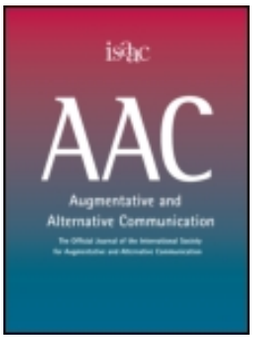

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Augmentative and Alternative Communication

ISSN: 0743-4618 (Print) 1477-3848 (Online) Journal homepage: informahealthcare.com/journals/iaac20

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To cite this article: Stephen E. Ryan, Tracy Shepherd, Anne Marie Renzoni, Colleen Anderson, Mary Barber, Shauna Kingsnorth & Karen Ward (2015) Towards Advancing Knowledge Translation of AAC Outcomes Research for Children and Youth with Complex Communication Needs, Augmentative and Alternative Communication, 31:2, 137-147, DOI: 10.3109/07434618.2015.1030038

To link to this article: https://doi.org/10.3109/07434618.2015.1030038

Augmentative and Alternative Communication, 2015; 31(2): 137–147
ISSN 0743-4618 print/ISSN 1477-3848 online
DOI: 10.3109/07434618.2015.1030038

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TUTORIAL AND SYNTHESIS ARTICLE

Towards Advancing Knowledge Translation of AAC Outcomes Research for Children and Youth with Complex Communication Needs

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Abstract

The production of new knowledge in augmentative and alternative communication (AAC) requires effective processes to leverage the different perspectives of researchers and knowledge users and improve prospects for utilization in clinical settings. This article describes the motivation, planning, process, and outcomes for a novel knowledge translation workshop designed to influence future directions for AAC outcomes research for children with complex communication needs. Invited knowledge users from 20 pediatric AAC clinics and researchers engaged in the collaborative development of research questions using a framework designed for the AAC field. The event yielded recommendations for research and development priorities that extend from the early development of language, communication, and literacy skills in very young children, to novel but unproven strategies that may advance outcomes in transitioning to adulthood.

Keywords: *Communication; Children; Outcome assessment; Participation; Transition; Assistive Technology; Parent; Consumer*

Introduction

The AAC Outcomes for Kids (AAC OK) Workshop was a research planning event conceived to advance the mobilization, generation, and translation of research evidence for augmentative and alternative communication (AAC) outcomes in children, youth, and young adults with complex communication needs. The workshop involved experienced speech-language pathologists and occupational therapists from 20 pediatric AAC clinics across Canada, and leading international scholars in AAC research and development.

The workshop provided a rallying forum to learn and foster capacity building among a diverse group of AAC knowledge users and researchers. The overarching goal of the event was to identify clinical priorities for new empirical evidence to address some of the most vexing and least understood areas of functional outcomes in children and youth (hereafter children) with complex communication needs. To do this, our team formulated the event to arm attendees with the latest empirical evidence relating to the measurement and effects of AAC interventions, and synthesize perspectives to identify important and pressing AAC research priorities.

This article describes the motivation, planning, process, and outcomes for this unique integrated knowledge translation event that was designed to influence future directions for AAC outcomes research for children.

Motivation

Some 12,000 young Canadians between the ages of 5 and 14 years need assistive devices to communicate because they have difficulty speaking or unintelligible speech (Statistics Canada, 2006). Yet Canadian children with complex communication needs have the highest rate of unmet needs for assistive devices compared to other disabilities. In 2006, 51% of these children had none of their communication device needs met and a further 20% had only some of their device needs met (Statistics Canada, 2006).

Unmet communication needs can hinder a child's ability to participate meaningfully in everyday settings and may result in profound and lasting health effects in

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(Received 8 September 2014; revised 3 March 2015; accepted 5 March 2015)

children and their families. Neglecting communication needs can lead to marked delays in academic achievement and vocational outcomes, foster social isolation, and encourage social marginalization in children with disabilities (Hodge, 2007; King, Baldwin, Currie, & Evans, 2005; Lindsay & Tsybina, 2011). Considering the overall increase in disability rates in children and the prevalence of communication-related disabilities, it is vital that children who could benefit from AAC devices obtain access to them so they can participate fully in society.

Notwithstanding the unmet needs for assistive devices, few Canadian provinces provide funding for communication devices and associated services for children. Because AAC devices can be complex, third-party payers in these jurisdictions require children to be assessed by AAC clinical teams that include speech-language pathologists, occupational therapists, and other communication specialists. AAC teams help children to obtain and learn to use customized communication systems that match their unique developmental, environmental, and personal needs.

Despite the availability of these highly specialized clinical services and advanced AAC technologies, early return and abandonment of AAC devices are common (Johnson, Inglebret, Jones, & Ray, 2006). Researchers have reported that nearly one in five communication device users stop using their devices prematurely (Murphy, Markova, Moodie, Scott, & Boa, 1995; Reimer-Reiss & Wacker, 2000). Adult surveys suggest that abandonment or non-use of communication technologies may be due to a combination of factors, including overburdened family members, inappropriate device selection, poor device performance, lack of training, lack of involvement in AAC system decision making, and psychosocial implications associated with using a device (Johnson et al., 2006; Murphy et al., 1995; Reimer-Reiss & Wacker, 2000; Shepherd, Campbell, Renzoni, & Sloan, 2009). However, the extent to which any or all of these factors predict the abandonment or non-use of communication technologies in children is largely unknown.

While efficacy research shows positive effects on communicative competence, language, and literacy skills in children following AAC interventions (Light & McNaughton, 2012; Romski et al., 2010), evidence demonstrating the impact of these interventions on participation, social inclusion, and health-related quality of life outcomes in children and their families is weak (Henderson, Skelton, & Rosenbaum, 2008). This leaves a serious gap in our understanding of AAC outcomes, and supports the need for a clearer portrayal of the functional impact of AAC interventions to change practice-driven into evidence-informed health services.

Evidence-based practice is an approach that AAC teams use to guide clinical decision making for assessment and interventions. As adapted from a definition proposed in the field of AAC (Schlosser & Raghavendra, 2004), evidence-based practice is the integration of current best research evidence with clinical/educational expertise and the values, preferences, and beliefs of individual children and their families. Given the costs and potential value of AAC systems and services, the high rates of device abandonment and unmet needs, and lack of research evidence to inform clinical practice and health service expenditures, an urgent need exists for knowledge users and researchers to identify research priorities and questions to understand better how AAC interventions impact the everyday lives of different populations, and what factors may influence their effective, long-term device use.

Although AAC researchers have called for closing the gap between research knowledge and clinical practice (Light & McNaughton, 2012), knowledge production requires effective collaborative processes to leverage the different perspectives of researchers and knowledge users, thereby improving prospects for utilization in clinical practice (Bowen & Graham, 2013). Indeed, the importance of leveraging the perspectives of different stakeholders to identify research priorities in AAC was recognized during the Consensus Validation Conference in 1992 (National Institute on Disability and Rehabilitation Research, 1992). This seminal event involving researchers, educators, parents, clinicians, and people with complex communication needs identified important but broad research directions for the field of AAC. Whereas authorities in knowledge translation now suggest that engaging researchers and knowledge users in the collaborative development of specific research questions is an important initial step (Graham et al., 2006). In the absence of a best practices approach for this type of focused collaborative activity in AAC, we conceived a novel research planning event to initiate and advance engaged scholarship in functional outcomes relevant to children with complex communication needs and their families.

Workshop Planning and Process

Attendees

To mobilize knowledge users and researchers to advance an outcomes research agenda for AAC services for children, we formulated a 2-day invitational research planning workshop. The workshop included nominated knowledge users from pediatric AAC clinics in Canada, noted researchers and theorists, and knowledge translation specialists. We invited the operations managers from 20 AAC clinics across Canada to nominate either a speech-language pathologist or occupational therapist to represent his or her service at the workshop. Managers of larger specialized clinics each nominated two to three clinicians to participate in the workshop. We secured funding through a research planning grant to offset basic expenses including hotel, travel, and food costs for clinicians and invited attendees and speakers to attend this inaugural event.

The AAC OK Workshop was held at a rehabilitation hospital housing a specialized AAC clinic for children. In

all, 52 people, including six invited AAC and childhood disability scholars, 30 speech-language pathologists and occupational therapists from 20 pediatric AAC clinics based in five Canadian provinces, small-group facilitators, members of the workshop organizing committee, and observers from the host institution and government funding agency attended the event. Knowledge users were generally very experienced in service settings for children with complex communication needs, based on their reported years of experience in an AAC clinic (range: 5–36 (years; months) *M*: 15.6).

Consumer Advice

In preparation for the workshop, two advisory groups of parents and youth with complex communication needs provided recommendations about AAC systems and health-related outcomes they believed to be important for workshop attendees to consider during their deliberations. One group was composed of parents of school-aged and younger children with complex communication needs; the other group was composed of adolescents and young adults who use AAC devices and their preferred communication partners. Our organizing committee invited known clients of our AAC clinics who we believed would offer candid advice about future research directions in AAC during the advisory group sessions. Groups included members representing a variety of AAC techniques and strategies for face-to-face communication; as well as emerging, context-dependent, and independent communicators (Dowden, 1999). Parents and youth attended one of two, 2-hr advisory meetings so that we could learn about their experiences, synthesize their recommendations about AAC systems, and share their perspectives with knowledge users and researchers during the workshop.

Workshop Agenda

The workshop included a mix of scientific presentations by research authorities in AAC outcomes for children with complex communication needs (Table I), and interactive, concurrent research planning sessions. We invited both known and emerging authorities in AAC research that had published diverse and topical, peer-reviewed articles relating to outcomes for children and youth with complex communication needs within the last 5 years. Researchers who we approached agreed to provide state-of-science presentations in these contemporary areas of research and to participate in planning activities with invited knowledge users. Using this participatory approach provided an important networking and integrated knowledge translation forum for this collective (Straus, Tetroe, & Graham, 2009; Wright, Foster, Amir, Elliott, & Wilson, 2010). We strategically organized the mornings of the workshop to share the latest research evidence and inform thematic roundtable discussions held in the afternoons of both days.

Each morning started with a brief overview of the day's activities by the conference co-chairs. This was followed by invited presentations by noted researchers in AAC outcomes and childhood disability. On the first day, we also shared advice from youth and families who took part in the two advisory groups. On the second day, we proposed plans to translate workshop outcomes and mobilize clinical knowledge user support for the proposed research directions.

The organizing committee was composed of clinical knowledge users, researchers, and trainees who identified the key research topics based on cumulative interests and knowledge of the field of AAC for children. Invited researchers presented 40–50 min state-of-science talks in six targeted domains: communication, language and literacy development for children with complex communication needs; interventions for successful transitioning for young adults who use AAC; the meaning of and experiences relating to childhood participation; novel AAC interventions for young people with autism spectrum disorders (ASD); advancements in AAC technologies and clinical decision making; and outcome measurement in AAC. Speakers also recommended relevant publications and areas for future research to catalyze the discussion of research priorities during the event.

The afternoons of both days promoted active engagement of attendees in small group discussions and consensus building for the creation of important clinical research questions. We shared the selected research topics with attendees before the workshop so they could rank order their preference to participate in one of six concurrent discussion groups that aligned with these foci. We assigned attendees to one of their top two preferences to begin discussions with four to six clinical participants in each group. Knowledge users were permitted to join other tables following the initial deliberation and no adjustments were made to balance table numbers if members elected to join other groups.

Development of Research Questions

Experts in evidence-based medicine recommend a systematic approach to the development of research questions (Haynes, Sackett, Guyatt, & Tugwell, 2006). They advise that questions must identify clearly the population sample of interest, the study intervention, the comparison group, and the primary outcome of interest. However, Schlosser and colleagues note important limitations and challenges in applying this recommended approach to the development of research questions in AAC (Schlosser, Koul, & Costello, 2007). The authors contend that well-built clinical questions in AAC should additionally reflect the transactional nature of communication and influences of environmental settings and stakeholder attitudes on functional outcomes. Their PESICO model for the development of research questions (described below) resonates with contemporary thinking about AAC and its relationship with childhood disability, functioning, and health (Granlund & Pless, 2012; Raghavendra, Bornman, Granlund, & Björck-Åkesson, 2007). Consequently, we adopted their model

Table I. Themes, Abstracts, and Recommendations for Future Research from Invited Speakers.

Research topic, invited speaker and affiliation	Abstract	Key research and development directions
Supporting communication, language, and literacy development of children with complex communication needs Janice Light, PhD, Department of Communication Sciences and Disorders, Penn State University	Two significant challenges were considered to maximize outcomes for children with complex communication needs: (a) investigating how to improve the design of AAC apps/ technologies and interventions in order to better meet the breadth of communication needs for the diverse population of children with complex communication needs, and (b) ensuring the effective translation of these evidence-based AAC interventions to the everyday lives of children so that the possible becomes the probable. The session included a summary of the state of the science and proposed directions for future research and development.	• Determine visual, cognitive, language, and motor processing/development of children with complex communication needs. • Design AAC interventions that respond to children's needs. • Compare effectiveness of AAC interventions. • Determine effective strategies to enhance public awareness of AAC. • Investigate the everyday lives of children with complex communication needs and their families across society. • Investigate AAC interventions that are easy and quick to implement and compatible with everyday life. • Investigate strategies required to support long-term infusion of practices in everyday lives.
Successful transitions for youth and young adults who use AAC David McNaughton, PhD, Department of Educational Psychology, Counseling, and Special Education, and the Department of Communication Sciences and Disorders, Penn State University	A successful transition to adult life requires attention to four major goals: having a safe and supportive place to live, participating in meaningful activities, maintaining access to needed services, and developing friendships and intimate relationships. Access to AAC plays a critical role in the achievement of these valued outcomes for young adults with complex communication needs. This session presented what is known about the use of AAC to support communication and participation by young adults, and identified areas for future research and development in AAC technology to support this successful transition.	• Develop AAC technologies that are understood by different people in a variety of situations and environments. • Develop technology that is understood by other devices and supports individual preferences. • Explore technology to support virtual participation in the workplace (e.g., telework). • Improve accessibility of mainstream technology. • Develop more efficient retrieval techniques to enhance turn taking and topic changes. • Study access to technology for people with cognitive challenges and specialized access. • Research the advancement of language and communication skills needed to develop intimate relationships and achieve individual identity.
Participation in developmentally favorable environments Beata Batorowicz, PhD(c), School of Rehabilitation Science, McMaster University	This session considered participation of children and youth in typical childhood activities and places in the following domains: (a) research related to participation outcomes for children with complex communication needs, with a focus on recreation and leisure participation, (b) current thinking about the construct of participation, highlighting the experiential aspects and meaningfulness of participation experiences for children and youth, and (c) implications for AAC outcome measurement, suggesting mechanisms of child-environment interaction and interventions that build capacity within children and their social environments.	• Study the objective and subjective experiences of children using AAC in everyday activity settings. • Examine child- and family-reported meaningfulness of involvement in environments. • Study psychosocial engagement in the moment and over time. • Evaluate the effect on child and family members of opportunities, supports, and resources within social environments. • Measure the long-term effects of participation-level interventions on child development and health.
Advances in AAC technologies and clinical decision making Jeff Higginbotham, PhD, Communicative Disorders and Sciences, State University of New York	This session was about the continual and ever-increasing change in assistive technologies organized around the following themes: technology flow, joint interaction, deconstruction, and redistribution – small, and personal. Content areas for this presentation included the augmented voice, designing the person into the technology, the Arduino revolution, and small data – large issues.	• Develop AAC making use of the increasing availability of accessible computer languages and programmable technologies. • Create evidence using a variety of AAC data (e.g., word frequency, diversity, target usage, utterances, and frequency of device use). • Conduct longitudinal studies to explore the impact of AAC intervention on the everyday functioning of children with complex communication needs in domains of participation, activity, and body function.

(*Continued*)

Table I. (*Continued*)

Research topic, invited speaker and affiliation	Abstract	Key research and development directions
Challenging beliefs about AAC interventions for children and youth with autism spectrum disorders Pat Mirenda, PhD, Department of Educational and Counselling Psychology and Special Education, University of British Columbia	This session challenged thinking about what we know about and how our current knowledge affects the way we provide language/communication supports to individuals with autism spectrum disorder. Specifically, the talk focused on past and current understandings about ASD in general, ASD and speech development, and both AAC and literacy interventions for this population.	• Identify predictive factors in people with ASD who are independent and competent communicators through the use of AAC. • Evaluate the impact of instructional techniques that align with the principles of motor learning on AAC acquisition. • Study evidence-based literacy instruction on the development of language, communication, and literacy skills.
Measuring outcomes of AAC interventions Nancy Thomas-Stonell, MSc, Bloorview Research Institute, Holland Bloorview Kids Rehabilitation Hospital, and Department of Speech-Language Pathology, University of Toronto	Outcome measures must have demonstrated reliability, validity, and responsiveness within the AAC population before being adopted into clinical use. Furthermore, measures need to be relevant to the goals of AAC intervention and reflect real-world changes that are important to clients, families, and clinicians. This session highlighted five different outcome measures that have evidence of validity for AAC intervention in children and youth with complex communication needs.	• Study the impact of AAC interventions on children's quality of life and participation. • Evaluate real world changes that are important to the child, parent, and clinician. • Evaluate outcomes using measures that have acceptable levels of reliability and validity and can detect change in individual and groups of children. • Develop new sound measurement scales to evaluate the impact of AAC interventions in children with complex communication needs.

as a biopsychosocial underpinning for the development of questions relevant to AAC outcomes in children with complex communication needs.

We asked attendees to read the seminal article on the PESICO model (Schlosser et al., 2007) before the workshop so that they would be prepared for the consensus-building session. In addition, an organizing team member presented a brief primer on research question development during the first day of the workshop, to ensure that all attendees understood and appreciated the fundamental elements of the model before the start of small group discussions. A facilitator at each table used probes and questions to stimulate conversation, provide clarification, and focus discussions in order to identify the key elements of the proposed research question (Table II).

The six facilitators were AAC clinicians, researchers, and graduate students in rehabilitation science who were trained to provide non-judgmental direction and advice and to allow for full debate among all members. Two weeks before the workshop, facilitators reviewed the PESICO model article and became familiar with the assigned content area by reading relevant articles written by the research authority assigned to their discussion table. The organizing committee chair met with the facilitators for a 1-hr training session to review their roles and responsibilities. Also discussed during the sessions were strategies to moderate small group discussions, and to encourage focused discussion among knowledge user participants using consensus-building approaches. Facilitators bounded table conversations on the broad population needs of children with complex communication needs and the PESICO element under consideration. Invited AAC researchers participated in separate groups as content experts related to their own topic area. However, they neither moderated the discussion nor directed decision-making for the research questions. Facilitators recorded key points raised by group members. At the workshop, the chair of the organizing committee visited discussion groups to assist facilitators and participants who required guidance and clarification while considering the PESICO elements. Facilitators met with the chair for a debriefing session at the end of the first day to share progress, challenges, and productive strategies for engaging knowledge user participants. During the first discussion period, group members reflected on both the persons of interest (P) and the communication stakeholders (S) in the proposed AAC investigation. Next, the groups discussed in turn the study intervention or exposure (I), the comparison intervention or exposure (C), and the targeted environmental settings and communication stakeholder attitudes (E). Finally, the groups identified the primary outcomes of interest (O) and, where possible, recommended measurement scales to consolidate their thinking for a proposed research question.

This systematic approach to question development allowed knowledge users to discuss their topic area, infuse their own clinical knowledge and experiences, and accommodate new and current understandings of empirical evidence derived from the research presentations. Although groups had 1 hr to address each PESICO element, they were permitted to revisit and reassess their earlier decisions during subsequent discussion periods. We encouraged attendees to visit other groups during breaks so that they could learn from other group facilitators and members about the research questions that were emerging.

Table II. Elements of PESICO Model with Discussion Group Probes.

PESICO element	Details	Sample probes
Person (P)	Describe the person most directly affected by the construct under study	• Who are the individuals or groups most directly affected by the proposed construct? They could be children or youth with complex communication needs; or parents, siblings, and other familiar and unfamiliar communication partners. Alternatively, a service or collective of services could be selected as the "persons" directly impacted. • What distinguishes the individual's or group's membership, for example, developmental level (preschool, early school age, late school age, early teenage, young adult); diagnosis; functional level for communicative competence (consider linguistic, operational, social, and strategic skills); and motor and cognitive functioning level, where relevant.
Environment (E)	Describe the environment and partner skills and attitudes	• What are the person's current or future environments that will provide the context for the research investigation? Recall that environmental factors are not within the person's control and make up the physical, social, and attitudinal environment in which people live and conduct their lives. • What attitudes do communication partners possess that may influence the study outcome?
Stakeholders (S)	Describe the stakeholders who may influence the outcomes	• Refer to same sample probes for Person above.
Intervention (I)	Describe the intentional steps to change an outcome	• Both intervention and exposure fit under this element. Intervention includes the intentional steps taken to change behaviors or attitudes of persons, interactions, procedures, events and environments to change an outcome. Whereas, exposure is the development of change in behavior or attitudes of the same that occur naturally through the presence of a stimuli or event rather than something intentional. • Can you describe clearly the intervention (or exposure) being studied?
Comparison (C)	Describe the comparison intervention	• Can you describe the comparison intervention or exposure being studied? This could be standard of care or wait-list controls. • Do you anticipate any ethical concerns? That is, the comparison intervention should offer participants no less than standard of care. • What would be physical, psychosocial, or other developmental risks associated with being part of the comparison group?
Outcome (O)	Describe the primary outcome of interest.	• Describe one or more of the key constructs that may be important to measure. From these constructs, identify a primary outcome of interest. • Is the primary outcome related to any or all of the categories of communicative competence? Is the primary outcome related to intervention effectiveness or efficiency? How? Is it related to other functional outcomes such as participation? • What health measurement scales may be appropriate to measure these outcomes?

Over the course of the workshop, groups discussed, identified, and agreed upon clinical populations of greatest interest, needs for the generation and translation of research evidence, and primary outcomes. Each group shared and defended their clinical rationale and research question/PESICO elements with all attendees during a final 1-hr plenary session held at the end of the workshop.

Post-Workshop Review

We reviewed the materials from the research presentations and relevant publications recommended by invited speakers to highlight important research and development priorities relevant to AAC outcomes and research for children with complex communication needs. Team members transcribed, checked, and consolidated group flip charts and discussion records supplied by table facilitators, in order to identify key discussion points and research questions developed within each group.

Anonymous post-workshop evaluations provided candid feedback from knowledge users on satisfaction with the time to interact with other attendees, the breadth and depth of topics covered, the research questions developed, and the perceived value of the workshop.

Workshop Outcomes

Research Priorities

Both consumer perspectives and recommendations by leading researchers in AAC outcomes aligned and provided an important underpinning for the research planning and small group deliberations. Advice from the consumer advisory groups included a call for workshop attendees (a) to consider AAC system enhancements and versatility, (b) to support the development of effective multi-modal communication systems, (c) to facilitate social interaction, and (d) to promote targeted education, training, and support for communication partners.

Recommended research priorities from invited researchers were (a) improving the design of AAC devices and comparing the real-world effectiveness of different interventions for children (Light &

McNaughton, 2012), (b) improving the everyday versatility and accessibility of AAC technologies in different settings for youth with complex communication needs (McNaughton, Bryen, Blackstone, Williams, & Kennedy, 2012), (c) examining the meaningfulness of participation, involvement, and psychological engagement of children who use AAC (King, Rigby, & Batorowicz, 2013), (d) developing personalized AAC devices that make use of accessible and programmable technology (Fager, Bardach, Russell, & Higginbotham, 2012), (e) exploring the effects of motor learning techniques and evidence-based literacy instruction on AAC outcomes in children with ASD (Mirenda, 2008), and (f) studying the real-world effectiveness of AAC interventions using sound outcome measures (Thomas-Stonell, Oddson, Robertson, & Rosenbaum, 2013) (Table I).

Research Questions

Each discussion group systematically and successfully identified the key elements of a research question, guided by the recommendations of advisory groups and research priorities presented by invited speakers (Table III).

The following convergent and divergent recommendations for the different topic areas were developed using the PESICO model.

Person of Interest. Knowledge user members generated questions that were generally consistent with the research directions proposed by invited speakers. Groups could have nominated the primary person to be studied to be close communication partners such as family members or friends, or groups of individuals such as clinicians or educators; instead, knowledge users consistently identified children with complex communication needs as the persons of interest in their proposed research questions. However, groups focused their population samples within small age bands that included preschool age, early primary grades, elementary school age, and early adulthood. Main populations of interest by diagnosis included children with cerebral palsy and autism spectrum disorders – both among the most common diagnoses seen in AAC clinics.

Stakeholders. Given the transactional nature of communication, groups chose stakeholders representing diverse communication partners mainly known to children. Blackstone and Hunt Berg (2003) conceptualized the social networks of people with complex communication needs as comprising five concentric circles ranging from family and close relationships (Circle 1) to strangers (Circle 5). Intermediate circles are extended families (Circle 2), acquaintances (Circle 3), and paid partners (Circle 4). The social networks recommended for study by knowledge user groups at the workshop were those residing primarily in Circles 1 through 4. Less-familiar partners (Circle 5) encountered at school, at work, or in

Table III. PESICO Elements by Assigned Topic Area.

PESICO element	Group 1: Communication, language, literacy	Group 2: Successful transitions	Group 3: Childhood participation	Group 4:Children with ASD	Group 5: New technologies and clinical decision making	Group 6: Outcomes of interventions
Person of interest	Preschoolers aged 3–5 years	Non-ambulatory youth aged 16–21 years with CP	Children aged 8–12 years	Children with ASD, aged 5–8 years	Primary school children aged 6–9 years	Preschoolers with CP, aged 3–5 years
Environment	Inclusive nursery school program	Accessible work environment	After school leisure program	Social play time	School-based, social environment	Nursery school
Stakeholders	Family, preschool, and future school team	Volunteers, coworkers, service providers	Peers, community partners, parents	Families, IBI staff, service providers	School facilitator, peers, service providers	One-to-one support person, parents, service providers
Intervention	Distance training	Supportive conversation	Group peer training in communication strategies	Aided language stimulation with SGD	Practitioner delivered	InterAACt™ language framework
Comparison	Focused literacy training	Communication passport	No training	SGD, no aided language stimulation	Facilitator delivered, client facilitated	Workshop
Outcome measurement	Improved literacy in key areas, stakeholder attitude and perception	Activity performance (COPM), experiences of activity settings (SEAS), conversational analyses	Frequency and quality of opportunities to communicate and experiences	Number of contextually-appropriate comments, multimodal turn taking, engagements	GAS and time spent to achieve level of communicative competence	Increase in utterances, positive communication behaviors, functional outcomes (FOCUS)

Note. ASD = autism spectrum disorder; COPM = Canadian Occupational Performance Measure; CP = cerebral palsy; FOCUS = Focus on Outcomes Under Six (FOCUS); GAS = goal attainment scaling; IBI = intensive behavioral intervention; SEAS = Self-Reported Measure of Activity Settings (SEAS); SGD = speech-generating device.

the community were not considered in the primary questions. Granlund and colleagues agree that studying the effect of communication interventions on these closer social networks should be a priority because research evidence is lacking (Granlund, Björck-Åkesson, Wilder, & Ylvén, 2008).

Environment and Attitudes. The groups targeted social, school program, and vocational settings as study environments. Groups chose not to study AAC outcomes in home environments and within the context of attitudes of family, friends, or other communication partners. However, the former may be inferred by the social play time of school-aged children with ASD (Group 4), and the latter may be explored indirectly in the outcomes studied, including attitudes and perceptions (Group 1), conversational analyses (Higginbotham & Engelke, 2013) (Group 2), and communication engagement (Group 4). Knowledge users generally heeded the advice of researchers who contend that functional outcomes such as experiences of involvement must be taken in context (King et al., 2013).

Interventions and Comparisons. Consistent with the recommendations of researchers, knowledge-user groups sought to compare the effectiveness of known but unproven AAC interventions. Priority study interventions included instructional and training innovations (distance training, group training, and facilitator developed training), which were then compared to either standard training or, in the absence of standard approaches, no training. Consequently, the groups in this workshop chose not to focus on the development and evaluation of new AAC interventions in recently identified areas of need, such as AAC that responds to the developmental needs of young AAC users (visual scene displays) (Wilkinson, Light, & Drager, 2012), improves access to mainstream technology (iPads™[2] and mobile technologies) (McNaughton et al., 2012), employs accessible and programmable technologies (Fager et al., 2012), and/or includes novel techniques that align with motor learning in children with ASD (Mirenda, 2008).

While groups considered intervention exposure (e.g., training blocks), little attention was paid to the length of a follow-up period to assess outcomes. Many invited researchers recommended the evaluation of important outcomes in children with complex communication needs over many years (Granlund et al., 2008; Light & McNaughton, 2012); however, this duration was not specifically recommended by groups.

Outcome Measurement. Knowledge user groups selected outcomes of interest that included a mix of subjective and objective indicators for functional performance. Change indicators occurred at different functional levels: (a) body function (literacy skills, change in utterances, quality of vocalizations), (b) activity (conversation context and engagement, goal performance), and (c) participation (frequency and quality of opportunities to participate and self-reported experiences). Outcomes of interest included the measurement of contextual changes, including both environmental factors (communication partner attitudes and perceptions, and peer engagement), and personal considerations (including both observed and self-reported behaviors).

The measurement of both functional and contextual factors requires the use of questionnaires with acceptable levels of reliability and validity (Streiner & Norman, 2008). Although outcomes of primary interest included evaluations of clinical competencies, identified outcome measures included individualized measures such as the Canadian Occupational Performance Measure (COPM) (Law et al., 2014) and Goal Attainment Scaling (GAS) (Schlosser, 2004); as well as both clinician- and parent-reported standardized outcome measures for younger children (FOCUS) (Thomas-Stonell et al., 2013), and Self-reported Experiences of Activity Settings (SEAS) (King et al., 2013). The measurement scales selected by the groups have current or emerging evidence of psychometric rigour, and so are appropriate to employ in research. Some outcomes of interest (stakeholder attitudes and perceptions, positive communicative behaviors, communicative competence) may require a significant time investment to conceptualize, develop, and ensure their measurement properties are adequate before being used to measure outcomes in a research study. Table IV presents research questions that were built using the derived PESICO elements.

End-of-workshop evaluations suggest that almost all attendees felt that they had sufficient time to interact with other clinical colleagues. They were also very satisfied with the depth and variety of topics, the research questions that were developed, and the workshop's clinical value. Attendees identified key areas of improvement, including time for general discussion of future research priorities, clarity regarding the next steps in the research question development process, and discussion of clinical challenges and strategies in transferring research evidence into practice.

Recommendations for Future Research

Compelling empirical evidence exists to support the use of AAC interventions to improve communicative competence, though little is known about their real-world effect on the lives of children and their families. We also know from research that successful transitions for young adults with complex communication needs require careful preparation and consideration of a safe living environment, participation in meaningful activities, access to important services, and support for the development of close relationships. However, we have much to learn because significant gaps remain in our understanding of the meaningful functional impact of AAC interventions on everyday participation, social inclusion, and life qualities of young people and their families.

Table IV. Research Questions Derived from PESICO Elements by Topic Area.

Group	Topic area	Research question
1	Communication, language, and literacy	Compared to interventionist distance training, do preschoolers with complex communication needs, aged 3–5 years, who are in inclusive nursery school programs show improvements in literacy and parent/educator attitudes and perceptions following focused literacy training?
2	Successful transitions	Do independent communicators with cerebral palsy, aged 16–21 years, using supportive conversation in an accessible work environment, report meaningful improvements in satisfaction and performance of individualized goals (as measured by the COPM, and improved experiences as measured by the SEAS), compared to using a communication passport in the same setting?
3	Childhood participation	Compared to no training, does a peer group training program in communication strategies for children aged 8–12 years in an after-school leisure program show greater frequency and improvement in the quality of opportunities to communicate, as well as improved childhood experiences, according to their peers, parents, and community partners?
4	Children with autism spectrum disorder (ASD)	Do emerging communicators with ASD, aged 5–8 years, demonstrate change in positive social behaviors with service providers and family members (as measured by the number of contextually-appropriate comments and turn-taking exchanges while playing games using an SGD) with 1 month of training through aided language stimulation compared to no training?
5	New technologies and clinical decision making	Compared to facilitator-delivered, client-facilitated interventions, do practitioner-delivered interventions in school-based social settings reduce the time spent to achieve individualized communicative competence goals (as measured by GAS) in children with complex communication needs, aged 6–9 years?
6	Outcomes of interventions	Do non-speaking preschoolers with CP, aged 3–5 years, using the InterAACt language framework, show positive communicative behaviors and meaningful improvements in communicative participation (as measured by the FOCUS) compared to traditional approaches, according to their parents, service providers, and one-to-one support persons?

Note. ASD = autism spectrum disorder; COPM = Canadian Occupational Performance Measure; CP = cerebral palsy; FOCUS = Focus on Outcomes Under Six; GAS = Goal Attainment Scaling; SEAS = Self-Reported Measure of Activity Settings; SGD = speech-generating device

Contemporary conceptualizations of functioning, disability, and health inform our thinking about how and what combination of AAC devices, instructions, training, and other interventions may yield optimal outcomes and positively influence the lives of children. New discoveries and understandings of the etiologies of prevalent childhood disabilities such as cerebral palsy and autism spectrum disorders are dispelling putative beliefs and providing exciting new avenues using evidence-based approaches that may influence the long-term developmental trajectories of children and youth with complex communication needs. For example, see the development of functional communication in children with cerebral palsy (Vos et al., 2014) and advances in evidence-based practice in autism (Anagnostou et al., 2014).

Given the scarcity of resources for research in AAC outcomes for children, it is crucial that both knowledge users and researchers converge on a common agenda for research to generate and translate new knowledge into everyday practice. Doing so will lead to novel findings that will advance our collective understanding and provide important new clues for AAC interventions to optimize the well-being and life qualities of children with complex communication needs.

The novel research planning process described earlier was designed to identify important research priorities and develop clinically relevant questions informed by research evidence and advice from parents and young adults who use AAC. We showed that knowledge users could be meaningfully engaged in the development of research questions using a framework specifically developed for the AAC field. The event yielded recommendations for research and development priorities that extend from the early development of language, communication, and literacy skills in very young children with complex communication needs to novel but unproven strategies that may advance outcomes in transitioning to adulthood.

Our hope is that sharing this research process and repository of research priorities and questions will be a catalyst for their adoption and the development of other relevant research questions. If answered, this work will ultimately lead to meaningful and impactful changes in the lives of children, youth, and young adults with complex communication needs.

Notes

1. InterAACt and Dynavox are products of Tobii Technology AB, Danderyd, Sweden.
2. iPad is a registered trademark and product of Apple Computers Inc., Cupertino, CA.

Acknowledgements

We are grateful for the advice offered by parents and young users who use AAC in preparation for the research

planning workshop. We are especially thankful to the knowledge users and invited researchers who invested their time and actively participated in workshop deliberations. In particular, we wish to acknowledge the contributions of facilitators who skillfully led discussions during their small group deliberations and managed the complex flow of innovative thinking.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

This research was supported by funding from a planning grant from the Canadian Institutes of Health Research, and the Centre for Leadership in Participation & Inclusion and Bloorview Research Institute at Holland Bloorview Kids Rehabilitation Hospital.

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