

DSD & Intersex Research Portfolio

A Snapshot of the NIH FY 2019 SGM Portfolio Analysis



National Institutes of Health
Sexual & Gender Minority Research Office

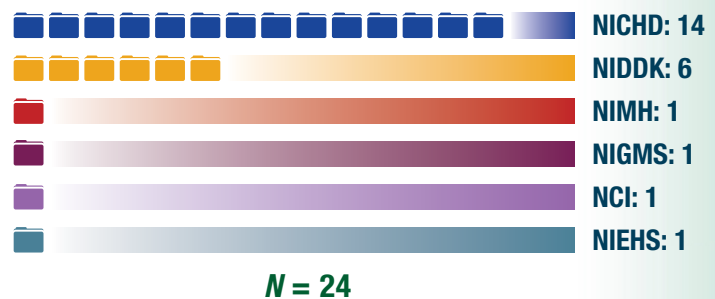
Introduction

Individuals who have a “difference of sex development” (DSD) and/or identify as “intersex” typically have a congenital variation in either sex chromosomes, gonadal development, sex hormone synthesis or function, and/or appearance of external genitalia that fall outside of binary notions sex. Not all individuals with a DSD may identify as intersex, as they may not wish to be defined by their biological histories nor do they think of it as an identity. Contrarily, not all individuals who identify as intersex were born with an identifiable DSD.

The National Institutes of Health (NIH) research projects specific to individuals with DSDs and/or intersex people for fiscal year (FY) 2019 were a subset of the full portfolio of 408 sexual and gender minority (SGM) projects. The full portfolio is identified using the SGM fingerprint, which includes a subset of key terms specific to DSD & Intersex conditions. The full SGM portfolio was reviewed manually to determine which of the projects in the SGM portfolio were related to DSD & Intersex. Those 24 DSD & Intersex projects are presented here. DSD & Intersex projects constituted approximately 5.9% of the SGM portfolio for FY 2019.

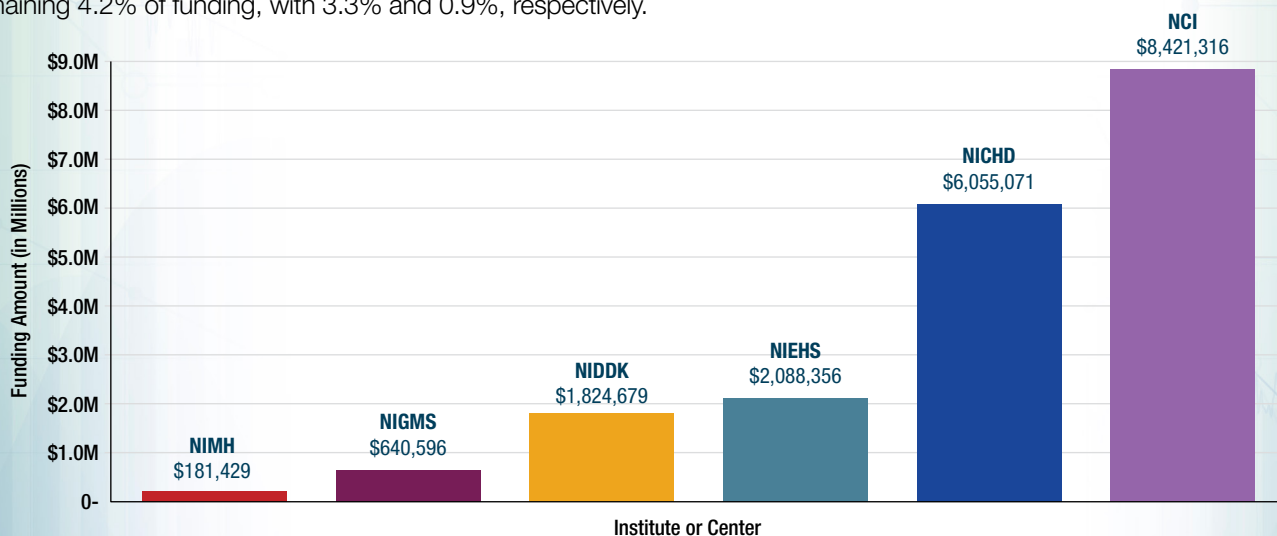
Projects by Institute or Center

The majority (58.3%) of DSD & Intersex projects were funded by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD). The only other Institute that had more than one project was the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), with six projects (25.0%).



Funding Amount by Institute or Center

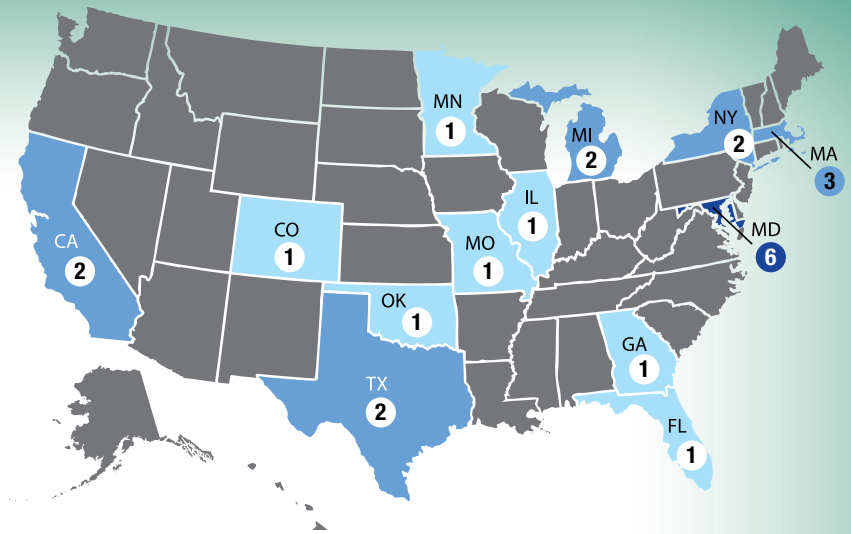
The National Cancer Institute (NCI) was the largest single funder of projects, with 43.8% of the \$19.2 million spent on DSD & Intersex projects. This single project appears large because the total funding amount for DSD & Intersex research is relatively small, and the NCI study is a broad epidemiological study. NICHD and the National Institute of Environmental Health Sciences (NIEHS) together accounted for roughly the same amount of funding, with 31.5% and 10.9% of the \$19.2 million, respectively. The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) accounted for 9.5% of funding in this area. The National Institute of General Medical Sciences (NIGMS) and the National Institute of Mental Health (NIMH) accounted for the remaining 4.2% of funding, with 3.3% and 0.9%, respectively.



Projects by State

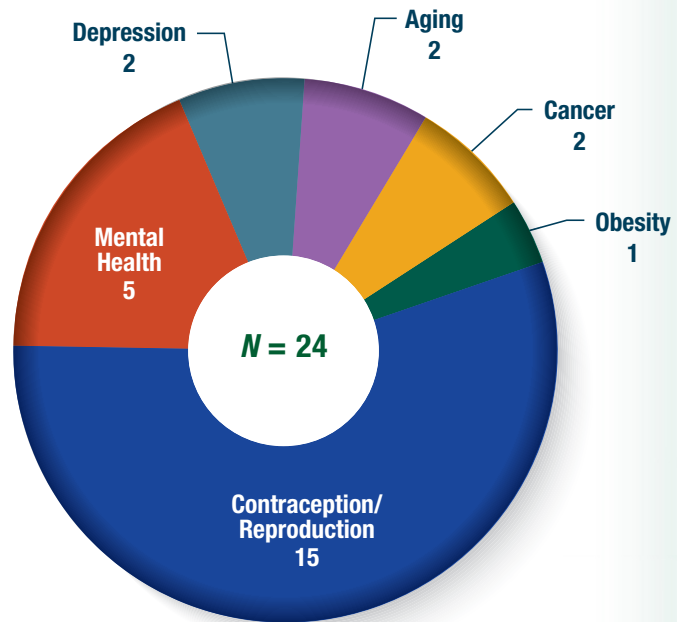
With four intramural projects located on the main campus of NIH and two projects administered by local organizations, Maryland housed a total of six (25.0%) DSD & Intersex projects. Massachusetts was home to three (12.5%); an additional four states had two projects (8.3%) each; and seven states each administered a single project (4.2%).

The map indicates the location of the funded institution and not necessarily where activity on a project took place.



Projects by Disease Area/Health Condition

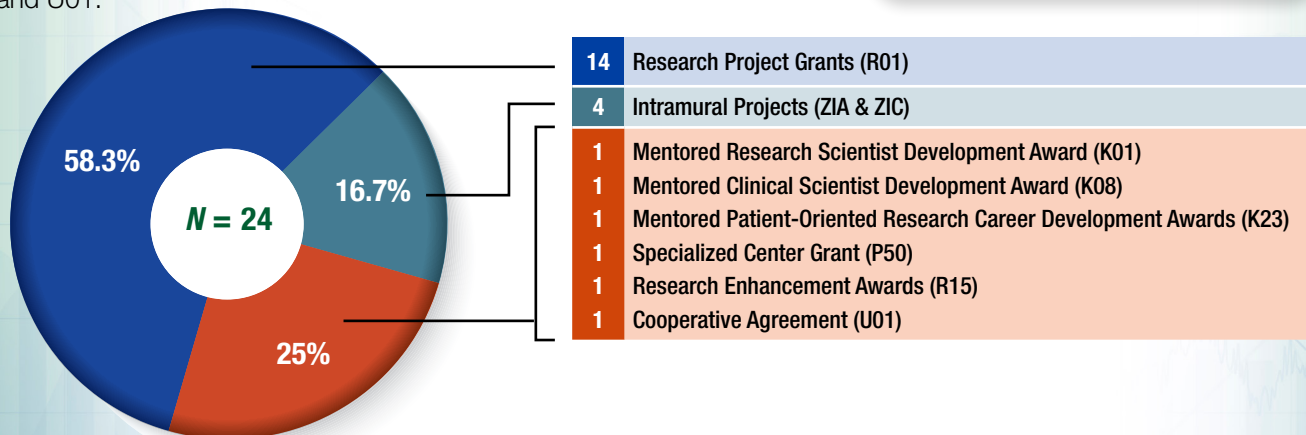
Almost two-thirds (62.5%) of DSD & Intersex projects pertain to Contraception/Reproduction. One in five (20.8%) was related to mental health. These pertained to the impacts of hormones on fetal development, affective disorders, neurodevelopment, and suicide. Other projects were related to aging, cancer, depression, and obesity. Please note that the total number across conditions is greater than 24 because projects may be counted in more than one category.



Projects by Grant Type (Activity Code)

More than half (58.3%) of DSD & Intersex projects were funded through R01 Research Project Grants. More than one in six (16.7%) were NIH intramural projects. The remaining six projects were supported by a variety of six different funding mechanisms: K01, K08, K23, P50, R15, and U01.

More than half of the projects were funded through the R01 mechanism.



Due to changes in the administration of projects from year to year, the number of projects for the Snapshots may differ somewhat from those published in the corresponding FY 2019 Portfolio Analysis.