

Intellectual and Developmental Disabilities

Developing and Evaluating the Fidelity and Understandability of Plain Language Summaries of Position Statements

--Manuscript Draft--

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Abstract:	The American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc of the United States (The Arc) have a long history of taking jointly held positions on matters of public policy that affect people with intellectual and developmental disabilities (IDD). This article describes the methods used to develop and evaluate the understandability and fidelity of written plain language summaries of the organizations' joint position statements for an audience of people with IDD who read. Implications for adapting source material for non-reading audiences are discussed.



June 14, 2023

Amy Hewitt, PhD, Editor,
Intellectual and Developmental Disabilities (IDD)

RE: Ms. No. IDD-D-23-00008, *Developing and Evaluating the Fidelity and Understandability of Plain Language Summaries of Position Statements*

Dr. Hewitt,

We thank the reviewers for their generosity in dedicating their time and expertise to review and comment on the manuscript, which we have edited to address their concerns.

Reviewer #1:

1. *Excellent paper, timely and informative. Though not intended to provide a method for writing plain language summaries, you offer a very useful model in your study design with the composition of work groups and feedback panels.*

RESPONSE: Thank you for your gracious feedback. We would be very pleased if our paper could inform future efforts in developing plain language summaries.

2. *"Plain language" rather than "clear language" may be semantic or it may be like VHS vs. Betamax. A sentence or two on your preference for "plain" given its connotations of overly simple would be helpful.*

RESPONSE: Thank you for raising this important point. We have expanded the discussion regarding the term "plain language" and its history one page 5 (lines 8–9, 19–22) and page 6 (lines 1–11), and additional source materials were added to the reference list. We hope you will agree that these changes address your comment.

3. *Regarding the feedback panel deviating substantially from the content of source documents, I've found the results of these somewhat off-track conversation are often fruitful, as members identify areas of concern that may have been overlooked in the original document. But this speaks more to content creation and knowledge translation, not your focus here.*

RESPONSE: We agree with your assessment and had the same observation.

Knowledge | Support | Empowerment

Reviewer #3:

4. *This manuscript outlines the process for creating plain language summaries of existing organizational position statements and the evaluation of these summaries by persons with IDD to assess fidelity to the source documents. This process was well articulated and outlined a successful approach to creating plain language summaries that are reflective of the content and intent of the position statement selected. This process recognizes the strengths of persons with lived experience as both creative partners and evaluative partners.*

RESPONSE: Thank you for your generous reaction to the article. We would be very pleased if our paper could help contribute to the development even more successful approaches for crafting plain language summaries.

5. *This reviewer appreciated the detail to the management of the project which is both replicable and has demonstrated validity. There are two areas that could be better fleshed out as they were critical to the process.*

The first is the determination that understandability should target an 8th grade reading level. More on how this specific reading level was selected is needed to justify this decision. Similarly, the author notes that some members of the workgroup had a high level of knowledge of readability standards for an IDD audience (pg. 10). More detail on the standards referenced and a citation would be helpful for future research in this area.

RESPONSE: Thank you for raising these points. We have:

- Expanded the discussion regarding the elements in common use to determine ease of reading on pages 6 (lines 12–22) and page 7 (lines 1–6).
- Elaborated on the work group’s rationale for selecting the reading level on page 7 (lines 15–22) and page 8 (lines 1–3),
- Added citations to the noted item (now on page 12, lines 18-19).
- Added additional source materials to the reference list.

We hope you will agree that these changes address your comment.

6. *Second, fidelity guidelines were developed which provided structure to the creation of the plain language summaries. There is no reference to sources or prior work that informed these guidelines. A bit more description of how these were determined is needed as they provided critical guidance for the process that followed.*

RESPONSE: Thank you for noting this omission. The citation for the framework used by the workgroup to develop the guidelines has been added to page 8 (lines 9–10), and the source material added to the reference list. We hope you will agree that these changes address your comment.

7. *Irrelevant to content, there is a small typo on page 13 where the number 13 is inserted into the last sentence of the second paragraph of the limitations section and should be removed.*

RESPONSE: Thank you for pointing out the typo. It has been corrected.

8. *The development of plain language summaries of these important position statements reflect the priority of the 'nothing about us without us' philosophy that has become a focus of the organizations who collaborated on this project and that is to be commended.*

RESPONSE: Thank you for your thoughtful consideration of our efforts.

Thank you for giving us the opportunity to strengthen our manuscript in response to the reviewer's valuable comments and queries. We have worked hard to incorporate reviewer feedback and hope that these revisions persuade you to accept our submission.

Sincerely,

A handwritten signature in blue ink, reading "Margaret A. Nygren".

Margaret A. Nygren, EdD, on behalf of all authors.

Developing and Evaluating the Fidelity and Understandability of Plain Language Summaries of Position Statements

Abstract

The American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc of the United States (The Arc) have a long history of taking jointly held positions on matters of public policy that affect people with intellectual and developmental disabilities (IDD). This article describes the methods used to develop and evaluate the understandability and fidelity of written plain language summaries of the organizations' joint position statements for an audience of people with IDD who read. Implications for adapting source material for non-reading audiences are discussed.

Keywords: intellectual disability, policy, position statement, plain language summary

Developing and Evaluating the Fidelity and Understandability of Plain Language Summaries of Position Statements

The American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc of the United States (The Arc) have a long history of collaborating on activities to advance their shared public policy interests on issues important both to and for people with intellectual and developmental disabilities (IDD). The organizations, often with the addition of other partners, have long developed public policy goals for each Congress; organized an annual Disability Policy Seminar; participated in the Consortium for Constituents with Disabilities (CCD); submitted amicus curiae briefs; commented on draft legislation, proposed rulemaking, and other federal activities; and promulgated joint position statements (Luckasson et al., 2017; Schalock et al., 2021). This article describes the methods used to develop and evaluate the understandability and fidelity of the first set of written plain language summaries of joint position statements of AAIDD and The Arc.

Position Statements

A position statement provides a unified voice in an area where there may be differing perspectives or controversy and, when issued by a national organization, represents that organization's expert assessment and stance on an issue (Bala et al., 2018). The joint position statements of AAIDD and The Arc, the two leading national organizations in the field of IDD, present an authoritative perspective on important policy and practice issues in the field.

These joint position statements are designed to advance the organizations' shared goals for public policies and practices to promote and sustain high-quality, evidence-informed, and outcome-oriented supports and services for people with IDD (Luckasson et al., 2017; Shogren et

al., 2017). The position statements cover a wide range of issues that address civil rights, self-determination, health, home- and community-based services, justice, education, quality of life, and professional conduct. They are made prominently available on each organization's website, and the contents of the statements are expressed in public policy activities and programmatic of AAIDD and The Arc.

The joint position statements of AAIDD and The Arc are developed and revised in a manner aligned with the organizations' shared values of inclusion, diversity, and equity and with the shared citizenship model described by Schalock et al. (2022). The development and revision processes affirm important elements of each organization's identity, engage members' experiences and talents, ensure the input of a variety of perspectives, leverage leadership resources, and provide opportunities for policy integration and advancement (Luckasson et al., 2017).

The relatively complex and nuanced language, detailed analysis, and overall length of these statements are designed to effectively communicate the organizations' positions primarily to an audience of policymakers and secondarily to researchers, practitioners, and journalists.

Rodriguez et al. (2020) provides a useful example of how a position statement, in combination with research evidence, rapidly influenced the practices of special education programs and teachers. Although the AAIDD/The Arc joint position statements are widely understood to be useful for their target audiences (Schalock, 2017), the organizations have recognized that they are not optimally accessible for most people with intellectual disability who work to shape public policies that affect their lives.

Development and Review Processes

AAIDD and The Arc's joint Policy and Positions Committee is composed of representatives from both organizations, including volunteer members and staff. The Committee reflects each organization's constituencies, including academics, policy analysts, clinicians, service providers, people with IDD, and family members of people with IDD. The organizations follow a schedule to ensure that their position statements are periodically reviewed and revised to reflect new knowledge and changing policy considerations. In addition, following an analysis process described by Turnbull and Stowe (2017), new statements are occasionally developed to communicate shared positions on emerging issues.

For each joint position statement to be developed or revised, a subcommittee of the joint Policy and Positions Committee is formed, composed of members with relevant professional expertise and lived experience. Each subcommittee consists of approximately 20 people—including one or more persons with IDD and one or more family members of such persons—who have subject matter expertise and reflect a diversity of perspectives.

At the beginning of its most recent work cycle, the joint Policy and Positions Committee recommended, and the Boards of Directors of the two organizations agreed, that plain language summaries should be crafted for future joint position statements to adapt their contents for the audience of people with IDD. In 2022, three revised (*Advocacy*, and *Human and Civil Rights, Responding to the Interrelated Causes of Intellectual and Developmental Disabilities*; AAIDD & The Arc, 2022a, 2022c, 2022d) and one new position statement (*Anti-Racism Joint Statement*; AAIDD & The Arc, 2022b) were finalized by the two organizations, and a pilot project was conducted to develop plain language summaries of the approved statements.

Plain Language

It is important to recognize that complex or specialized language is highly effective in particular situations and with certain audiences. To be effective with policymakers, position statements need to communicate complex and nuanced ideas in a way that resonates with that audience and reflects current legislative language. Similarly, written materials better connect with people with IDD when they are short, use the active voice, and align with that audience's lived experience.

Concept of Plain Language

In contrast to complex or specialized language, plain language is a communication strategy that adapts complex information for a non-expert audience so members of that audience can understand and act on it (Nygren, 2022). Although it may be supposed that plain language is merely simple speech that “everyone” can understand, plain language is actually an adaptation that is specifically attuned to the needs and experiences of a particular audience (Dingwall et al., 2019; Willerton, 2015).

Rather than being line-by-line translations, plain language summaries are adaptations of source documents that (a) focuses on a document's most important points and (b) present its particulars in a way that members of a target audience can understand and use to inform their future actions (Nygren, 2022; Schindler, 2022).

Recent History of the Term

Since the 1940s there has been a growing movement in the United States to adopt plain language in various governmental and medical settings (Schriver, 2017). The federal cross-agency Plain Language Action and Information Network (PLAIN) was created in the 1990s, and

its current resources and guidelines are available on its website, www.plainlanguage.gov. Federal agencies were directed to use plain language in their regulations and communications by President Clinton (Exec. Order No. 12866, 1993; Exec. Order No. 12988, 1996) and President Obama (Exec. Order No. 13563, 2011). When the Plain Writing Act of 2010 was signed into law by President Obama, federal agencies were required to write all future public documents in plain language.

Willerton (2015) has suggested that the decision to use plain language becomes an ethical issue when people rely on the knowledge being transferred to act in their own self-interests. He further noted that people are entitled to understand the information that they rely on to make potentially life-altering decisions, particularly when that information comes from government agents (including the police) and health care providers.

Ease of Reading

Academic grade level is often used to describe the ease with which a document can be read. The elements used to evaluate ease of reading reflect a variety of linguistic features, including sentence length, word length, imaginability, word concreteness, active voice, and first-person construction (Barnard-Brank et al., 2023). Yaneva (2015) suggested that the most salient of these elements to consider for readers with ID are use of familiar words and avoidance of abstract concepts (a combination of features of both imaginability and word concreteness). In addition to linguistic factors, reading comprehension among people with ID is also markedly influenced by subjective and motivational factors such as a personal interest in the material and the delivery mechanism (Fajardo et al., 2014; Hua et al., 2019).

There is likely no single optimal reading level for materials designed for an audience of

people with ID. Hua et al. (2019) noted that the reading level among school-age children with ID is typically 3 years below grade level, while DiBlasi et al. (2018) found that adult readers with ID can effectively consume and utilize multi-step directions written at reading levels up to Grade 7. Yaneva et al. (2016) suggested that readability goals for materials should result—on a case-by-case basis—from consideration of the target audience, the source texts, and the purpose of the material to be read.

Project Goals

Using Schindler’s (2022) ethical framework and the participatory framework described by Francisco et al. (2022), a work group was assembled, a project plan was developed, and three desired outcomes were established to guide the development and evaluation of plain language summaries of the source documents (position statements) in this project: (a) understandability, (b) fidelity, and (c) inclusion.

Understandability

To be successful, the summaries needed to be comprehensible to an audience of readers with IDD. The source documents ranged from 2.5 to 3.5 pages in length and had a readability level ranging from Grade 11 to college; largely due to a small number of “difficult” words (*accommodation, discrimination, marginalized, equity, etc.*) that were very familiar to the target audience.

The members of the workgroup set the readability goals for the project’s plain language summaries at Grade 8 following their consideration of (a) the elements suggested by Yaneva et al. (2016; i.e., the relationship between the audience, the source texts, and the purpose of the resultant summaries); (b) their estimation—based on past experience—of the intended

audience's high level of motivation for reading (Fajardo et al., 2014; Hua et al., 2019); and (c) their past experience in developing plain language summaries of similarly complex materials. To further optimize readability, a target length of one page was established for the summaries.

Fidelity

To be faithful to the substance of their source documents, the summaries needed to present those documents' most important points and be in alignment with their contents and values. All summaries are shorter than—and, crucially, limited to—the material presented in their source documents, and plain language summaries are no exception. Using the framework proposed by Haynes et al. (2015) to identify essential elements for contextual fidelity, the workgroup established the following guidelines to promote the summaries' fidelity to source documents:

- To optimize the transmission of important points, presentation of overarching concepts was prioritized over recitation of precise and interrelated material.
- To optimize alignment with content, a goal was established to dedicate space for/emphasis on ideas roughly analogous to those found in the source document.
- To optimize alignment with values implicit in the use of language, use of person-first or identity-first language and value-neutral word choices were prioritized.

Inclusion

The source documents were composed by subcommittees of the joint Policy and Positions Committee, which included people with relevant professional expertise, people with lived experience of disability, and people representing a diversity of perspectives. For the development of plain language summaries, the inclusion of people with relevant professional

expertise, with relevant lived experience, and who represented a diversity of perspectives was also established as a priority.

Method

A workgroup of four staff members from AAIDD and The Arc was assembled for the project. Each person in the workgroup had served on at least one of the four subcommittees that developed the 2022 joint position statements. The workgroup consisted of two women and two men; one person in the group identified as a person with IDD, and one identified as a family member of a person with IDD.

A feedback panel was assembled, composed of people with IDD serving on The Arc's National Council of Self-Advocates, several of whom had also served on the joint Policy and Positions Committee. Twelve people served on the feedback panel; however, not every member of the panel provided feedback on every plain language summary. To facilitate Zoom calls, a staff person of The Arc (the feedback panel facilitator), who did not serve on the workgroup, was identified to gather feedback from the feedback panel.

The workgroup met via Zoom to identify the project goals, communication strategies, and resources and to set a timeline for completion within 3 months. The following procedures and timelines were followed:

1. Week 1: Each member of the workgroup was assigned a leadership role for managing the development of one plain language summary of a joint position statement.
2. Week 2: Each summary leader created a first draft (D1) of their assigned plain language summary and shared the draft with the other members of the workgroup.
3. Week 3: Each member of the workgroup provided written feedback on the D1

summaries in “track changes” via Google Docs. The feedback focused on enhancing understandability and maintaining fidelity to the source documents. Then the workgroup met via a Zoom call to further discuss the written feedback and finalize the second drafts (D2s) of the summaries. Both the source documents and the D2 summaries were provided to the feedback panel facilitator.

4. Weeks 4–8:

- a. The feedback panel facilitator (a) shared the source documents and the D2 summaries with the feedback panelists via email, (b) hosted Zoom calls that (i) reviewed the source documents and D2 summaries and (ii) elicited feedback on the summaries, and (c) provided written feedback on each D2 summary to its summary leader. One overarching recommendation by the panel, subsequently implemented by the workgroup, was to include definitions of the key terms used in each summary.
- b. The leaders first reviewed the feedback panel’s written comments and then participated in a Zoom call with the feedback panel. In a call with the panel hosted by the feedback panel facilitator, the leaders clarified the comments and discussed strategies to optimize the understandability of the summaries. In addition, at the close of the call, members of the panel reflected on their experiences of the project.
- c. Each leader revised their summary in response to reviewer feedback. Feedback items that prioritized minor concepts or did not align with the contents and values of the source documents were noted but not included in the revised third

drafts (D3s). The D3 summaries were provided in “track changes” to the members of the workgroup for review.

5. Weeks 9 and 10: The workgroup met via Zoom to review, on a line-by-line basis, the D3 summaries. An additional policy staff member of The Arc participated in this review. The workgroup reviewed all feedback from the panel—including those items that were disregarded by the leader—and came to a consensus on the final edits, which resulted in the fourth and final version of each plain language summary. In addition, during their final call, the workgroup members reflected on the project.

Results

This section discusses the extent to which project goals were achieved, evidence for the validity of the resultant plain language summaries, and observations by the workgroup and the feedback panel that may inform future teams in developing plain language summaries.

Understandability

The iterative strategies used in this project resulted in plain language summaries of the joint position statements that were demonstrably understandable by an audience of readers with IDD. Panel members required varying levels of support to read and understand materials; however, the supports needed for the source materials was greater than for the summaries. That members of the feedback panel read D2 summaries and provided feedback to enhance their readability demonstrated achievement of the project goal and provided face validity evidence of the summaries’ understandability.

The most notable recommendation of the feedback panel for increasing the summaries’ understandability was to provide definitions of key terms. . In step 4a, the feedback panel

identified several words in each summary that should be defined. Definitions were developed, reviewed, and edited as part of the summaries in Steps 4b, 4c, and 5 and included in the final version of the plain language summaries.

Using several online reading-level estimators, the source documents were determined to have a readability level ranging from Grade 11 to college. Excluding the key terms, the plain language summaries' reading levels were estimated to be at Grade 8 or 9. Interestingly, the key terms themselves, although commonly used in the IDD public policy arena, were estimated to be at a college reading level.

The length of the source documents ranged from 2.5 to 3.5 pages. Excluding the key term definitions, which required additional formatting space, the lengths of the final versions of the plain language summaries ranged from 1 to 1.5 pages.

Workgroup members noted that the differences between the texts of the D1s and the final versions of the summaries were fairly modest, the most significant difference being the introduction of key term definitions in the final versions. The expertise of workgroup members likely contributed to the quality and understandability of their initial drafts—the summary leaders were highly knowledgeable about their assigned position statements, exceptionally well-versed in current federal IDD public policies, and very familiar with generally accepted readability standards for an IDD audience (as described by Di Blasi et al., 2018; Fajardo et al., 2014; Hua et al., 2019; and Yaneva et al. 2016). The relative modesty of the changes between D1 and the final version should in no way suggest that the iterative process with the feedback panel was unnecessary. The iterative process was important for validating the understandability of the summaries and essential for ensuring the full participation and inclusion of people with

IDD in the project.

Workgroup members also noted that they had underestimated the amount of space that would be needed for the summaries. In particular, they noted that they had substantially underestimated how much precise language would ultimately be omitted in favor of more global statements. They also underestimated the number of short, clear sentences that were required to translate the complex ideas found in the source documents.

Fidelity

The workgroup used an iterative consensus process of repeated review and agreement on the points to be prioritized for inclusion in D2, D3, and the final version of each plain language summary. This process resulted in plain language summaries that demonstrably presented the most important points of the source documents and also aligned with the contents and values. That only modest changes resulted from the iterative consensus process provided evidence of the summaries' content validity and consistency, a type of internal validity.

Workgroup members noted that the comments provided by the feedback panel contained substantial deviations from the content of the source documents. Although the panel was reminded that the plain language summaries were translations of existing documents, many of the suggestions sought to include content and language that exceeded the scope of a source document. One possible explanation could be that the D2 summaries were highly understandable, which provided limited opportunities to enhance understandability but allowed the feedback panel time to reflect on possible enhancements to the source document contents.

Inclusion

The project included people with relevant professional expertise, relevant lived experience, and a diversity of perspectives. The four members of the workgroup had each served on at least one of the subcommittees that had created the source documents. In addition, they reflected a diversity of perspectives, were balanced by gender, and included one person with IDD and one family member of a person with IDD. The feedback panel comprised 12 people with IDD serving on The Arc's National Council of Self-Advocates, several of whom had also served on the joint Policy and Positions Committee. The demographics of the individuals who contributed to the project were demonstrably inclusive, and their demographics provided face validity evidence of inclusion.

Members of the feedback panel noted that they appreciated the opportunity to participate in a time-limited project. Members also noted that the follow-up call to clarify comments and discuss solutions provided the opportunity for a greater level of engagement.

Discussion

This project provides encouraging initial evidence that the piloted method is feasible for developing valid, written plain language summaries of position statements that are understandable by readers with IDD.

Limitations and Future Directions

This pilot did not compare different strategies or variables to determine their relative efficacy. A well-designed investigation is needed to identify what strategies are most likely to produce optimal written plain language translations of position statements for readers with IDD. While the strategies described here achieved project goals, it is possible that other strategies could produce the same or even better results.

In particular, there may well be an optimal composition for workgroups and feedback panels. Although the assumptions used to select the workgroup members had face validity, it is possible that the selection of workgroup members on the basis of other variables could produce the same or even better results. For this project, participation in the feedback panel was not limited to people with IDD who were particularly strong readers or who were intimately familiar with the contents of the source documents. It is possible that the selection of a feedback panel of people with IDD who were more closely--or less closely--aligned with the anticipated audience would have produced markedly different results.

This project was restricted to the production of written plain language summaries intended for an audience of people with IDD who are readers. Additional exploration is needed to determine if this approach could be used to develop valid (a) written plain language summaries of position statements for people with IDD who read at a lower level than Grade 8 or (b) plain language summaries in audio, video, or graphic formats.

Finally, the project did not attempt to explore how the plain language summaries could be effectively disseminated to, or used by, readers with IDD. Although the assumption that such documents will be useful for people with IDD who engage in public policy advocacy may be well founded, it remains to be tested.

Conclusion

Although these initial results are encouraging, well-designed research is needed to identify optimal methods for developing written plain language summaries of position statements and to explore how source materials can be effectively adapted for people with IDD who read at a lower level than Grade 8 and for those who do not read at all. Finally, once plain language

resources are available, it will be important to determine how they can be most effectively used to support people with IDD to shape future public policy.

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