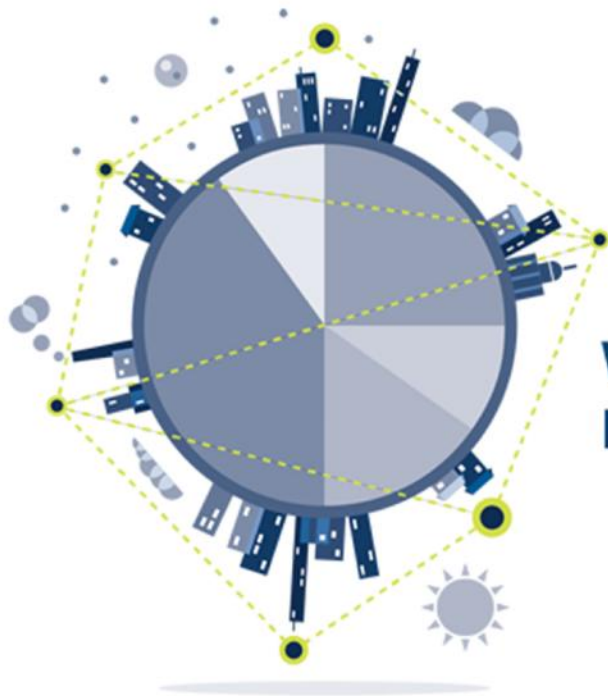


Client-Centric Approaches to Written Consent and Data Sharing

Andrea Miller and Ryan Burger



What's Next:
In Data, Leadership, and Community



**Client-Centric Approaches to Informed
Consent and Data Sharing
Andrea Miller and Ryan Burger**

Presenters

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HUD TA Provider



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Overview

- A client-centric approach ensures readability, clarity, and client comprehension in privacy and data sharing processes



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- **And** can be achieved by using plain language standards*



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- A client-centric approach ensures readability, clarity, and comprehension in privacy and data sharing processes
- And can be achieved by using plain language standards*
- **And** can be implemented through the use of practical techniques and easy-to-use tools



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Overview

- A client-centric approach ensures readability, clarity, and comprehension in privacy and data sharing processes
- And can be achieved by using plain language standards*
- And can be implemented through the use of practical techniques and easy-to-use tools

**And humanizes the data collection process while yielding
valid and reliable data**



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- And can be achieved by using plain language standards*
- And can be implemented through the use of practical techniques and easy-to-use tools

***mostly!**



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What is a Client-Centric Approach to Plain Language?

- ACKNOWLEDGES that clients are accessing services and sharing data at a most vulnerable time



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What is a Client-Centric Approach to Plain Language?

- ACKNOWLEDGES that clients are accessing services and sharing data at a most vulnerable time
- ASSERTS that building trust and conveying respect begins right away, inclusive of the data sharing encounter
- ASSURES that forms, policies, and notices help clients:
 - Find the information they need
 - Understand what they find
 - Make informed decisions about how their data is used



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Why is a Client-Centric Approach to Plain Language Important?

Data = A representation of people!

- Meets people where they are at
- Places clients first during the earliest encounter



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Why is a Client-Centric Approach to Plain Language Important?

Incorporates a trauma-informed approach by accounting for known barriers and challenges! such as

- Cognitive impairments due to mental illness or substance use
- Disabilities or chronic health conditions
- Low educational attainment
- Limited English Proficiency



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Why is a Client-Centric Approach to Plain Language Important?

Data quality begins before data entry!

- Meeting the client where they are at engages them in a human encounter



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Why is a Client-Centric Approach to Plain Language Important?

Data quality begins before data entry!

- Meeting the client where they are at engages them in a human encounter
- **Which** allows the client and the data collector to be invested in the transaction



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Why is a Client-Centric Approach to Plain Language Important?

Data quality begins before data entry!

- Meeting the client where they are at engages them in a human encounter
- Which allows the client and the data collector to be invested in the transaction
- Which yields valid and reliable data
- **To produce actionable information**



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Rules of Plain Language

- 1. Write for your clients**
- 2. Organize content to meet your client's needs**
- 3. Address a single person rather than a group**
- 4. Use formatting, headings and sections to convey information**
- 5. Write like you talk**



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1. Write for your Clients

- Who are my clients?
- What do my clients already know about the subject?
- What do my clients need to know about how their data is used?
- What additional questions will my clients have?



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Write for your Clients

Techniques

- Write using low literacy techniques
- Write a script for staff who will be seeking client consent
- Include prompts and probes in the document or the script or both



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Write for your Clients Example



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2. Organize Content

Provide general information first, then conditions and exceptions later!

- > Present the purpose of data collection first
- > Discuss how data will be used or shared
- > Provide information on who will have access to the data
- > Describe conditions and exceptions



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Organize Content Techniques

- Present the purpose of data collection first
- Discuss how data will be used or shared
- Provide information on who will have access to the data
 - > For what purpose(s)
 - > For how long
- Describe conditions and exceptions
 - > Sharing data only with consent
 - > Process for revoking consent
 - > Ability to access services even without providing consent



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Organize Content Example



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3. Address the Client Directly

- Address the client in the first person with an active voice
- Reflect the client's reality by localizing the document as much as possible



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Address the Client Directly Techniques

- Address the client in first (or second) person
 - > Insert the person's name whenever possible
 - > Use an active (vs. passive) voice



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Address the Client Directly

Example

“You must provide written consent before your information is shared”

instead of

“consent must be provided prior to the sharing of any client information”



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4. Use Formatting & Styles

- Use sections with headers
- Use font styling to call attention to sections and organization
- Use white space and wide margins



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4. Use Formatting & Styles Techniques

- Use sections with headers
 - > Simple, short paragraphs and headings make information easier to understand



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4. Use Formatting & Styles Techniques

- Use font styling to call attention to sections and organization
 - > **Bold fonts**
 - > **Larger fonts**
 - > **Serif fonts**



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4. Use Formatting & Styles

Example



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5. Write Like You Talk

- Minimize abbreviations and acronyms
- Use common vernacular, including nicknames, as needed
- Eliminate redundancies



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Write Like You Talk Techniques

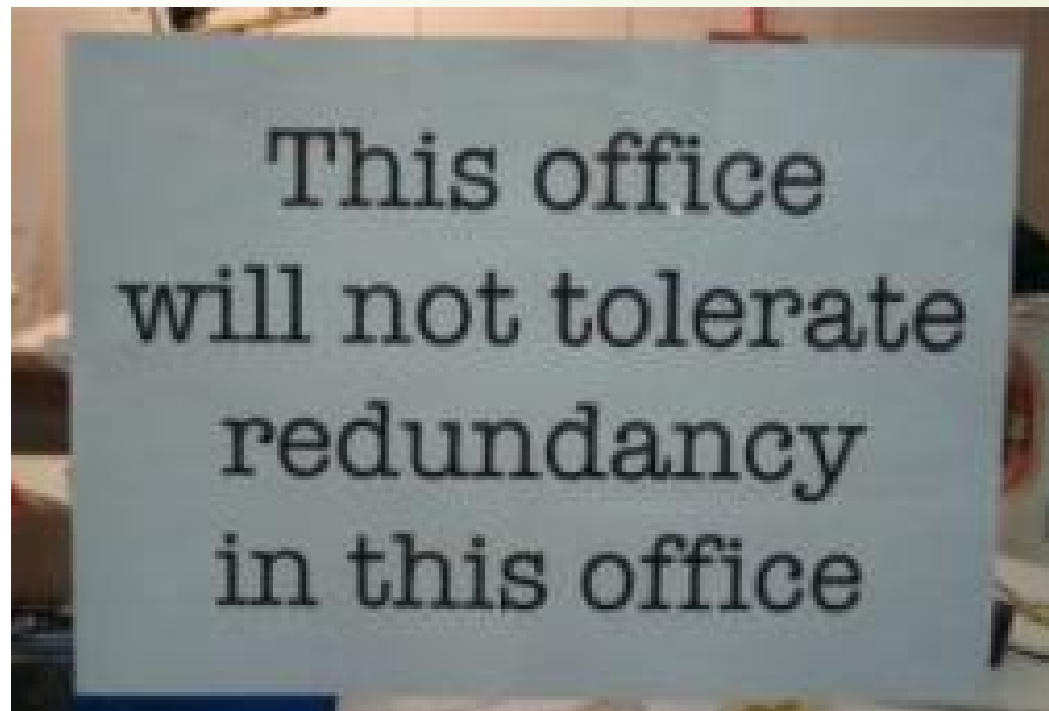
- Minimize abbreviations and use nicknames as needed
 - > “Coordinated Entry Participating Agencies” becomes “Agencies”
- Eliminate redundancies
 - > “The information contained in your HMIS record will be used to make referrals to programs and services...”
 - Information and record
 - Programs and services



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Write Like You Talk

Example





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Plain Language in Action

Before

“Title I of the CARE Act creates a program of formula and supplemental competitive grants to help metropolitan areas with 2,000 or more reported AIDS cases meet emergency care needs of low-income HIV patients. Title II of the Ryan White Act provides formula grants to States and territories for operation of HIV service consortia in the localities most affected by the epidemic, provision of home and community -based care, continuation of insurance coverage for persons with HIV infection, and treatments that prolong life and prevent serious deterioration of health. Up to 10 percent of the funds for this program can be used to support Special Projects of National Significance.”



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Plain Language in Action

After

“Low income people living with HIV/AIDS gain, literally, years, through the advanced drug treatments and ongoing care supported by HRSA’s Ryan White Comprehensive AIDS Resources Emergency (CARE) Act.”



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Tools



Readability Tools

- Readily available
- Long history of use to>>>
 - Assess the readability of educational materials
 - Improve health information communications
 - Create informed consents that require IRB approval
- Easy to implement



Readability Tools

- Flesch-Kincaid Reading Ease
- Flesch-Kincaid Grade Level
- Gunning Fog Index
- SMOG Index
- Consensus Score



Readability Tools

- **Flesch-Kincaid Reading Ease**

Description: One of the oldest and most commonly used readability scores. Incorporates the average number of syllables per word and the average number of words per sentence for a 100-word block of text. Results are measured on a scale of 1-100.

Recommended writing level: On the 1-100 scale, 1 is very complicated to read and 100 is very easy to read. Most readability resources recommend writing to the 60-70 range.



Readability Tools

- Flesch-Kincaid Reading Ease
- **Flesch-Kincaid Grade Level**

Description: Like the Flesch-Kincaid Reading Ease score, this is a mathematical formula that measures syllables and sentence length. However, the results are given as an academic grade level, from 0-12.

Recommended writing level: That depends on your audience, but 7th-8th grade is a good standard—that captures more than 80% of U.S. adults.



Readability Tools

- Flesch-Kincaid Reading Ease
- Flesch-Kincaid Grade Level
- **Gunning Fog Index**

Description: The Gunning Fog Index takes into account “complex” words, those with three or more syllables, as part of its formula for readability. It also omits proper nouns, jargon and compound words.

Recommended writing level: Typically, technical documentation has a Fog Index between 10 and 15, and professional prose almost never exceeds 18. The ideal score is between 7 and 8, depending on your audience.



Readability Tools

- Flesch-Kincaid Reading Ease
- Flesch-Kincaid Grade Level
- Gunning Fog Index
- **SMOG Index**

Description: This index is a common measure of readability. Take 30 sentences (10 from the beginning, middle and end of your text), then count every word with three or more syllables in each group of sentences, then calculate the square root of that number and round it to the nearest 10, then add 3 to that number.


Recommended writing level: 7-8, depending on your audience.



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Readability Tools

- Flesch-Kincaid Reading Ease
- Flesch-Kincaid Grade Level
- Gunning Fog Index
- SMOG Index
- **Consensus Score**

Readability Grade Levels  	
Readability Formula	Grade
Flesch-Kincaid Grade Level	7.1
Gunning-Fog Score	8.8
Coleman-Liau Index	8.6
SMOG Index	9.8
Automated Readability Index	6.3
Average Grade Level	8.1



Readability Tools

General strategies

- Shorter word length
from polysyllabic to monosyllabic
- Shorter sentence length
from multiple-part or conditional sentences to action-oriented sentences
- Shorter paragraph length
from too many sentences per paragraph to 3-4 sentences per paragraph



Readability Tools

Specific strategies

- Some penalize the use of jargon, acronyms, etc.
from reliance on complexity to use of plain language
- Most vary in how they sample the text, e.g. how much text they sample, and the location of that text



Readability Tools

Take Away

- Replace polysyllabic words with 1 or 2 syllable words
- Reduce or eliminate compound words, Proper Nouns, and HUD acronyms
- Reduce compound sentences; use short sentences and short paragraphs



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Readability Tools Demo



Readability Tools Demo

- MS Word
- Online Tools



Readability Tools Demo

- **MS Word**
 - > How to configure Word to return Readability Statistics
 - > How to review text in Word for Readability

[[[SCREENSHOTS & LIVE DEMO]]]



Readability Tools Demo

- MS Word
- **Online Tools**
 - > How to access and use web-based analysis tools
 - > How to select a specific formula or a consensus score

[[[SCREENSHOTS & LIVE DEMO]]]



Readability Tools Demo

- MS Word
- **Online Tools**
 - [Readability Test Tool](#): Measures Flesch-Kincaid Reading Ease and Grade Level, Gunning Fog Score, SMOG Index, Coleman Liau Index and Automated Readability Index. Can test an entire web page or a block of text.
 - [Microsoft Office](#) : Measures Flesch-Kincaid Reading Ease and Flesch-Kincaid Grade Level. Tests content in your document.
 - [ReadabilityFormulas.com](#): Measures Flesch-Kincaid Reading Ease, Flesch-Kincaid Grade Level, Gunning Fog Score, Coleman-Liau Index, SMOG Index and Automated Readability Index, as well as the [Linsear Write Formula](#). Tests a block of text.



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Accomodation



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To Offer Accommodations

- Need translated documents and/or translator
- Need large font versions
- Need a Short Form Consent Process



To Offer Accommodations

- **Translated versions and/or translator**
- Large font versions
- Short Form Consent Process



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To Offer Accommodations

- Translated versions and/or translator
- **Large font versions**
- Short Form Consent Process



To Offer Accommodations

- Translated versions and/or translator
- Large font versions
- **Short Form Consent Process**
i.e., oral presentation of informed consent information
in conjunction with a short form written consent



To Offer Accommodations

Little is known about how to implement accommodation practices during the written authorization process.

A protocol should be on hand to specify how these encounters can successfully incorporate person-centric strategies including when and how to use short consent procedures.



Summary of Best Practices

1. Use a Plain Language approach
2. Use Readability Tools to achieve a 6th-8th grade reading level
3. Use low literacy techniques to assure comprehension
4. Use a Short Form Consent when accommodation is needed



For More Information

- [Federal Plain Language Guidelines](#)
- [The National CLAS Standards](#)
- [CDC Literacy and Readability Guide](#)
- [Raven Tools Blog](#)

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