

Appendix B: Input into Development of the Revised Plan

On April 13, 2020, multiple National Institutes of Health (NIH) Institutes, Centers, and Offices (ICOs), including the Office of the NIH Director, issued the Request for Information (RFI): [Invitation to Comment on Updates to NIH Research Plans on DS \(NOT-HD-20-013\)](#) in response to direction from NIH leadership to combine previously published plans relevant to the Down syndrome (DS) and update them to create the *NIH INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome (INCLUDE) DS Research Plan*. NIH asked for comments from the public concerning the effectiveness of the previous plans, advances made since 2014, remaining research gaps, and suggestions concerning new future research objectives. The RFI was widely disseminated by Down Syndrome Consortium members and organizations, through research and professional societies, and to investigators funded by the INCLUDE Project.

A total of 11 responses were submitted, which together combined input from 154 members of the DS community. Responses came from self-advocates, family members, professional societies, researchers, clinicians, and other members of the DS community. They were grouped according to each of the plan's categories: Basic Research, Cohort/Epidemiology, Clinical/Co-Occurring Conditions, Living and Aging with DS/Services Research, and Research Infrastructure.

Ten out of the eleven received responses were [published in whole on the INCLUDE Project website](#) for public comment. (One respondent could not be reached to provide permission for posting.)

On March 10, 2021, NIH, led by NICHD and the Office of the NIH Director, issued a second RFI: [Invitation to Comment on the Draft NIH INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome \(INCLUDE\) Down Syndrome Research Plan \(NOT-HD-21-014\)](#) to solicit comments and suggestions from a range of stakeholders regarding the draft NIH INCLUDE DS Research Plan, which was posted on the INCLUDE Project website. In particular, NIH requested comments about the content of the draft research plan, whether the goals and objectives captured the priorities of the DS community, feedback about the conclusion, and suggestions for ways that NIH can carry out the objectives, including strategies for disseminating evidence-based information from funded research and facilitating collaborations to accomplish these goals.

A total of 9 responses were received, representing feedback from 16 individuals and DS organizations. This feedback has been incorporated into the final version of the research plan in the Goals and Objectives as well as [Appendix F](#) on Training in DS Research.