. I have had to go back and follow up. We are almost at the end of May but won't see someone this school year.
- The roles aren't clearly laid out and communicated. Who takes what on?
- No real collaboration unless I push – no ambition from the professionals.
- We don't know how many children uses devices in Calgary
- How do we navigate the system? Who do we go to? I go to ACETS.
- Who do I collaborate with? It is not clear.
- The amount of collaboration totally depends on the teacher.
- My goal is to create a team with a teacher floating in every year, maybe an aide. The aide has no voice, but needs to be able to talk to me because s/he sees my child. On the team we would need: peers, family, grandparents, SLP, OT, anyone who works with my child. The initial collaboration should be everyone.
- There are person-centred meetings in Grande Prairie to create IPPs.
- When I did the IPP everyone was in the room and it worked well. The therapists were involved in all my child's meetings, so she didn't see a therapist for months. We want therapists with the children, not just in meetings so we need to be careful about how we use SLPs. There is a cost.
- The last contact with the teacher was in October. We need a way to keep the teacher on the same path.
- When we updated the IPP in March we had a goal of use 60%. They modified the goal instead of trying to reach it. IPP doesn't guarantee follow-through. They can set lower standards.
- Collaboration is facilitated by meeting more than three times a year and not just around IPPs. It is hard to have a meeting without the aide because s/he implements the IPP. The aide needs to be involved in meetings but not just 3 times a year,
- The SLP hasn't been in on the IPP. It doesn't look like she has been consulted. There is one SLP for the whole school.
- They need to get the IPPs done so they call us in.
- I want them to use their time in direct service so I have mixed feelings about meetings.
- Parents dropping into the school once a week prompts casual conversations with the teacher.
- I talk to them but don't see how to get things done; my son needs an aide or a volunteer.
- The new teacher is working very well. We have half hour meetings and she only has 6 kids in class and two aides.
- Put the SLPs in the school so they get to know our kids. Stop contracting with AHS, as it is too expensive.

4. BARRIERS AND ENABLERS

Barriers

- The OT and SLP came to see her but they didn't tell me they were coming. if they are working with her I want to know so I can make the decision to be there or not.
- I have yet to meet the SLP who has been in the school.
- Not being part of my child's meetings is a barrier.
- Parents don't get programming support; e.g. putting in stories.
- The school decides where resources go. There are huge inconsistencies – some parents don't know what is possible.
- I just want to be a parent, not try and solve all these problems.
- ESL gets support why don't our kids? This is a language so why don't we get the support?
- Alberta Education needs to better support inclusion—set priorities. Our kids are supposed to get what they need. Our hands are tied at school and Board level. If a school is pulling funds for special education they need to use it for that student. They are happy to take the resources but may not be using them appropriately.
- There is a lack of time/resources to educate these teachers and aides. We can't always pull the teachers and aides out of classes for training.
- CBE doesn't know how many children are using these devices.
- One programmer can't predict what the child needs to do today. One programmer can't facilitate both home and school – need a programmer at school and at home. (disagreement)
- With the PUF program we saw every therapist once a month. Now that we are in the CBE we have only seen the SLP once. I think she works with my child more but I don't know. Before they came to my house.

Enablers

- If they add something to the device at the school, tell me—send a note.
- We need more one-on-one with teachers or SLPs. This could happen right after school or in the morning. It should happen more frequently but not for as long. It could be an interview right after school or before school. It could be over the phone or by Skype.
- If the meeting is just about apps it can be a shorter meeting; we need more meetings that are shorter or use technology.
- Is there some way of sharing through a Google group, or having a group chat? Everyone could see what files are being shared etc.
- We all have different devices, different programs. This is good because we can find what works for our kids but there is some problem with consistency. Is it realistic to pick one type of device – not specific to child?
- There could be a decision-tree about choosing devices – lead by the collaborative group and the SLP. This would be a universal plan to make an informed decision. Parents still need a voice in choosing devices.
- The ACETS clinic met with the SLP; we had some equipment trials and choices of equipment.
- I never heard about ACETS; paid for the device myself.
- We need a central place where parents can get information about devices. I learned the most from PACE.
- SLPs and others should call me and say who they are and what they will be doing with our child.
- She won't use it so I need help. I need support for moms about using equipment.

- The teacher should wear the device and model use of it.
- Take screen shots and tape them up and then you can point to the picture and say “making supper”.

5. RESOURCES

- There are getting to be more SLPs but they are not necessarily trained in AAC.
- ACETS SLP
- PUF SLP
- Internet
- Camps (Ontario, Idaho)
- Other parents
- Manufacturers' websites
- Online support – 100 days video where you watch others use the equipment.
- Seeing modelling by others

Suggested resources

- My dream is to have a classroom for AAC users with SLP, a tech person, a teacher, and then go out to their regular school. It would also be a learning place for teachers, centre of excellence around AAC. A central excellence point is needed.
- A support group would be valuable.
- Have a chat group facilitated by parents. I did one before through ACETS—for the child using the device.
- Bring experts to Calgary or Alberta.
- Have a workshop where they are using the device with parents and teachers – a hands-on workshop about using the device.
- Parents' conference – a special focus on communication needs for Alberta.
- We need school boards to support awareness of conferences

6. TRANSITIONING

- It makes a difference who facilitates the transition. A bridge person is needed to provide more consistency during bigger moves.
- A team from PUF went to my daughter's new school before she moved. She ended up in a class focusing on movement whereas she was working on academic matters. I was not consulted. I thought the new school would have known all her goals etc.

- There is a need to work together to find out what is best for child. There is a lack of parent involvement and of collaboration about what is the best. There should not be just one individual making decisions.
- I am educating them about my daughter. I have a portfolio about her. It includes a one page profile, an outline of what a good day at school looks like, what a bad day at school looks like etc. The IPP requires everyone to read this.
- Parental involvement is critical.
- The school needs knowledge about the child before the child comes in to class.
- Start the child in the class the week before classes start.
- The parents need to be involved in decisions about what is next. The teacher has been awesome in the setting that I wouldn't have picked. She has also given a trial period for my daughter in an academic class and in a communication class. It is important to have a few days trial before the new location
- Schools don't offer options as ways of easing transition. We have to suggest but we don't always know what it is appropriate to ask for. It would be better if they asked more about what would work or made it a general practice to transition for two days – five days in June.

7. FINAL COMMENTS

- I am excited thinking about optimizing resources. A lot is on us as parents but I would love to feel supported through the school board. If we optimize resources we don't have to all reinvent wheel.
- The child should have support on helping her work with her language. They should see her as a person; she is not xxxx (condition).
- A child-centred focus is needed. You need different skills to get to know her; you need to have a different focus on my child. Work towards needs of her not just general practice. Don't forget her because you don't know how; get together and learn together because we are all learning. How can we support each other and work tougher with resources we have? We need to prioritize around what we have.
- When you don't want to do something you find an excuse; when you want to do something you find a way. They are the professionals – find a way to support kids. Don't use the excuse of funding—use volunteers.
- Use everyone to help raise a child. Ask for help and support without exhausting one person or blaming each other.
- Build a centre of excellence. It should be a place where teachers, parents and children can get what they need. Every school board in Alberta should have access to an excellence centre – a classroom for AAC users. It could be a Travelling resource centre. It could have an outreach resource centre. Children could come for a semester or a few weeks. Teachers could see how to engage a child. It would like the Bridges School in California. It could be a drop-in or come for a semester or a few weeks. Teachers could see/watch what to do. Bridges School has access for typical children.
- See AAC girls' blog.
- One parent offered to share her book about her daughter.

Date and Time: 1-3 pm, May 12

Number of Attendees: 9

Location: St. Leo Centre

1. SUCCESSES

- Collaboration with ACETS and SSIL is good.
- ACETS – tracks children through the life span and follows the transition from pediatrics to adults. This is important for good transitioning.
- We are more successful when we know who to call at the school level. This includes the SLP at school and the AHS SLP.
- It helps when we have designated people who have specialists such as competency in technology, competency with children.
- Multidisciplinary teams are good when they include the range of professionals working with the child – e.g., OT, PT, psychologists, SLP, vision
- The assistive technology team at Renfrew knows a lot about technology and is able to support staff. They have experience from solving technical problems and additional training.
- Having a SLP responsible for a school helps with consistency.
- Working alongside teachers results in better use of technology. They are more supported when this is in place.
- It is a success when children use the technology at home.
- Working across contexts promotes success. This includes the transition from home and school as well as training about the device at school.
- Some classes are very strong and have well-trained people working with children.
- Specialized classrooms often contribute to success. There is usually more support and can be more focus on the child's needs.

2. CHALLENGES

- It is a challenge when the multidisciplinary team is watered down – dispersed geographically or by facility or by program. It is better if a multidisciplinary team is located within one organization.
- A lack of familiarity with agencies and how they work can be challenging.
- Not all teams work across the lifespan. Transitions are not as smooth.
- There is a lack of teachers' aides.
- There is a waiting list to access service at ACETS or SSIL.

- There are not enough trial devices.
- Keeping up with technology is always a challenge
- Transitioning from an agency to CBE. The child may have the device but is not getting the support.
- RCSD lacks caseload and expertise.
- Information doesn't follow the child especially in upper grades (e.g., 7-12)
- Communication between home and school is fragmented at times.
- There is little professional development on front lines – teachers, aides.
- The Knowledge base is limited at the community level.
- ACETS gets referrals but doesn't know who to contact. Families don't know who is working with child or don't have an SLP.
- The CBE area strategist role is lacking.

3. CHAMPIONS

- Community of Practice – Alberta Education offers this.
- Teachers – some teachers are incredibly committed and knowledgeable.
- ACETS Team – helps choose technology.
- AADL – provides funding support.

4. COLLABORATION

Collaboration works well in these circumstances:

- The focus is on the child.
- There is familiarity with those one is collaborating with. It works better if you know the people you are collaborating with – their skill level, knowledge of teams.
- Trust has been built – People who have worked together for a long time have developed trust.
- Knowing and understanding roles – It helps collaboration when you know what each person can do, what can be expected from that person. It has been a challenge with RCSD and with moving to SSIL. It could be an OT now that I work with and I don't know their roles and skills.

Gaps in collaboration:

- There is a gap between CBE and AHS; it is hard to find the people to collaborate with.
- When I am going out to SSIL I know who to call but it is not easy finding SLP in AHS who works in Education, I usually call the principal to find out who is the SLP as that is the best bet, or the key contacts at the school
- There is more switching around in AHS. The SLP team functions more in isolation from OT/PT. RCSD AHS meets more with OT/PT but in a separate area. The baseline team in AHS is almost completely independent of OT/PT.
- The AHS SLPs assigned schools vary from year to year. As well, there are two SLPs per school so there is not always consistency in which one you work with.

- Some schools don't know our service (SSIL) exists.
- There has been a change from REACH to SSIL. RCSD is recent. There are two different organizations changing roles; everybody is changing everything.

5. BARRIERS

- Lack of resources – money and people.
- The attitude of staff/administration – some don't understand what devices can do.
- It is not consistent between administrations. Some find money for support – others don't. It is not consistent across the school board. The principal decides. You wonder how it is possible that they are in the same school district.
- It is hard to transition from PUF where there is lots of money to grade one where there is no funding. As well there is pressure to spend PUF money in kindergarten when assessment may still be underway.
- It is hard to keep devices current – to keep up with the ever-changing technology. We keep having to teach about new devices. Devices are more integrated now with the internet and email—it is hard to keep up.
- Some families cannot afford to pay for a device at home.
- There are issues with setting functional goals in the classroom to improve collaboration. The goals might not be as functional as desired. Putting effort into setting these goals makes a difference to collaboration.
- Faulty technology – The child might have no speech in class as the device goes back and forth for repair particularly if going to USA. We don't have many loaners especially for new devices.
- Access to the device – Sometimes it doesn't make it to school from home or it isn't charged.
- Clear referral criteria – We used to know who makes referrals and who they refer to but with this year's changes, pathways to access devices aren't clear.

6. ENABLERS

- Training, mentoring, modeling, monitoring.
- User groups – When children see other children using these it helps support use. It is also good for parents to connect. However, all kinds of different devices are being used so we would have to pre-program everything before.
- Camps are enablers but because of budget constraints these camps have gone.
- Training is important. It would be good to have a program designed around device use through peer interaction. This would be good in the school setting but a lack of resources prevents this. Everyone in contact with the child should be modelling.
- There needs to be more understanding that communication is a central part of education, not just literacy and numeracy.
- Understanding what the device can do supports use.
- Upfront time to get familiar with the device is needed before parents use it.
- In the three surveys the definitions about use per day were different. For instance if it is used three times a day it could be three times in 10 minutes. A consistent definition of consistent use of devices is needed in all three surveys. Right now it is different between surveys. How to look at behavior as communication – behavior is a form of communication.
- A colleague is looking at books and providing the vocabulary around using device – actually giving a package describing what can be worked on. Teachers like this, as it is concrete.

- A learning road map for teaching language based on ImPAACT (Improving Partner Applications of Augmentative Communication Techniques) would be helpful.

7. CHILDREN WHO HAVE DEVICES BUT DON'T USE THEM

Reasons include:

- The parents might want the child to develop speech and think the device will impede use of speech.
- The device is too hard to use.
- Students don't want to use the devices. They are not motivated.
- Devices tend to be used more at schools if they have taken the time to get them set up. It helps if school staff are trained, if the child has personalized vocabulary, and if they have helping with navigation.
- Programming and vocabulary need to be up to date. We need to stay ahead of the children so they can communicate. We need resources to keep up with kids and ahead of them.
- In general devices are used less at home as the parents understand the child's speech but the child may have more to communicate than parents understand.
- How to help: Provide support from aide or therapist around modeling; provide more intensive work with the device showing parents how it could be used; have someone designated to make sure it has been charged and turned on. We need a champion in each context for the child— a champion who has enough time. Lots of people want to help but they are stretched too thin.
- Use is enhanced when parents, all adults involved with the child and peers are educated about the device, trained and are modeling use.
- It helps to provide education about the easiest way to fit device use into the day – fit it into the routine at home. The service is designed to set the device up and then let go but we need ongoing mentoring.

8. CHILDREN WHO DON'T HAVE DEVICES AT HOME

- Same as above.

9. RESOURCES

- RCSD asked about top ten resources. This is a good step to collecting a list of resources.
- ACETS and SSIL – These specialized teams are good resources.
- SSIL and ACETs can now do assessments.
- Community of practice from Alberta Education is helpful
- Manufacturers'/vendors sites, helplines, tutorials, webinars etc. These are used by SLPs but not as much by teachers.
- Ideally in-services would be good but that is not realistic – webinars are free or cheap.
- U of A has a course for teachers and SLPs on AAC but it is fairly basic.

- YouTube presentations include videos from experts.
- Provincial or national association resources – e.g. articles to give to parents, videos to suggest.
- Training those who are with the children in schools.
- Praactical website (<http://praacticalaac.org>)
- AAC website
- There are gaps in resources to give parents or teachers. They need to be appropriate to the level of the child.
- Not all speech therapists know about devices; many were trained years ago.
- A lot of material is already out there. Having everybody putting out their top ten is a good idea so we can see where the holes are.
- AAC is intimidating for a SLP generalist so I went to a conference and saw videos of how they did language therapy with a device. This demystified the use of devices for me. It was like me modelling what I want the child or teacher to do. Training works best for teachers when they have it demonstrated and broken down.
- Hands-on help is best.
- The temptation is to put up a website or develop something on paper but these are probably available – there is a lack of awareness of what is available.
- Generalists and teachers have a lot of other needs beyond AAC. They need someone who researches this for them and then presents it to them.
- There are problems with becoming generalist – a jack-of-all-trades but a master of none. Somebody still has to do the work of figuring it out.
- iPads – if teachers don't have access to specialized services they had in the past they move to iPads because they are more familiar.
- iPads – it isn't a huge communication device – more education is needed for administration and teachers to understand low tech through to high tech. iPads are not the solution for everyone.

10. TRANSITIONING

- Transition support is considered “poor” overall.
- There may not be a multi disciplinary team or therapists might be moving from a school and there is not consistency.
- There is a lack of transition planning between agencies.
- There can be a six month gap in services if there is no transition planning.
- CBE personnel may not know that if a child has a device it is an automatic referral to SSIL.
- Transition planning–alerting the next agency to the child's needs–doesn't happen because we don't know that child exists; the children drop through the cracks.
- Having the family be at centre of the planning since they are consistent in the child's life
- If a child is coming from a specialized school to a specialized school/program we get good reports to support transition.
- Historically REACH followed the child and it was consistent from year to year. We don't know if that will happen now with SSIL.

- Some teachers are good at the reports “All about me” which pass on specifics about the child and supports needed.
- There are problems making plans because schools don’t know their budgets for the next year.
- Planning starts in the fall but could start in the spring so it is set up for the fall. There could be more trials of the new placement in the spring.

11. FINAL COMMENTS

- Relationships are key – with ACETS I know who I can contact. I am building relationships with specialized teams in the schools.
- It is a great value to have specialized professionals who are integrated into the school or agency. For instance, assistive technology is what they do; staff can access the tech team to come and look at what they can do to help. Technology professionals have developed knowledge through webinars and dealing with problems.
- An interdisciplinary environment needs to be encouraged.
- When there is a specialized multidisciplinary team within the same agency I can turn to the OT or PT who is nearby and ask them what they think. I can collaborate with AHS but it takes a lot of time to track them down.
- When dealing with another organization’s specialists we don’t have the familiarity, comfort or trust.
- Parents recognize a streamlined team versus a fragmented team. Teachers value a focused team not a stream of people coming into the class.
- High tech devices transition from year to year but not so much the low-tech devices. Schools think it is their money so they will keep the device.
- Equipment doesn’t necessarily transfer between schools.

1. WELCOME AND OVERVIEW (10-15 MINUTES)

- As participants arrive, make introductions as appropriate and collect signed consent forms. Hand out consent forms as necessary.
- Facilitator introduces self, welcomes and thanks participants for coming.
- Housekeeping
 - This focus group will be two hours long.
 - Identify location of washrooms.
 - Please help yourself to refreshments.
- Introduction and purpose of focus group
 - The Calgary and Area Regional Collaborative Service Delivery is undertaking a project, funded by Alberta Education, to explore how to best support children and youth with complex communication needs, specifically those requiring communication devices.
 - The project has included a literature review and a survey, which many of you completed.
 - We are doing four focus groups (parents, teachers and speech language pathologists), which will give us the opportunity to explore your thoughts in more depth. The focus groups, survey and literature review will help guide the development of resources, training and support for children using communication devices.
- Review facilitator's role and focus group discussion basics
 - My role is to guide discussion, keep it on topic and summarize key points.
 - I am an independent consultant and I am not affiliated in any way with the sponsor of this study.
 - I am not an expert on the topics we'll be discussing today/tonight. I am not here to provide information or persuade you in any way.
 - Focus groups are most valuable when we hear from all participants. It is valuable to hear your point of view even if it differs from what others have said. There are no right or wrong answers. We respect all points of view. We are not here to debate or come to consensus but rather to hear the range of opinions.
 - There will be a report summarizing these focus groups and you will receive a copy of this if you are interested. Your name will not be associated with the report findings. Participants' comments may be quoted in the report but only attributed to "parent", "teacher", or "speech language pathologist". Only the facilitator will see the focus group notes and listen to the audio recordings. The facilitator will destroy transcripts and recordings once the report has been finalized.
 - Share the air, one at a time, all perspectives have value confidentiality
- Review that permission was given to record session and **TURN ON TAPE.**

2. CURRENT STATE (25 MINUTES)

Successes

- We want to make sure that we capture **what is working well** with supporting the children you are working with/your child who have/has complex communication needs and use/uses communication devices. Can you tell me what is working well now?
 - This could be supports, resources or people who are helping. (e.g. equipment, training, SLP).
 - It could be things occurring at school, at home or in the community.
- Facilitator tracks comments on flip chart and also categorizes each as at school, at home, in community.
- Prompts:
 - If SLP is working well, is it in community, school, clinic?
 - What did that person do
 - Are there champions? Who?
 - What has been most helpful?
 - What made this work well?

Challenges

We want to identify **the challenges** with supporting the children you are working with/your child who have/has complex communication needs and use/uses communication devices. Can you tell me what is not working as well as you would like?

- This could be supports, resources or people who are helping. (e.g. equipment, training, SLP).
- Prompts:
 - Where are the challenges? (school, home; with SLP, teacher)
 - Who has been involved?

Collaboration

- How are people **working together – collaborating** – around your child/children's needs? Again this could be at school, at home or in the community.
- Prompts:
 - Is there enough collaboration?
 - How are they collaborating?
 - What works? What helps increase collaboration? Who is collaborating?
 - What did that person do that made it work?
 - What are they collaborating about?
 - Where is collaboration the strongest?
 - Where are there gaps?
- How has communication been between home, school and community settings?

- What has worked well?
- What are the areas for improvement?

3. BARRIERS AND ENABLERS (15 MINUTES)

Barriers

- What do you see as the major barriers supporting children with complex communication needs?
- Within the resources available what would help children with complex communication needs?
- Prompts only if necessary:
 - This could include: knowledge about using the equipment, access to it, time spent using it, repairs, availability.
 - Over the last few years, have some barriers increased and others decreased? If so, which ones?
 - E.g. access to device, home use, draining.

Enablers/Opportunities

- Within the resources available what would help to improve children's use of communication devices?
- Prompts only if necessary:
 - This could include: education or training, more use at home, at school, or in the community.
 - What kind of training would you like?
 - When are these devices used most?
- Do you see more opportunities to support use of the devices? What are they? (This is another way of getting at the question above.)
- Some children with complex communication needs have devices but do not use them.
- Why are these children not using the devices that they have?
- When do they use the devices? When not?
- Prompts only if necessary:
 - This could be things like time or support people and could be needs at school, in the community or at home.
 - They might not need it at home.
 - What environment is this used in the most?
- What would help support these children?

4. CHILDREN WHO DO NOT HAVE DEVICES (10 MINUTES) **SLPs ONLY**

- To this point we have talked about children with complex communication needs who have devices but not all children use these.
- How are the support needs of children who don't have devices different from those who do?
- Prompts only if necessary:
 - This could be things like time or support people and could be needs at school, in the community or at home.

- What would help support these children?

5. RESOURCES (15 MINUTES)

- What resources have you had that helped?
- What ones do you like? E.g. webcast, print media etc.

6. TRANSITIONING (15 MINUTES)

- The children you work with/your child (using devices) may be **transitioning into other settings** now or will be in the future. For example, this could mean becoming more active in community activities now, or moving into a post-secondary education or workplace setting in the future. What concerns do you have with the children you work with/your child making these transitions?
- Prompts only if necessary:
 - This could include timeliness, equipment compatibility, and transfer of information.
- What worked, didn't work?
- What helped with past transitions?
- What would you want to have known?
- What is being done now that is supporting these transitions? Is this sufficient?
- What could be done to better support these transitions?

7. CLOSING COMMENTS/WRAP-UP (10 MINUTES)

- We need to begin wrapping up the discussion.
- Is there **anything else that we have not already covered** that you would like to pass along to the project team?
 - Depending on the group and time go around the table and invite each person to offer his/her final words of advice or reflections.
- Facilitator thanks participants and ends the session.