



The U.S. Society of Augmentative & Alternative Communication is approved by the Continuing Education Board of the American Speech-Language-Hearing Association (ASHA) to provide continuing education activities in speech-language pathology and audiology. See course information for number of ASHA CEUs, instructional level and content area. ASHA CE Provider approval does not imply endorsement of course content, specific products or clinical procedures.



Program Planner/Instructional Personnel Relationship Disclosure Form

In compliance with American Speech-Language Hearing Association’s Continuing Education Board’s Requirements, ISAAC Conference 2016 requires program planners and instructional personnel to disclose information regarding any relevant financial and non-financial relationships related to course content prior to and during course planning.

Based on the information provided, ISAAC Conference 2016 will engage the program planner /instructional personnel in a guided interview process which seeks to understand how the relevant financial or nonfinancial relationship may influence the content of the course.

Program Planner/Instructional Personnel’s Name:

Course Title:

HIPAA REQUIREMENTS

To comply with the Health Insurance Portability and Accountability Act (HIPAA), we ask that all program planners and instructional personnel insure the privacy of their patients/clients by refraining from using names, photographs, or other patient/client identifiers in course materials without the patient’s/client’s knowledge and written authorization.

I am in compliance with these policies: (INITIAL HERE)

Relevant financial relationships are those relationships in which the individual benefits by receiving a salary, royalty, intellectual property rights, gift, speaking fee, consulting fee, honoraria, ownership interest (e.g., stocks, stock options, or other ownership interest, excluding diversified mutual funds), or other financial benefit. Financial relationships can also include “contracted research” where the institution gets the grant and manages the funds and the individual is the principal or named investigator on the grant.

Do you have relevant financial relationships to disclose?
 No Yes (if yes complete Financial Relationship Disclosure Form)

Relevant non-financial relationships are those relationships that might bias an individual including any personal, professional, political, institutional, religious or other relationship. May also include personal interest or cultural bias.

Do you have relevant non-financial relationships to disclose?
 No Yes (if yes complete Non-Financial Relationship Disclosure Form)

I attest that the information in this disclosure is accurate at the time of completion and I agree to notify ISAAC Conference 2016 (conference2016@isaac-online.org) of any changes to this information between now and the scheduled presentation date. **I also understand that all completed Disclosure Forms must be incorporated within my paper proposal, as part of my Long or Extended abstract upload to the ISAAC Conference 2016 paper submission system.**

Signature

Date



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Financial Relationship Disclosure Form

Copy this page as many times as you need to complete information regarding each of your relevant financial relationships. Program Planners/Instructional personnel have a **relevant** financial relationship if that relationship could influence the information presented in the course and could be perceived as a conflict of interest by learners.

Planner/Presenter name:

Financial relationship with (name of Company/Organization):

Date form completed:

What was received? (Check all that apply)

- | | |
|---|--|
| <input type="checkbox"/> Salary
<input type="checkbox"/> Consulting fee
<input type="checkbox"/> Intellectual property rights
<input type="checkbox"/> Speaking fee
<input type="checkbox"/> Royalty
<input type="checkbox"/> Honoraria
<input type="checkbox"/> Hold patent on equipment
<input type="checkbox"/> Other financial benefit (please describe): <input style="width: 440px;" type="text"/> | <input type="checkbox"/> In kind
<input type="checkbox"/> Grants
<input type="checkbox"/> Gift
<input type="checkbox"/> Ownership interest (e.g., stocks, stock options or other ownership interest excluding diversified mutual funds) |
|---|--|

For what role? (Check all that apply)

- Employment
- Management position
- Teaching and speaking
- Board membership
- Ownership
- Consulting
- Membership on advisory committee or review panels
- Independent contractor (including contracted research)
- Other activities (please describe):



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Non-Financial Relationship Disclosure Form

Copy this page as many times as you need to complete information regarding **each** of your relevant **non-financial relationships**. Program Planners/instructional personnel have a **relevant** non-financial relationship if that relationship could influence the information presented in the course and could be perceived as a conflict of interest by learners.

Planner/Presenter name:

Non-financial relationship with (name of Company/Organization/Institution):

Date form completed:

What is the nature of the non-financial relationship? (Check and complete all that apply)

- Personal, please describe:
- Professional, please describe:
- Political, please describe:
- Institutional, please describe:
- Religious, please describe:
- Personal interest, please describe:
- Bias, please describe:
- Other relationship, please describe:

For what role?

- Volunteer employment
- Volunteer teaching and speaking
- Board membership
- Volunteer consulting
- Volunteer membership on advisory committee or review panels
- Other volunteer activities (please describe):

Title: Characterising supported decision-making for people who communicate informally

Introduction: Article 12 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD) emphasises equal legal capacity of all citizens (United Nations., 2006). From this premise, the Convention stipulates the right of everyone to receive appropriate support in decision-making. Nations that have ratified the Convention have an obligation to ensure this principle is upheld for all citizens, including people who communicate informally and unintentionally. Despite the UNCRPD's clear mandate, little is known about what decision-making and supported decision-making looks like for this population. Perhaps due to this shallow knowledge base, this group has routinely been excluded from trials of supported decision-making across within the authors' home country. This paper seeks to shine some light on decision-making and decision-making support for people who communicate informally and unintentionally.

Aim: In this paper, the authors investigate what engagement in decision-making looks like within an intervention specifically designed to support decision-making with people who communicate informally and unintentionally (i.e.: people with severe to profound intellectual disability). The authors characterise supported decision-making for people who communicate informally, with a particular focus on the role of their supporters in responding to their expressions of preference. It explores supporters' role of responsiveness within a supported decision-making process, characterising it and identifying factors that impact on it.

Method: This paper draws from a review of the literature and a qualitative study carried out by the first author. The literature was explored to develop a picture of supporter responsiveness specifically to expressions of preference of people with severe to profound intellectual disability. The research study used a multiple case design. Five people who communicate informally and their circles of support participated in a supported decision-making process, targeting a range of life decisions. Interview, focus group, questionnaire and observation data were collected and analysed.

Findings: A review of the literature found that supporter responsiveness is an important factor in ensuring people who communicate informally, including unintentionally, have their preferences realised (Bloomberg, West, & Iacono, 2003; Bunning, 2009; Coupe et al., 1985; Finlay, Walton, & Antaki, 2008; Guess, Benson, & Siegal-Causey, 1985; Ware, 2004). Despite this importance, it is well documented that responding to these expressions of preference is highly complex (Cannella, O'Reilly, & Lancioni, 2005; Finlay et al., 2008; Hughes, Pitkin, & Lorden, 1998; Virués-Ortega et al., 2014). In spite of this large body of literature, little is known about the mechanics of effective responsiveness, particularly to the expressions of preference of people who communicate informally and unintentionally. This study has highlighted that supporter responsiveness is a multi-faceted activity, made up of a number of tasks mentioned in the literature as synonymous with responsiveness, including acknowledging, interpreting, and acting upon a person's will and

preference. The study has highlighted, that although each of these tasks are important, none of them in isolation, characterise responsiveness within a supported decision-making context. Rather, supporter responsiveness is reliant on the implementation of these tasks collectively and sequentially. Firstly, supporters acknowledge/notice (as opposed to ignore) expressions of preference, secondly they interpret these expressions of preference, assigning meaning to them, and thirdly they act on this meaning. Characterised in this way, supporter responsiveness was examined within this study. Several factors, organised into four themes and eight sub themes, were identified as affecting supporter responsiveness within the context of a supported decision-making process with people with severe to profound intellectual disability.

Conclusion: The paper furthers understanding of what supported decision-making looks like for people who communicate informally, including those who communicate unintentionally, focusing specifically on the role of supporters in responding to the will and preference of those they support. It identifies a range of factors that impact on supporter responsiveness within the context of supported decision-making. These findings give a focus for practice and policy efforts for ensuring people who communicate informally receive appropriate support in decision-making, a clear obligation of signatory nations under the UNCRPD (2006).

The authors disclose they have no financial or other interest in objects or entities mentioned in this paper.

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