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Autistic Self Advocacy Network Re: USCIS-2021-0013, "Public Charge Ground of Inadmissibility"

The Autistic Self Advocacy Network (ASAN) appreciates the opportunity to provide comments to DHS on their proposed rule on how they will determine whether or not an immigrant is "likely at any time," under Section 212(a)(4) of the Immigration and Nationality Act (INA), to become a public charge.[1] ASAN strongly supports the Department of Homeland Security (DHS)'s intent to craft public charge regulations that do not discriminate against immigrants with disabilities to the extent possible under the law and therefore provides recommendations.

ASAN is the nation's largest nonprofit disability advocacy organization run by and for autistic people. We seek to advance equal opportunity, access, and rights for all people with intellectual and developmental disabilities (IDD), including immigrants with disabilities.[2] ASAN has long been invested in ensuring that the public charge rule is applied fairly and without discrimination towards people with disabilities. This is because the public charge rule arose from an ableist, racist, and eugenicist law enacted in 1880 and could be used to exclude many immigrants with disabilities from the United States.[3] ASAN commented on

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[1] Public Charge Ground of Inadmissibility, 87 Fed. Reg. 10570, 10570 (Feb. 24, 2022)(to be codified at 8 C.F.R § 212, 8 C.F.R §245).
[2] *About,* Autistic Self Advocacy Network, https://autisticadvocacy.org/about-asan/ (last visited Apr. 6, 2022).
[3] *See* Cori Alonso-Yoder, *Publicly Charged: A Critical Examination of Immigrant Public Benefit Restrictions*, 97 Denv. L. Rev. 1, 7-8, 13-19, 20-21 (2020), *available at* https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3429368&dgcid=ejournal_htmlemail_urban:transnational:anthropology:ejournal_abstractlink (describing the historical, political, and legal context of the public charge rule's development at various times, and its basis in racist and ableist anti-immigrant sentiment).

the 2019 Final Rule when it was still an NPRM, objected to the finalization of the 2019 rule when it was released, and provided information for the new DHS' Advance Notice of Proposed Rulemaking (ANPRM) released in August 2021.[4]

ASAN appreciates DHS' efforts, in its rule discussion, to clarify how U.S. Citizenship and Immigration Services (USCIS) adjudicators can use the proposed regulations in a nondiscriminatory manner, for example, by recognizing during their determination that an immigrant's past history of long-term institutionalization might violate federal law.[5] ASAN's current comments therefore focus on aspects of the proposed rule that may nonetheless have a potential negative impact on people with disabilities with the highest need for long term services and supports and other services.

ASAN recommends that DHS either not consider public benefits or make significant alterations to its proposed rule that reduce its potential impact on Supplemental Security Income (SSI) recipients with disabilities and other recipients of "direct cash assistance for income maintenance" as defined in this rule.

ASAN primarily recommends that USCIS not consider past or present receipt of public benefits as relevant to the public charge determination. ASAN will discuss specific problems with including long-term institutionalization at government expense in a later section and will focus on the inclusion of Supplemental Security Income (SSI) and other direct cash benefits in this section.

ASAN recommends excluding direct cash benefits from consideration (especially as a part of the required "assets, resources, and financial status" factor or the "health" factor) because use of any public benefit would harm people with disabilities who depend upon direct cash assistance to remain eligible for the services they need to survive. There is no explicit legal requirement to include public benefits. Section 212(a)(4) of the INA does not require the consideration of benefits; the law instead requires only that USCIS consider five mandatory factors and any affidavit of support submitted under U.S.C. §1182(a)(4)(B)(ii).[6]

ASAN appreciates DHS' effort to reduce the proposed rule's impact on these services by removing Medicaid-funded home and community-based services (HCBS), as well as

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[4] *ASAN Comments on Proposed Public Charge Rule,* Autistic Self Advocacy Network (Dec. 11, 2018), https://autisticadvocacy.org/2018/12/asan-comments-on-proposed-public-charge-rule/; *ASAN Condemns Finalization of the "Public Charge" Rule,* Autistic Self Advocacy Network (Aug. 13, 2019), https://autisticadvocacy.org/2019/08/asan-condemns-finalization-of-the-public-charge-rule/; *ASAN Comments on Public Charge ANPRM,* Autistic Self Advocacy Network (Oct. 26, 2021), https://autisticadvocacy.org/2021/10/asan-comments-on-public-charge-anprm/.

[5] 87 Fed. Reg. at 10614.

[6] 8 U.S.C. § 1182(a)(4)(B)(i)(2022); 8 U.S.C. § 1182(a)(4)(B)(ii)(2022).

Medicaid generally, from consideration.[7] Nonetheless, by including SSI in particular, DHS is indirectly bringing the receipt of Medicaid-funded long term services and supports (LTSS) back into the public charge determination - even when they are supports delivered in the community.

Medicaid, as DHS is aware, funds the vast majority of HCBS provided and is the primary payer for LTSS.[8] In order to maintain eligibility for Medicaid, a person must meet specific, stringent asset and income limits. While states are permitted some flexibility in setting slightly higher income limits for individuals receiving HCBS, no state permits individuals receiving HCBS to earn more than 300% of SSI, which was 222 percent of the federal poverty limit in 2021.[9] It is well-documented that individuals receiving Medicaid HCBS are required to impoverish themselves in order to receive such services.[10] Additionally, asset limits for SSI are nearly always only $2,000, which is lower than some state income limits for HCBS. This means that for most people receiving Medicaid-funded services receipt of SSI is effectively *required* in order to maintain access to their services.

While it is possible for beneficiaries who do not receive SSI and work full-time to remain on Medicaid and receive HCBS via Medicaid Buy In Programs,[11] these programs have extremely limited uptake due to the complex eligibility requirements which are not easily navigated by all people with disabilities. Many people with disabilities may not qualify for their state's program, as eligibility requirements vary from state to state. Some states do not offer Medicaid buy-in programs at all. The practical effect of these limitations is that most people with disabilities who rely on Medicaid-funded HCBS must also rely on SSI and other cash assistance programs. Therefore, ASAN urges that receipt of these programs be

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[7] *Id.*

[8] 87 Fed. Reg. at 10614; Molly O'Malley Watts, MaryBeth Musumeci and Priya Chidambaram, *Medicaid Home and Community-Based Services Enrollment and Spending,* Kaiser Family Foundation (Feb. 4, 2020), https://www.kff.org/medicaid/issue-brief/medicaid-home-and-community-based-services-enrollment-and-spending/.

[9] MaryBeth Musumeci, Priya Chidambaram, and Molly O'Malley Watts, *Medicaid Financial Eligibility for Seniors and People with Disabilities: Findings from a 50-State Survey,* Kaiser Family Foundation (Jun. 14, 2019), https://www.kff.org/report-section/medicaid-financial-eligibility-for-seniors-and-people-with-disabilities-findings-from-a-50-state-survey-issue-brief/; Medicaid and CHIP Payment and Access Commission (MACPAC), Exhibit 37, Medicaid Income Eligibility Levels as a Percentage of the Federal Poverty Level for Individuals Age 65 and Older and Persons with Disabilities by State, *available at* https://www.macpac.gov/wp-content/uploads/2015/01/EXHIBIT-37.-Medicaid-Income-Eligibility-Levels-as-a-Percentage-of-the-Federal-Poverty-Level-for-Individuals-Age-65-and-Older-and-Persons-with-Disabilities-by-State-2021.pdf (last updated 2021).

[10] *See, e.g.,* Am. Council on Aging, *Delaware Medicaid (Diamond State Health Plan) Eligibility for Long Term Care: Income & Asset Limits,* https://www.medicaidplanningassistance.org/medicaid-eligibility-delaware/ (last updated Jan. 31, 2022).

[11] Administration for Community Living and Office of Disability Employment Policy, Grant #OD-23863-12-75-4-11, Medicaid "Buy-in" Q&A 1 (2019), *available at* https://www.medicaid.gov/sites/default/files/2019-12/medicaid-buy-in-qa.pdf.

removed from consideration, as to do otherwise would inevitably discriminate against people with disabilities who require HCBS.

To the extent that DHS decides that it will instead continue to count "direct cash assistance" benefits, ASAN proposes that individuals with disabilities who specifically use SSI or another public benefit *because they are individuals with disabilities,* as contemplated above, be excluded when DHS considers receipt of public benefits. ASAN does not believe that the class of people who receive public benefits for this reason should be deemed more likely to become a public charge solely because they need services to live.

ASAN does not consider this a perfect solution, as eligible immigrants with disabilities who are not found eligible for these benefits on the basis of their disability or who do not identify as having a disability may still be judged negatively due to their receipt of benefits on another basis. For example, individuals with disabilities who receive Temporary Assistance for Needy Families (TANF) benefits are receiving them because they qualify for reasons other than disability. Nonetheless, ASAN provides this recommendation because it is an improvement over considering these benefits without reference to their purpose in an individual's life.

While ASAN is aware that the receipt of public benefits would only be one factor that USCIS considers when determining whether an immigrant is likely to become a public charge, and that no factors by default would be weighted positively or negatively, USCIS decision-makers are still likely to consider the receipt of public benefits negatively.[12] Additionally, USCIS personnel may have high caseloads, and the adjudications will be performed using paperwork as evidence. Therefore, we believe it is quite likely that adjudicators may consider the receipt of public benefits in a vacuum or without determining the relationship between one public benefit and another.

Eliminating the consideration of public benefits in individual public charge determinations, would benefit the many immigrants with disabilities who rely upon these programs. We recommend instead that USCIS limit the discussion to an immigrant's financial circumstances sans their receipt of public benefits, as is required by law. In situations where the immigrant's only income is public benefits, we recommend that this be recorded neutrally without reference to specific benefits (such as by stating that the immigrant does not earn income and having this fact, rather than the individual benefits, be considered relevant to the determination).

[12] 87 Fed. Reg. at 10620 ("DHS will consider the current and/or past receipt of these benefits in the totality of the noncitizen's circumstances…"); 87 Fed Reg at 10622.

ASAN opposes the inclusion of "long-term institutionalization at government expense" among public benefits which are counted for the purposes of determining whether, under a totality of the circumstances test, an immigrant is likely to become a public charge.[13]

While ASAN appreciates DHS' efforts to minimize the impact of the inclusion of this factor on immigrants with disabilities and to specifically promote the use of HCBS, the Proposed Rule nonetheless fails to adequately consider the circumstances surrounding most long-term institutionalization, in the United States and elsewhere.[14]

The vast majority of people currently receiving services in an institution do not actually want to be in an institution. They are there because it is the only location that is required to provide them with the LTSS they need to survive. Medicaid-funded HCBS are typically paid for as optional benefits neither mandatory or available to all people.[15] The services offered may be critical supports that ensure the beneficiary's survival or long-term health in the community, such as personal care services, assistance with activities of daily living, and mental health services.[16] Nonetheless state Medicaid programs are allowed to place limits on the number of people who can access some of these critical services- specifically services offered under Medicaid waivers.[17] As a result, hundreds of thousands of people with disabilities have been waiting for years, on state waiting lists that can be tens of thousands of people long, to access the community-based, long term services and supports they need to live full, self-determined lives.[18] While waiting, because these individuals must

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[13] 87 Fed Reg. 10613.

[14] 87 Fed Reg. at 10614.

[15] Some individuals can receive HCBS, if eligible, as State Plan HCBS services rather than optional waiver services, but these are services provided because the state agreed (as a state option) to provide them to all eligible enrollees, rather than because the state is required to provide them. *Assessing the Health and Welfare of the HCBS Population: Availability and Use of State Medicaid HCBS,* Agency for Healthcare Research and Quality, https://www.ahrq.gov/patient-safety/settings/long-term-care/resource/hcbs/findings/find3.html (last updated Dec. 2012); *Home & Community-Based Services 1915(c),* Centers for Medicare and Medicaid Services, https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html (last visited April 14, 2022); Molly O'Malley Watts, MaryBeth Musumeci,, and Meghana Ammula, *Medicaid Home & Community-Based Services: People Served and Spending During COVID-19,* Kaiser Family Foundation (Mar. 4, 2022), https://www.kff.org/report-section/medicaid-home-community-based-services-people-served-and-spending-during-covid-19-issue-brief/.

[16] Molly O'Malley Watts, MaryBeth Musumeci,, and Meghana Ammula, *Medicaid Home & Community-Based Services: People Served and Spending During COVID-19,* Kaiser Family Foundation (Mar. 4, 2022), https://www.kff.org/report-section/medicaid-home-community-based-services-people-served-and-spending-during-covid-19-issue-brief/.

[17] *Home & Community-Based Services 1915(c),* Centers for Medicare and Medicaid Services, https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c/index.html (last visited April 14, 2022).

[18] *See, e.g.,* Rebecca Tan, *She's desperate to get home care for her mom. In Maryland, 21,000 are on the wait list,* Wash. Post (Oct. 9, 2021, 6:47PM), https://www.washingtonpost.com/local/maryland-covid-medicaid-

still receive care, their only options are to pay out of pocket for these services (an unaffordable choice for most people with disabilities) , to rely on considerable and often unsustainable unpaid support from their families, or institutionalization. Unless Medicaid-funded HCBS is made a mandatory benefit, there will therefore always be institutionalized people with disabilities who *want* to receive HCBS rather than institutional services but cannot get it. The same is just as true of immigrants with disabilities newly entering the country with a past history of institutionalization. It is very unlikely that *all* or even *most* of those in institutions in foreign countries were there of their own will, and not because they could not otherwise receive care. In short, if the proposed rule continues to count past or present long-term institutionalization at government expense, and public benefits are at all considered in a negative fashion by decision-makers at USCIS, people with disabilities' need for LTSS will continue to be counted against them in a discriminatory manner, even though receipt of HCBS is excluded.

Although we acknowledge and appreciate that DHS attempts to account for these problems by requiring adjudicators to consider whether a person's past or present institutionalization would violate federal law, this provision also does not reflect the true circumstances of institutionalized people and incorrectly assumes there are cases in which institutionalization is ever required.[19] ASAN firmly believes that there is no reason any person with a disability needs to be institutionalized. Well-substantiated research evidence exists showing that even those with the highest support needs and the most significant disabilities, including cognitive and intellectual disabilities, can live in the community when the supports and services they need are provided there, and that we all benefit from living in the community.[20]

Given this, there is never a situation in which institutionalization is the "most integrated setting appropriate," and therefore *all* institutionalization at government expense, in our view, would violate the Americans with Disabilities Act's integration mandate as required by Olmstead v. L.C, and thus federal law.[21] Additionally, because the overwhelming

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waitlist/2021/10/07/37dfc41e-2214-11ec-b3d6-8cdebe60d3e2_story.html; Kaitlyn Jasper, *Thousands of Disabled Oklahomans Stuck on Medicaid Waiting List,* Oklahoma Council of Public Affairs (May 9, 2019), https://www.ocpathink.org/post/thousands-of-disabled-oklahomans-stuck-on-medicaid-waiting-list.

[19] 87 Fed. Reg. at 10614.

[20] Am. Assoc. on Intellectual and Developmental Disabilities and Assoc. of University Ctrs. on Disability, *Community Living and Participation for People with Intellectual and Developmental Disabilities,* American Association on Intellectual and Developmental Disabilities (Jun. 2016), https://www.aaidd.org/news-policy/policy/position-statements/community-living-and-participation; Nat'l Council on Disability, Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community (2015), *available at* https://ncd.gov/publications/2015/02242015.

majority of institutionalization occurs only because the person cannot obtain LTSS in any other way, *present-day* institutionalization has bearing on the likelihood of future institutionalization. USCIS decision-makers that predict institutionalization into the future for a currently institutionalized person would be incorrectly assuming that the institution is a proper placement and not a violation of federal law when, in fact, these individuals can and should be receiving HCBS. ASAN can in fact think of only one situation in which such institutionalization would not violate federal law- the rare circumstance where it is directly chosen by the person with a disability. These rare instances are not frequent enough to support the idea that an institution is sometimes "the most integrated setting appropriate," particularly as this information pertains to immigrants, who may have experienced institutionalization outside the United States under very different circumstances. For all of the reasons listed above, ASAN recommends that DHS not consider long-term institutionalization at all.

Although we believe that the institutionalization provision above conflicts with this commitment, ASAN appreciates DHS' provision requiring that disability alone not be considered to make someone more likely to become a public charge.[22] ASAN recommends, when adjudicators are weighing the "health" factor, that aspects of health other than social determinants of health (and viewed only in a positive manner) on overall wellness (which should be considered without reference to disability to the extent possible) be rendered irrelevant to the "health" factor.

ASAN proposes the framing above for the "health" factor out of its understanding that DHS wants to avoid considering disability alone as influencing the likelihood of an immigrant being determined "likely to become a public charge."[23] Nearly all chronic, long-term health conditions (including HIV, cancer, and other conditions) are considered disabilities, both under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act, because they "substantially limit one or more major life activities.[24] This limits the number of ways that DHS can view the "health" factor that would not involve the consideration of disability. Additionally, even if all disabilities are not considered relevant by themselves to the public charge determination, their presence or absence may nonetheless inform how decision-makers evaluate the "health" factor, due to all aspects of the immigrant's profile

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[21] *See Olmstead v. L. C. by Zimring*, 527 U.S. 581, 595, 606 (1999) (finding that Title II of the ADA required the placement of individuals in community-based settings if they were the most integrated setting appropriate to their needs). The definition of what would be considered the "most integrated setting appropriate" has developed since *Olmstead,* for the reasons outlined above.
[22] 87 Fed. Reg. at 10669 ("Disability alone not sufficient").
[23] *Id.*
[24] 42 U.S.C. § 12102(1)(A); 29 U.S.C. § 705(9)(B).

being evaluated within the "totality of the circumstances."[25]ASAN proposes instead that inequities in the health services available to different groups of immigrants, either in their own country or otherwise, be considered social determinants of health[26] *reducing* the likelihood of someone being found inadmissible on public charge grounds. This will help reduce any disparate impact racism and ableism present in the public charge determination.

A policy is said to have a "disparate impact" when a facially neutral policy (i.e. a policy that does not intentionally discriminate) nonetheless has a disproportionate impact on a protected group and thus produces discriminatory results. The current proposed rule would have just such an impact if decision-makers evaluated the "health" factor without considering the health disparities faced by people of color in many countries. For example, Black people are more likely to have disabilities and BIPOC are more likely to have chronic health conditions than non-Hispanic whites in the United States.[27] BIPOC also tend to receive poorer health care in the U.S. and get the worst illnesses more frequently, which would impact the "health" factor even if disability were not considered at all.[28] The COVID-19 pandemic's unusually high impact on BIPOC communities in the U.S. is a particularly salient example of how social determinants of health can impact and worsen the health of those at a systemic disadvantage.[29] Therefore, if immigrants of color experienced health disparities of any kind, either in the United States or abroad, a failure to take these disparities into account would bias the health factor's evaluation against these immigrants. Our proposal would help adjudicators avoid these disparate impacts and fairly evaluate the health of immigrants of color.

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[25] 87 Fed. Reg. at 10699 ("The determination of an alien's likelihood of becoming a public charge at any time in the future must be based on the totality of the alien's circumstances…").

[26] For more information on the social determinants of health, reference U.S. Dep't Health Hmn. Servs., *Healthy People 2030: Social Determinants of Health,* https://health.gov/healthypeople/priority-areas/social-determinants-health (last visited Apr. 14, 2022).

[27] Nanette Goodman, Michael Morris, and Kelvin Boston, Financial Inequality: Disability, Race and Poverty in America 5 (2019), *available at* https://www.nationaldisabilityinstitute.org/wp-content/uploads/2019/02/disability-race-poverty-in-america.pdf ("Fourteen percent of working-age African Americans have a disability compared with 11 percent of Non-Hispanic Whites and eight percent of Latinos (Figure 2). In fact, African Americans are more likely than Non-Hispanic Whites to have a disability in every age group…"); James H. Price, Jagdish Khubchandani, Molly McKinney, and Robert Braun, *Racial/Ethnic Disparities in Chronic Diseases of Youths and Access to Health Care in the United States,* BioMed Research International, Sept. 2013, at 1 ("Racial/ethnic minorities are 1.5 to 2.0 times more likely than whites to have most of the major chronic diseases…").

[28] *See, e.g.* Heidi Ledford, *Millions of black people affected by racial bias in health-care algorithms*, Nature (Oct. 24, 2019), https://www.nature.com/articles/d41586-019-03228-6.

[29] Samantha Artiga, Rachel Garfield, and Kendal Orgera, *Communities of Color at Higher Risk for Health and Economic Challenges due to COVID-19,* Kaiser Family Foundation (Apr. 7, 2020), https://www.kff.org/coronavirus-covid-19/issue-brief/communities-of-color-at-higher-risk-for-health-and-economic-challenges-due-to-covid-19/.

ASAN recommends, when issuing written denial decisions to applicants, that all decisions describing the impact of each of the statutory minimum factors be written in plain language or Easy Read format.

ASAN appreciates DHS' intent to clarify and make its decision-making process transparent to prospective immigrants by providing them with a written list of the reasons behind any denial decision made by USCIS.[30] If DHS plans to do so, ASAN proposes that DHS create versions of these decisions in a manner that can be read by immigrants with significant cognitive disabilities. Immigrants, just like all other people, have people among them with intellectual disabilities and other mental disabilities. Helping these immigrants understand the documents they have received will improve the immigration process' accessibility, including for people who do not speak English well or do not read English at as high a level as they speak it, which may be the case for some immigrants.

ASAN recommends that DHS' materials aim for a third grade reading level or below, and at a sixth grade reading level if this is not possible. Ideally, versions of each document DHS sends immigrants should be rendered into an Easy Read format. Pictographic comprehension aids known as icons, large print text, bulleted lists, conveying only a single idea per sentence, defining important concepts within the text or in a definitions page, and using easy-to-read text are all aspects of Easy Read that make a document more accessible. ASAN's resource "One Idea Per Line: A Guide to Making Easy Read Resources" explains general ways of making Easy Read documents.[31] Plain language may be an additional option.[32] We recommend that DHS consider converting the decisions into both plain language and Easy Read.

If DHS decides to consider public benefits at all, ASAN recommends that "government" be defined to encompass only federal and not state-level benefits.[33]

While we reiterate our recommendation to remove consideration of all public benefits, should public benefits be continued to be considered, ASAN offers this recommendation to minimize the number of immigrants impacted by the public charge rule. Under some circumstances, immigrants may be eligible for state-level benefits, and rely on them, even

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[30] 87 Fed. Reg. at 10699 ("Every written denial decision issued by USCIS based on the totality of the circumstances set forth in paragraph (b) of this section will… specifically articulate the reasons for the officer's determination").

[31] Autistic Self Advocacy Network, One Idea Per Line: A Guide To Making Easy Read Resources (2021), *available at* https://autisticadvocacy.org/wp-content/uploads/2021/07/One-Idea-Per-Line.pdf.

[32] *Id.* at 24-25.

[33] 87 Fed. Reg. at 10616 ("DHS welcomes public comments on whether DHS should define government in this rule and, if so, whether it should be limited to Federal, State, Tribal, territorial, and local entities, and why or why not").

when they are not yet eligible for federal benefits. We want to encourage immigrants to receive the maximum possible services and supports that a state has chosen to make available, without fear of jeopardizing their status.

ASAN thanks DHS once again for the opportunity to comment on its proposed rule and to help ensure that the "public charge" determination is as minimally discriminatory and inequitable for as long as it continues to exist. For more information on ASAN's positions on public charge, please contact Kelly Israel, our Policy Analyst, at kisrael@autisticadvocacy.org.