Attachment B Informed Consents for Study of Disability Service Coordinators and Inclusion in Head Start

Table 1 List of Consent Forms

Informed Consent Phase 1 Director Survey
Informed Consent Phase 2 Disability Services Coordinator Survey
Informed Consent Phase 3 Disability Services Coordinator Interview

INFORMED CONSENT PHASE 1 DIRECTOR SURVEY

Informed Consent for the Study of Disability Services Coordinators and Inclusion in Head Start
Survey of EHS/HS Directors

Title of Project: The Study of Disability Services Coordinators and Inclusion in Head Start, 2019-2024

Principal Investigator(s): Michael López and Shannon TenBroeck

Why are we doing this study? This study will provide a national picture of the Disability Services Coordinators (DSC) workforce for Early Head Start (EHS) and Head Start (HS), including American Indian/Alaska Native (Region XI) and Migrant and Seasonal Head Start (MSHS) (Region XII) grantees and/or delegate agencies. This study will improve Head Start's understanding of how programs implement disability services for children and families.

Who is funding this study? The Office of Planning, Research, and Evaluation in the Administration for Children and Families (ACF) within the Department of Health and Human Services (HHS). The study is being conducted by NORC at The University of Chicago, their partners at SRI International, and their consultant, Amanda Schwartz.

How do I participate? We invite all Head Start grantee or delegate agency directors to complete a brief 25-minute web-based survey that will provide information about DSC(s) and inclusion in your program. If it would be helpful to you, you may request to complete it by phone.

Your responses to this survey will provide important information about:

- Names and contact information for your program's DSC(s);
- Details about your program; and
- Your perspective on disability services and inclusion in your program.

How long will it take? It will take about 25 minutes to complete the online survey. The survey allows you to stop and save your responses at any time and return to them later for completion.

Risks: There are no risks to participating in this research.

Benefits: The study will provide the first national picture of how HS provides disability services. HS is a national early childhood leader, and the variety of ways that HS programs implement the Head Start Program Performance Standards for disability services will inform practice, policy, guidance and technical assistance. Your participation in this study will also help HS to improve disability services and to design supports for programs to enhance their disability coordination programming.

Privacy: The study is descriptive; it is not designed to capture individual program, child- or family-level data or evaluate compliance with the Head Start Program Performance Standards (HSPPS). Data will not be used for monitoring purposes. Your responses will not impact ACF funding for your program.

The data collected will be kept private to the extent permitted by law. To minimize risks to privacy, we use a secure system to collect these data. Once the data is collected, we remove all identifying information and replace it with a study ID. Only the researchers involved in the study will know that someone from your program participated in the study. The only program identifying information that will be retained is the state, territory or district where your program is located. In any written reports of the data, your responses will be combined with others and reported together so that individual information is not identifiable. If quotes are used in any reports, they will not be connected to an individual or grantee/delegate agency. If you would like to withdraw from the study, please notify the research team at HeadStartDSCStudy@norc.org. If you choose to withdraw from the study, we will maintain and analyze the data collected up to the time of withdrawal. If at the time of withdrawal you request that we destroy all of your data and exclude your responses from the study results, we will honor your request unless the data has already been aggregated, at which point we will no longer be able to separate person-level data.

NORC will securely maintain the data from this study. At the conclusion of the study, the data will be archived as a restricted use file. A restricted use file means that only qualified researchers will be able to access the data for use in future research projects, without collecting additional consent, to help further our understanding of disability services and inclusion in Head Start. The data will be linked to administrative data such as the Program Information Report (PIR), Head Start Enterprise System (HSES), and state disability policy data such as the DaSy.

Right to Ask Questions: If you have any questions, concerns, or comments about the study, please contact the research team at HeadStartDSCStudy@norc.org. If you have questions about your rights as a research volunteer, please call the NORC Institutional Review Board toll free at 1-866-309-0542.

Voluntary Participation: Your participation is voluntary. You may stop the survey at any time or skip any question you do not wish to answer. The only question that requires a response to continue asks about the ages of the children you serve. Your answer determines which questions will be asked in the rest of the survey.

You must be 18 years of age or older to take part in this research study.

Proceeding with the survey implies that you have read the information in this form and consent to take part in this research study.

Please keep this form for your records or future reference. **Programmer's note**: include link to a PDF-version of the form for download.

Do you agree to participate in this study?
Yes → Proceed to survey
No → Thank you for your consideration

INFORMED CONSENT PHASE 2 DISABILITY SERVICES COORDINATOR SURVEY

Informed Consent for the Study of Disability Services Coordinators and Inclusion in Head Start Survey of EHS/HS DSCs

Title of Project: The Study of Disability Services Coordinators and Inclusion in Head Start, 2019-2024

Principal Investigator(s): Michael López and Shannon TenBroeck

Why are we doing this study? This study will provide a national picture of the Disability Services Coordinators (DSC) workforce for Early Head Start (EHS) and Head Start (HS), including American Indian/Alaska Native (Region XI) and Migrant and Seasonal Head Start (MSHS) (Region XII) grantees and/or delegate agencies. This study will improve Head Start's understanding of how programs implement disability services for children and families.

Who is funding this study? The Office of Planning, Research, and Evaluation in the Administration for Children and Families (ACF) within the Department of Health and Human Services (HHS) and is being conducted by NORC at The University of Chicago, their partners at SRI International, and their consultant, Amanda Schwartz.

How do I participate? We invite DSCs within EHS and HS programs to complete a 45-minute online survey. If it would be helpful to you, you may request to complete it by phone. Your participation will help the study capture current practices, strengths, and challenges related to disability services in EHS and HS programs.

Your responses to this survey will provide important information about:

- The characteristics and responsibilities of DSCs;
- The processes and approaches to partnering with agencies and community partners to offer services to children with disabilities and their families;
- Collaboration with families of children with disabilities; and
- Challenges to inclusion and providing disability services, support, and education to children, families, and staff.

Risks: There are no risks to participating in this research.

Benefits: The study will provide the first national picture of how HS provides disability services. HS is a national early childhood leader, and the variety of ways that HS programs implement the Head Start Program Performance Standards for disability services will inform practice, policy, guidance and technical assistance. Your participation in this study will also help HS to improve disability services and to design supports for programs to enhance their disability coordination programming.

The study is descriptive; it is not designed to capture individual program, child- or family-level data or evaluate compliance with the Head Start Program Performance Standards (HSPPS). Data will not be used for monitoring purposes.

You also will be able to print or save a copy of your responses to the survey for your own records and for program planning. However, given that this material will contain your personal opinions, take any necessary precautions to protect your own privacy when using the survey within your program.

How long will it take? It will take about 45 minutes to complete the online survey. The survey allows you to stop and save your responses at any time and return to them later for completion.

Privacy: The study is descriptive; it is not designed to capture individual program, child- or family-level data or evaluate compliance with the Head Start Program Performance Standards (HSPPS). Your responses will not be shared with your supervisor and the data will not be used for monitoring purposes. Your responses will not impact ACF funding for your program.

The data collected will be kept private to the extent permitted by law. To minimize risks to privacy, we use a secure system to collect these data. Once the data is collected, we remove all identifying information and replace it with a study ID. Only the researchers involved in the study will know that someone from your program participated in the study. The only program identifying information that will be retained is the state, territory or district where your program is located. In any written reports of the data, your responses will be combined with others and reported together so that individual information is not identifiable. If quotes are used in any reports, they will not be connected to an individual or grantee/delegate agency. If you would like to withdraw from the study, please notify the research team at HeadStartDSCStudy@norc.org. If you choose to withdraw from the study, we will maintain and analyze the data collected up to the time of withdrawal. If at the time of withdrawal you request that we destroy all of your data and exclude your responses from the study results, we will honor your request unless the data has already been aggregated, at which point we will no longer be able to separate person-level data.

NORC will securely maintain the data from this study. At the conclusion of the study, the data will be archived as a restricted use file. A restricted use file means that only qualified researchers will be able to access the data for use in future research projects, without collecting additional consent, to help further our understanding of disability services and inclusion in Head Start. The data will be linked to administrative data such as the Program Information Report (PIR), Head Start Enterprise System (HSES), and state disability policy data such as the DaSy.

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Voluntary Participation: Your participation is voluntary. You may stop the survey at any time or skip any question you do not wish to answer. The only question that requires a response to continue asks about the ages of children you serve. Your answer determines which questions will be asked in the rest of the survey.

You must be 18 years of age or older to take part in this research study.

Proceeding with the survey implies that you have read the information in this form and consent to take part in this research study.

Please keep this form for your records or future reference. **Programmer's note**: include link to a PDF-version of the form for download.

Do you agree to participate in this study?
Yes → Proceed to survey
No → Thank you for your consideration

PHASE 3 INFORMED CONSENT DISABILITY SERVICES COORDINATOR INTERVIEW

Informed Consent for the Study of Disability Services Coordinators and Inclusion in Head Start Interview of EHS/HS DSCs

[ASK IF YOU CAN BEGIN RECORDING PRIOR TO RECORDING:] We are first going to go over what the study is about, how the data will be kept, and your rights as a participant. Is it okay if I begin recording now?

(to be read orally to interviewee and shared on screen)

[BEGIN RECORDING]

Thank you for taking the time to complete the online survey of EHS/HS DSCs. We appreciate you agreeing to talk to us today to tell us more about your role and the services you provide to children with disabilities and their families. Specifically, we are interested in hearing from you today about [selected interview topic]. Before we start the interview, we have a brief consent process. We will share the consent form with you in writing following our conversation.

Why are we doing this study? This study will provide a national picture of the Disability Services Coordinators (DSC) workforce for Early Head Start (EHS) and Head Start (HS), including American Indian/Alaska Native (Region XI) and Migrant and Seasonal Head Start (MSHS) (Region XII) grantees and/or delegate agencies. This study will improve Head Start's understanding of how programs implement disability services for children and families.

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How long will it take? The interview will take about 45 minutes.

Risks: There are no risks to participating in this research.

Benefits: The study will provide the first national picture of how HS provides disability services. HS is a national early childhood leader, and the variety of ways that HS programs implement the Head Start Program Performance Standards for disability services will inform practice, policy, guidance and technical assistance. Your participation in this study will also help HS to improve disability services and to design supports for programs to enhance their disability coordination programming.

Privacy: The study is descriptive; it is not designed to capture individual program, child- or family-level data or evaluate compliance with the Head Start Program Performance Standards (HSPPS). Your responses will not be shared with your supervisor and the data will not be used for monitoring purposes. Your responses will not impact ACF funding for your program.

The data collected will be kept private to the extent permitted by law. To minimize risks to privacy, we use a secure system to collect these data. Once the data is collected, we remove all identifying information and replace it with a study ID. Only the researchers involved in the study will know that someone from your program participated in the study. The only program identifying information that will be retained is the state, territory or district where your program is located. In any written reports of the data, your responses will be combined with others and reported together so that individual information is not identifiable. If quotes are used in any reports, they will not be connected to an individual or grantee/delegate agency. If you would like to withdraw from the study, please notify the research team at HeadStartDSCStudy@norc.org. If you choose to withdraw from the study, we will maintain and analyze the data collected up to the time of withdrawal. If at the time of withdrawal you request that we destroy all of your data and exclude your responses from the study results, we will honor your request unless the data has already been aggregated, at which point we will no longer be able to separate person-level data.

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Voluntary Participation: Your participation is voluntary, and you may skip questions, and stop the interview at any time without any penalty.

You must be 18 years of age or older to take part in this research study.

Do you consent to participate in this interview? **[All parties on line must say “yes” to proceed. If “yes” then proceed. If “no” then terminate interview.]**

Do you have any questions before we begin?

NORC would also like to record this interview in order to ensure our notes are as accurate and comprehensive as possible. We will delete the recording at the end of the project.

Do you consent to have this interview recorded?

[If all parties indicate “yes” then proceed, and continue to record the interview.”]

[If “no” then say: “That's fine. Instead of recording, in order to gather the information from the interview, I will be taking notes. We might pause now and then to make sure I get the details. Thanks for your patience." Then, stop recording.]