

ICR Non-Substantive CHANGE REQUEST MEMO

Study to Explore Early Development (SEED) Follow-up Study

OMB NO. 0920-1392

Expiration Date 4/30/2026

Spanish Translation of the SEED Follow-up Study Instruments

Summary:

For this change request, we are seeking approval of the Spanish translation of the instruments for the SEED Follow-up Study. This project was previously approved by OMB on 4/12/2023. The Spanish translation of the instruments will allow families for whom English is not their primary language to participate in this important study.

Attachments:

Attachment 1: Att 2f_S - Spanish First Follow-up Core Survey of SEED 1-3 Caregivers

Attachment 2: Att 4a_S - Spanish First Follow-up Survey Supplement for Caregivers of Adolescents

Attachment 3: Att 5_S - Spanish First Follow-up Survey Supplement for Caregivers of Young Adults

Attachment 4: Att 6b-d_S - Spanish Enrollment Call Script and Second Follow-up Survey of Caregivers of Young Adults

Attachment 5: Att 7e_S - Spanish Survey of Young Adults

Background & Justification:

The Study to Explore Early Development (SEED) Follow-up Study (OMB NO. 0920-1392; expiration date 4/26/2026) seeks to understand the services and supports needed to maximize the quality of life for people with autism spectrum disorder (ASD), especially as they progress into adulthood. SEED was initially implemented in three phases during 2007-2021 to understand the risk factors for ASD and the characteristics and healthcare needs of young children (ages 2-5 years) with ASD and other developmental disabilities. The SEED Follow-up Study has been approved for carrying out longitudinal follow-up surveys on participants who originally participated in SEED Phases 1-3. The information collected from this study will allow us to better understand the developmental trajectory of children with ASD, their health outcomes and co-occurring conditions at older ages, and the associated early predictors of these outcomes, including intellectual abilities.

The project also provides the opportunity to obtain important self-reported measures of well-being among young adults with ASD. Because most SEED Phase 1 participants will reach young adulthood in years 2021-2026, data collected through this study will provide an opportunity to assess changes in service access and utilization that may occur following high school exit. This information can help inform service delivery and programs on the supports needed to achieve greater independence.

The English versions of the SEED Follow-up Study were previously approved by OMB on 4/12/2023. For this change request, we are seeking approval of the Spanish translation of five surveys. This will allow families for whom English is not their primary language to participate in this important study.

Effect of Proposed Changes on Current Approved Instruments:

This request only adds Spanish translations of the already approved instruments: 1) First Follow-up Core Survey of SEED 1-3 Caregivers, 2) First Follow-up Survey Supplement for Caregivers of Adolescents (SEED 2 Caregivers), 3) First Follow-up Survey Supplement for Caregivers of Young Adults (SEED 1 Caregivers), 4) Enrollment Call Script and Consent and Second Follow-up Survey of SEED 1 Caregivers, and 5) Second Follow-up Survey of SEED 1 Adult Children. This will allow for families for whom English is not their primary language to participate in this important study.

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Form	Current/Question Item	Requested Change
Att 2f_S - Spanish First Follow-up Core Survey of SEED 1-3 Caregivers ¹	All	English to Spanish Translation
Att 4a_S - Spanish First Follow-up Survey Supplement for Caregivers of Adolescents ²	All	English to Spanish Translation
Att 5_S - Spanish First Follow-up Survey Supplement for Caregivers of Young Adults	All	English to Spanish Translation
Att 6b-d_S - Spanish Enrollment Call Script and Second Follow-up Survey of Caregivers of Young Adults	All	English to Spanish Translation
Att 7e_S - Spanish Second Follow-up Survey of Young Adults ³	All	English to Spanish Translation

Effect on Burden Estimate:

There will be no burden change.

Form	Approved Burden	Requested Burden
Att 2f_S - Spanish First Follow-up Core Survey of SEED 1-3 Caregivers	40 minutes	No change
Att 4a_S - Spanish First Follow-up Survey Supplement for Caregivers of Adolescents	20 minutes	No change
Att 5_S - Spanish First Follow-up Survey Supplement for Caregivers of Young Adults	20 minutes	No change
Att 6b-d_S - Spanish Enrollment Call Script and Second Follow-up Survey of Caregivers of Young Adults	10 minutes	No change
Att 7e_S - Spanish Second Follow-up Survey of Young Adults	30 minutes	No change
Total		No change

¹ Attachments 2g and 2h are also part of the First Follow-up Core Survey. They are copyrighted assessments that cannot be posted but are published in both English and Spanish.

² Attachments 3a and 3b are part of the First Follow-up Survey Supplement for Caregivers of Children that includes copyrighted assessments that cannot be posted but are published in both English and Spanish. Attachment 4b is part of the First Follow-up Survey Supplement for Caregivers of Adolescents and is a copyrighted assessment that cannot be posted but is published in both English and Spanish.

³ Attachments 7f, 7g, 7h, and 7i are part of the Second Follow-up Survey of Young Adults. They are copyrighted assessments that cannot be posted but are published in both English and Spanish.