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Health Equity for People with Intellectual and Developmental Disability Requires Vast Improvements to Data Collection: Lessons from the Covid-19 Pandemic

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Abstract:

The Covid-19 pandemic drastically underscored the lack of proper health surveillance for people with intellectual and developmental disability (IDD) in the US. This data equity failure resulted in researchers having to rely on nontraditional data sources to develop an understanding of how this population was faring during the pandemic. To begin addressing this concern, in this commentary, we: 1) discuss the difficulties in accessing data during the pandemic specifically related to people with IDD; 2) provide guidance regarding how existing data can be used to examine Covid-19 outcomes for people with IDD; and 3) provide recommendations for improving data collection for people with IDD in light of lessons learned during the pandemic. In sum, the data currently available to examine Covid-19 as well as other health outcomes among people with IDD is severely limited, compromising the ability to both understand and address health disparities among this populatio

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19 improving data collection for people with IDD in light of lessons learned during the pandemic. In
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21 people with IDD is severely limited, compromising the ability to both understand and address
22 health disparities among this population.

23 Health Equity for People with Intellectual and Developmental Disability Requires Vast
24 Improvements to Data Collection

25
26 Research on the health and health care of disabled people has frequently been limited by
27 insufficient measures for the identification of disability within US surveys and health records.
28 This is especially the case among people with intellectual and/or developmental disability (IDD),
29 conditions that are typically present at birth or onset early in life, and involve lifelong physical,
30 developmental, learning, language, and/or behavioral impairments.^{1,2} Pre-pandemic, the US
31 public health system failed to engage in adequate health surveillance for people with IDD.^{3,4} This
32 disability data equity failure⁵ – the failure to identify and sometimes even include disabled
33 people in data collection – continued and was pointedly underscored during the Covid-19
34 pandemic.

35
36 As a result of this dearth of nationally representative data, researchers investigating the severity
37 of Covid-19 outcomes among people with IDD during the early part of the pandemic were forced
38 to rely on data from private electronic medical records platforms,⁶ IDD provider agencies,⁷
39 private insurance companies,⁸ and the handful of states who shared data on people receiving
40 services.⁹ Though not the primary topic of this commentary, the dearth of data was equally if not
41 more pronounced for other disabled people.¹⁰ Results from these early studies about people with
42 IDD were startling, consistently reporting higher Covid-19 case rates and case-fatality rates
43 among people with IDD than the general population.

44
45 Several recent commentaries advocate for improving disability data equity – data equity broadly
46 defined as the collection and reporting of data without bias or exclusion – as part of health
47 equity,^{5,11,12} all in some way emphasizing that “who counts depends on who is counted.”¹² The
48 pandemic brought to light the inability to identify disability in general health surveillance, and
49 specifically for people with IDD, due to limitations and inaccessibility of existing data and
50 information. Individuals with IDD are identified through state and federal programs related to
51 services and/or supports, typically receive a high level of medical care, and yet clear information
52 related both to health and disability are not routinely collected. Since people with IDD die at
53 younger ages, experience high rates of death from potentially preventable diseases, are not well

54 understood within the health care system, and have well documented health care access
55 disparities,¹³ an effort to provide health and community living surveillance is in order.

56

57 This commentary will provide a historic overview of Covid-19 data and outcomes for people
58 with IDD from federal, state, and administrative sources. Limitations specific to data access
59 related to Covid-19 outcomes for people with IDD will be identified and guidance provided on
60 how existing data can be used to examine future pandemic outcomes. In closing,
61 recommendations to improve health surveillance of people with IDD in Covid-19 and other
62 public health emergencies will be offered.

63

64 **Missed opportunities**

65 *Federal data*

66 In response to early evidence of more severe Covid-19 outcomes among people with IDD, in
67 October of 2020 the US Senate Committee on Health, Education, Labor and Pensions sent a
68 letter to the Centers for Medicare and Medicaid Services (CMS), Department of Health and
69 Human Services (HHS), “requesting CMS issue guidance for mandatory comprehensive data
70 collection and reporting on congregate care settings to better understand and address the impact
71 of Covid-19 on people with disabilities and older Americans in these settings.”¹⁴ As of the time
72 of the writing of this commentary (July 2023), CMS continues to provide weekly updates of
73 Covid-19 cases, deaths, and vaccination status among nursing homes in the US¹⁵ from the CDC’s
74 National Healthcare Safety Network (NHSN) Long Term Care Facility (LTCF) Covid-19
75 Module.¹⁶ While Intermediate Care Facilities (ICF/IDD) serving individuals with intellectual
76 disability are ‘eligible’ to report Covid-19 data in the NHSN system, reporting is voluntary.¹⁷ To
77 date, neither the CMS nor the CDC website for the NHSN provide any data on ICF/ID or
78 assisted living facilities. As summarized in a July 2021 HHS report, no efforts were made by
79 CMS to establish either a mandatory comprehensive data collection effort, or to ensure
80 standardization of data collection among those states that voluntarily chose to collect Covid-19
81 among people with IDD.¹⁸

82

83 *National surveys*

84 In late April of 2020, the US Census Bureau, in collaboration with other federal agencies, began
85 data collection for the Household Pulse Survey (HPS). The HPS was designed to provide insight
86 into the impact of the pandemic on American households. Cross-sectional data for this survey
87 has been collected in consecutive Waves, with Covid-19 questions for each Wave reflective of
88 the current state of the pandemic (e.g., teleworking, Covid-19 diagnosis, Covid-19 severity,
89 vaccination status, booster status, long Covid-19 diagnosis). As such, the data is ideal for
90 tracking the effect of the pandemic on groups within the American population. Unfortunately,
91 disability measures were not included in the early Waves of the HPS. Four disability questions
92 from the Washington Group-Short Set (WG-SS) questions (hearing, vision, mobility, cognition)
93 were added in the April 14-26, 2021 Wave. Additional WG-SS disability questions (self-care,
94 communication) were added in the June 1-13, 2022 Wave. While exclusion of disability
95 questions in early Waves eliminated the usefulness of the data to examine data points related to
96 spread of Covid-19 and early vaccination status, the post April 14-26, 2021 data are useful for
97 studying differences in pandemic related outcomes between people with/without disability such
98 as access to food and health care.¹⁹

99
100 Two aspects of the WG-SS questions render the HPS data inutile for examining Covid-19
101 outcomes specifically among people with IDD. First, the WG questions rely on broad global
102 measures for disability that do not delineate age at onset or IDD within the six questions.⁴ As an
103 example, the broad cognitive disability measure in the WG questions that may be applicable to
104 many people with IDD (i.e., specifying any limitations/difficulty remembering or concentrating)
105 does not allow differentiation of intellectual disability (alone or as an associated condition with a
106 developmental disability) from other cognitive disabilities such as Traumatic Brain Injuries or
107 Alzheimer's disease and other dementias.^{4,20} In addition, the WG measures do not delineate
108 whether the respondent has difficulty with impairments more common among people with IDD –
109 learning, developmental, behavioral. The WG notes their questions may not identify everyone
110 with a disability; concerns noted here could be reasons that people with IDD may not be reported
111 as having a disability when responding to WG questions. It should be noted that the WG
112 questions were designed to consider disability broadly by function; however, this approach is
113 much less useful for inclusion of people with IDD.

114

115 The National Health Interview Survey (NHIS), designed to provide a nationally representative
116 annual cross-sectional overview of the health and health behavior of the US also uses the WG-SS
117 to measure disability. The 2020 survey added measures for Covid-19 diagnosis, test results, and
118 symptom severity, then vaccination status in the 2021 survey. NHIS data are ideal for comparing
119 Covid-19 outcomes among disabled and nondisabled people in the US. Unfortunately, for the
120 same reasons articulated above in the discussion of the HPS, the NHIS's use of the WG
121 questions eliminates the possibility that this rich dataset can be used to examine Covid-19
122 outcomes among people with IDD. Prior to 2019, the NHIS survey did include a distinct measure
123 for whether an intellectual disability caused limitations among adults in its survey (but not for
124 any other developmental disability conditions such as Down syndrome or cerebral palsy).²¹ This
125 allowed researchers to explore differences in health outcomes among people with and without
126 intellectual disability through 2018 if they did not reside in an institution.²²⁻²⁴ However, as part
127 of the 2019 redesign, the NHIS ceased inclusion of the intellectual disability measure.²¹ Due to
128 this decision, the NHIS data also cannot be used to examine Covid-19 outcomes specifically
129 among people with intellectual disability, or with any other IDD. The limitation of interviewing
130 only respondents who do not live in institutions also eliminates a large group of people with
131 IDD.

132
133 The inclusion of WG disability questions in the NHIS and HPS provide opportunity, albeit
134 limited, for researchers desiring to document Covid-19 outcomes among people with hearing,
135 vision, mobility, cognitive, communication, and self-care disability, all as broadly defined
136 undifferentiated categories or groupings of categories. There are publications that use either data
137 set for this purpose, all focusing on an aspect of socioeconomic or health care access disparities
138 experienced by disabled people during the pandemic,^{19,25-28} and one that documents differences
139 in vaccine uptake among adults with/without a hearing or visual disability.²⁹

140
141 *State data*

142 The July 2021 HHS report about the national response to Covid-19 related to people with IDD
143 stated that of the 28 states queried for the report (no description was provided regarding
144 sampling strategy for this report), 27 were collecting some Covid-19 outcomes data for people
145 with IDD.¹⁸ Among the 27 states that did report data, there was no standardization regarding

146 whether or how Covid-19 outcomes for people with IDD were being reported,¹⁸ with little ability
147 to accurately compare outcomes. The one peer-reviewed study that examined IDD Covid-19
148 case-fatality rates among US jurisdictions through early 2021 reported that only 12 jurisdictions
149 publicly reported data, and also emphasized the lack of standardization in data collection and
150 reporting across states.⁹ As of the time of writing this commentary, no jurisdictions currently
151 publicly share updated Covid-19 outcomes data for people with IDD receiving services within
152 the state, though a few such as Arizona, New York, and Washington DC still have historic data
153 posted on IDD and/or Covid-19 related state websites. Among US states that reported Covid-19
154 outcomes, it appears that data related to people with IDD were the only Covid-19 disability data
155 that was reported.

156

157 **Potential opportunities**

158 *Death certificates*

159 Death certificate data – provided by the National Vital Statistics System (NVSS) – are crucial in
160 understanding the mortality burden of a disease – the number and percentage of deaths from a
161 specific disease. This data depends on health care clinicians using International Classification of
162 Diseases, Tenth Revision (ICD-10) codes to accurately identify all health care
163 encounters/procedures by diagnosis and/or symptoms for billing and claims processing. The
164 importance of this data became increasingly apparent during the pandemic, with analysis from
165 the CDC and researchers reporting that Covid-19 was the third leading cause of death in the US
166 in 2020 and 2021.^{30,31} One study used 2020 US death certificate data to determine whether the
167 Covid-19 mortality burden was similar or different for people with IDD during the first year of
168 the pandemic. Results demonstrated distinct difference in Covid-19 mortality burden between
169 adults with/without IDD. Whereas Covid-19 was the 3rd leading cause of death among people
170 without IDD, it was the leading cause of death among people with intellectual disability, cerebral
171 palsy, and Down syndrome, considered as distinct conditions.³²

172

173 The persistent challenge with death certificate data pre-pandemic and during the first year of the
174 pandemic was that it was not publicly available until 11 months after the close of the calendar
175 year. For example, the 2020 data was not publicly available until December 2021. This resulted
176 in analysis of mortality burden, a data point essential for understanding Covid-19 patterns, being

177 one year behind real time. Fortunately, the CDC addressed this time lag during the pandemic,
178 and as of December 7, 2021, began posting provisional death certificate data through the
179 previous month on its CDC Wonder website. While this allows researchers, public health
180 officials, and the general public to track Covid-19 mortality burden through the previous month,
181 the provisional data provided is not accurate for people with IDD.

182

183 This inaccuracy relates to the CDC allowing,³³ and in some instances instructing,³⁴ postmortem
184 diagnostic overshadowing – the reporting of IDD as the underlying cause of death. The
185 underlying cause of death is intended to be the disease or injury that started the chain of events
186 leading to death. IDD is a disability, not a disease or injury, and it should not be reported as the
187 underlying cause of death. Doing so ‘obscures’ the actual disease mortality burden among people
188 with IDD.³⁵ Due to this data inequity, revision of death certificates with postmortem diagnostic
189 overshadowing is required,³⁵ and cannot be completed with the provisional death certificate data
190 provided on the CDC Wonder site, but can only be completed once the final data is released 11
191 months after the end of the calendar year.

192

193 *Administrative data*

194 Administrative data refers to information collected during health care encounters, generated for
195 administrative and billing purposes, composed of demographics, descriptive encounter codes,
196 ICD-10 and billing codes, pharmacy data, and hospital/care site data. Data may be from single
197 hospitals/practices or hospital systems, allowing assessment across payers. Data from
198 private/public insurance plans may span large populations, although payer source will be
199 focused. Disability conditions can be identified through ICD-10 codes, assuming accuracy in
200 recognition or diagnosis by clinicians. A diagnostic code may be useful to classify underlying
201 etiologies for disability, where there may be common comorbidities to consider from a medical
202 management perspective. However, level of care need is less clear, especially when considering
203 housing, social participation, or use of community support services. There is the ability to tap
204 into rich clinical information from electronic health records (EHRs), however data extraction can
205 be complex and time consuming.

206

207 Administrative data has been used to explore the health effects of the pandemic on people with
208 disability, including IDD. Using a federated network of electronic health records from 42 health
209 care organizations internationally, people with IDD were found to be at high risk for severe
210 outcomes.⁶ Data from 900 hospitals in the US further identified those with IDD who were
211 hospitalized had higher risk for severe outcomes, 30-day readmission, and longer lengths of
212 stay.³⁶ A cross-disability study, including those with IDD, used discharge destination data in
213 EHRs from 866 hospitals, reported people with IDD or a mobility impairment were over twice as
214 likely to be discharged to a skilled nursing facility and people with IDD were over twice as likely
215 to be discharged to a long term care facility than those without disabilities.³⁷ In all three studies,
216 the number of cases identified with IDD through ICD-10 codes was comparatively much smaller
217 than those without IDD. Without details about previous living situation, understanding choices
218 for discharge destination is unclear. Also, the databases do not represent the general population,
219 but rather those receiving care within the organizations; interpretations must be made with
220 caution.

221

222 **Recommendations**

223 This commentary has focused on the paucity of useful and accurate data available to further
224 understand the high case rates and case-fatality rates for people with IDD related to the
225 pandemic. The critical missed opportunities through CMS, HPS, NHIS, and state data, and
226 potential opportunities that existed during the pandemic and still exist with NVSS, and
227 administrative data that researchers have used to attempt to piece together the puzzle of health
228 outcomes for people with IDD have all been described. To further assure health opportunities for
229 people with IDD, we, as researchers who struggled with limited and at times less accurate data
230 sources, offer the recommendations below.

231

232 *National data*

233 **1. Organize an integrated national emergency preparedness plan with enhanced** 234 **surveillance and data collection about disabled people and other vulnerable groups.**

235 The Covid-19 pandemic demonstrated the inability of federal and state systems to recognize the
236 most vulnerable in the country, identify any risk differences compared to the general population,
237 and prioritize support. Retrospective studies have brought more clarity, and this commentary has

238 provided a historic account of how researchers attempted to address the paucity of data. As an
239 aside, while it is not possible to determine how many IDD providers submitted Covid-19 data to
240 CMS, and it is estimated that only 7.1% of people with IDD receiving long term care supports
241 and services reside in an ICF/IDD,³⁸ sharing the available data could be useful to provide more
242 insight into outcomes among this population during the pandemic, even at this late date.
243 However, more important is having an integrated approach to address the present data gaps.
244 There has been some interest at the federal level to address these inequities, although progress
245 has been slow. Documented exploratory efforts underway are those through the Administration
246 for Community Living³⁹ and the Office of the Assistant Secretary for Planning and Evaluation.²⁰

247

248 **2. Review and restructure disability-related items on national surveys.**

249 Related to national surveys such as the HPS and NHIS, our recommendation is to continue to
250 collect data on disability, but reevaluate the adequacy of the WG-SS or Extended Set (WG-ES)
251 questions for this task. The WG questions are broadly based on function, but do not allow for a
252 level of specificity which can be helpful in analysis. Age of onset, length of time living with a
253 disability, or the progressive nature of the underlying condition all may impact outcomes in
254 different ways and are examples of information that may be important to separate groups for
255 comparisons. More specific to Covid-19 outcomes, adding a timing of disability onset question
256 would allow investigators to differentiate long Covid-19 outcomes between those who were
257 disabled prior to the pandemic and those who acquired disability from this disease. Though the
258 WG questions do not aim to measure specific disabilities, we believe that adding specific
259 questions reporting IDD is necessary and would be ideal to enhance our knowledge about
260 outcomes for people with IDD.

261

262 **3. Revisit and change the CDC guidance related to completion of Death Certificates.**

263 CDC guidance now permits postmortem diagnostic overshadowing on US death certificates by
264 allowing and in some case promoting use of the IDD-specific ICD-10 code as the underlying
265 cause of death.³³ As has been argued regarding other data collection interfaces, presence of a
266 disability should be reported as a demographic characteristic.¹¹ For US death certificates, it
267 would be ideal to include a yes/no question in the demographic section regarding presence of
268 disability, with instruction for the medical personnel certifying the death certificate to report the

269 ICD-10 code for the specific disability conditions in Part II of the death certificate, the section
270 that reports other diseases and conditions present at the time of death not necessarily implicated
271 in the chain of events leading to death. This change would increase the accuracy of death
272 certificate data for people with IDD, and expand available mortality data for this population to
273 include preliminary death certificate reporting.

274

275 *Administrative data*

276 **4. Encourage use of administrative databases.**

277 There is more opportunity to examine Covid-19 outcomes among people with IDD in private
278 administrative databases such as TriNetX or the Covid-19 Research Database, and public
279 administrative data such as Healthcare Costs & Utilization Project (HCUP) data, All Payer
280 Claims Data (APCD), and the newly available Transformed Medicaid Statistical Information
281 System (T-MSIS). ICD-10 codes can be used to identify various IDD conditions (intellectual
282 disability, cerebral palsy, Down syndrome) in these records, which allows comparison of Covid-
283 19 outcomes (cases, hospitalizations, interventions, deaths) between people with/without IDD.
284 To date, studies using this type of administrative data have been limited, often devoted to an
285 epoch at the beginning of the pandemic and/or not differentiating outcomes by IDD condition.
286 Future studies examining outcomes across the full period of the pandemic and differentiated by
287 IDD condition (e.g., intellectual disability, Down syndrome, cerebral palsy, autism) would
288 provide much needed information on the impact of Covid-19 on this population.

289

290 **5. Support considerations of EHR required elements.**

291 While the administrative data available for the period of the Covid-19 pandemic is useful, there
292 are some improvements that could be made to this data to improve its effectiveness going
293 forward. The reporting of a diagnostic code from EHRs may be sufficient for some analysis,
294 however additional information about the level of impairment and/or functional limitation would
295 be helpful to better understand the effects of this pandemic or future health concerns. There are
296 three concepts with accompanying recommendations: 1) The ACS or WG questions, in
297 association with the ICD-10 codes, may offer more details about the disability,¹¹ but may not
298 provide enough differentiation of the support needs of people with IDD. Reporting limitations
299 based on intellectual functioning and adaptive behavior, required for diagnosis and identified

300 through specific ICD-10 codes would allow the ability to differentiate care needs by level of
301 impairment. 2) As instituted by the University of Michigan,⁴⁰ a patient completed form that
302 identifies the need for and type of accommodation provides more details for the medical visit
303 accommodations. Having this as a required patient completion tab in all EHRs could be used not
304 only for accessibility in office visits and other healthcare encounters, but also for in-depth data
305 analysis. 3) Questions related to living situation (e.g., home, congregate setting, skilled nursing
306 facility) or social determinant of health (SDoH) could assist in management options or discharge
307 planning, and possibly be useful for data analysis. Housing instability is typically collected with
308 SDoH tools and type of living setting would be of more interest for people with IDD. While
309 there are examples of SDoH tools that collect information about housing instability, none collect
310 information about type of living situation.⁴¹⁻⁴³ To date, the utility of these patient-directed
311 questions has not been established. Clinicians may also be burdened with entering the
312 information for some tools. However, the concept of collecting SDoH information from those
313 living in the community could be helpful. Item 2 would seem to be the easiest to implement at
314 local levels. Item 1 would require a national agenda or federal mandate. Usefulness of the SDoH
315 tools in their present iterations, item 3, is not clear. Items 1 and 3 likely increase clinicians'
316 cumulative EHR responsibilities, and without incentives. The burden of EHR documentation
317 should be considered in choice of additions. However, any of these options could enhance the
318 ability to better clarify the health and health care needs of people with IDD.

319

320 **Conclusion**

321 The aim of this Commentary was to identify gaps and limitations in Covid-19 data, and
322 potentially other pandemic or emergency situations, for people with IDD. Data are essential to
323 monitor the health of all populations, including people with IDD. Without modifications to
324 national, state, and local data collection, the IDD data equity failure that occurred prior to and
325 during the pandemic will continue. If continued, the IDD data equity failure will limit the
326 amount of meaningful data available for research on health outcomes, and thereby, limit the
327 information needed to design and implement public health interventions aimed at improving the
328 health for this population.

329

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