

# September 28, 2018

## By email and certified mail

Roger Severino Director, Office of Civil Rights U.S. Department of Health and Human Services 200 Independence Avenue, SW Room 509F, HHH Building Washington, D.C. 20201 OCRMail@hhs.gov

Centralized Case Management Operations U.S. Department of Health and Human Services 200 Independence Avenue, S.W. Room 509F HHH Bldg. Washington, D.C. 20201 OCRComplaint@hhs.gov

Daria Neal Deputy Chief, Federal Coordination and Compliance Section Civil Rights Division U.S. Department of Justice 950 Pennsylvania Avenue, N.W. Washington, DC 20530 Daria.neal@usdoj.gov

> Complaint Under Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000d, 45 Re: C.F.R. Part 80

Dear Director Severino and Deputy Chief Neal,

For decades, the black residents of rural Lowndes County, Alabama have suffered disproportionately from inadequate access to basic sanitation. The inadequate and failing sewage treatment systems release raw sewage, which contaminates local water bodies, pools in back yards, and exposes residents to diseases such as the recent nineteen confirmed cases of hookworm in the county. The Alabama Department of Public Health ("ADPH") has known about the problem of inadequate sanitation for years. Yet, the agency has failed to protect residents from this grave and urgent threat to the environment and human health, and has even affirmatively and incorrectly informed residents there is no evidence of hookworm in Lowndes County. By failing to address the inadequate access to functional wastewater treatment in Lowndes County, which has led to the proliferation of insanitary conditions and public health problems, ADPH and the Lowndes County Health Department ("LCHD") have caused and are



causing an unjustified disproportionate and adverse effect on the black community of Lowndes County, Alabama.

The Alabama Center for Rural Enterprise ("ACRE") submits this complaint against ADPH and LCHD for violations of Title VI of the Civil Rights Act of 1964 and HHS's implementing regulations, 45 C.F.R. Part 80, on behalf of James Jackson, Yolanda Peoples, John Jackson, and other Lowndes County residents. ACRE requests that the U.S. Department of Health and Human Services ("HHS") Office for Civil Rights ("OCR") promptly and thoroughly investigate the allegations set forth in this complaint and take all actions necessary to ensure that the agencies comply fully with the law. ACRE requests that the OCR investigate and ensure that the policies, programs, and activities of the ADPH and LCHD comply with Title VI of the Civil Rights Act of 1964.

#### I. **PARTIES**

#### Complainant A.

ACRE is a non-profit organization that was founded in 2002 in Lowndes County, Alabama, and promotes sustainable initiatives to improve the lives of impoverished rural citizens in Alabama, with a focus on Lowndes County. ACRE tackles the root causes of poverty by providing education, tools, and expertise to communities, empowering them to define their own problems and become the main protagonists for implementing effective solutions. Among other issues, ACRE is dedicated to advocating for affordable and functional wastewater treatment systems for rural families. ACRE has conducted wastewater surveys and helped secure wastewater treatment systems for impoverished families in Alabama, and continues to work towards wastewater equity in Lowndes County, Alabama. ACRE has many African American participants and volunteers who live in Lowndes County and are directly impacted by inadequate onsite sewage systems in the area.

#### B. Recipients

ADPH is an agency of the State of Alabama charged with implementing and enforcing the state's public health laws, among other responsibilities. ALA. CODE § 22-2-2(1). ADPH's duties include investigating the causes of and preventing disease, id. § 22-2-2(2), correcting or abating insanitary conditions, id. § 22-2-2(4), and supervising county health departments, including discharging the duties of county health officers who have failed to discharge their own duties, id. § 22-2-2(7). As described below, ADPH is a recipient of federal funds.

<sup>&</sup>lt;sup>1</sup> Under Alabama's public health laws, the terms "state health department" and "state board of health" are used interchangeably. ALA. CODE § 22-1-1; see also ALA. ADMIN. CODE r. 420-3-1-.01(4) (defining ADPH as "the Alabama Department of Public Health, the administrative arm of the Board, including variations in the name such as State of Alabama Department of Public Health, State Department of Public Health, State Health Department, or Public Health Department").



LCHD is the county health department for Lowndes County, Alabama and is the local arm of ADPH in that county. As a county health department, LCHD is charged under Alabama law with implementing and enforcing the health laws, with ADPH supervising and controlling all of its functions. ALA. CODE § 22-3-2. LCHD's website is housed on ADPH's website. LCHD's duties include investigating cases or outbreaks of certain regulatory "notifiable diseases," including "outbreaks of any kind" and "cases of potential public health importance." ALA. ADMIN. CODE r. 420-4-1, App. I; ALA. CODE § 22-3-2(2). LCHD also has a duty to prevent diseases, ALA. CODE § 22-3-2(2), investigate and take "proper steps" to abate nuisances to public health, *id.* § 22-3-2(3), and abate insanitary conditions. *Id.* § 22-3-2(4). LCHD's county health officers have an overarching duty to remove or abate any "condition detrimental to the health of the people," and if no authority exists to remove or abate the condition, they must make recommendations to LCHD as to any "special action" they deem proper. *Id.* § 22-3-5.

#### II. JURISDICTION

Title VI of the Civil Rights Act of 1964 provides that "[n]o person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." 42 U.S.C. § 2000d. Acceptance of federal funds, including HHS assistance, creates an obligation on the recipient to comply with Title VI and the federal agency's implementing regulations. As explained below, both ADPH and LCHD receive federal assistance from HHS and are a "program or activity" under Title VI, making them subject to the requirements of Title VI and HHS's implementing regulations. In addition, this complaint is timely and satisfies all other jurisdictional requirements.

#### A. Program or Activity

A "program or activity" includes "all of the operations of . . . a department, agency, special purpose district, or other instrumentality of a State or of a local government . . . any part of which is extended Federal financial assistance." 42 U.S.C. § 2000d-4a; 45 C.F.R. § 80.13(g). "[I]f any part of a listed entity receives federal funds, the entire entity is covered by Title VI." Ass'n of Mexican-Am. Educators v. State of Cal., 195 F.3d 465, 475 (9th Cir. 1999), rev'd in part on other grounds, 231 F.3d 572 (9th Cir. 2000) (citing Grimes v. Superior Home Health Care, 929 F. Supp. 1088, 1092 (M.D. Tenn. 1996)).

<sup>2</sup> Alabama Public Health, Lowndes County Health Department, http://www.alabamapublichealth.gov/lowndes/ (last visited Sept. 25, 2018).

<sup>&</sup>lt;sup>3</sup> HHS's regulations require that applicants for agency funds give "assurance" that they will comply with the agency's Title VI implementing regulations. 45 C.F.R. § 80.4.



Congress intended Title VI of the Civil Rights Act of 1964 to apply broadly to state and local governments. In the Senate Committee on Labor and Human Resources' 1987 report on a bill amending Title VI of the Civil Rights Act of 1964 to define the term "program or activity," the Committee explained the scope of Title VI as follows:

[W]hen any part of a state or local government department or agency is extended federal financial assistance, the entire agency or department is covered. If a unit of a state or local government is extended federal aid and distributes such aid to another governmental entity, all of the operations of the entity which distributes the funds and all of the operations of the department or agency to which the funds are distributed are covered. Examples:

If federal health assistance is extended to a part of a state health department, the entire health department would be covered in all of its operations.

If the office of a mayor receives federal financial assistance and distributes it to local departments or agencies, all of the operations of the mayor's office are covered along with the departments or agencies which actually get the aid.

## S. Rep. No. 100-64, at 16 (1988), reprinted in 1988 U.S.C.C.A.N. 3, 18.

ADPH is an agency or instrumentality of the state of Alabama and is accountable to the Legislature of Alabama. ALA. CODE § 22-2-7. LCHD is a local department of ADPH and an instrumentality of ADPH, under ADPH's control and supervision. Id. § 22-3-1. Therefore, both ADPH and LCHD, as one of its local departments, must comply with Title VI.

#### В. Federal Financial Assistance

HHS's regulations define a "recipient" as "any State, political subdivision of any State, or instrumentality of any State or political subdivision, any public or private agency, institution, or organization, or other entity, . . . to whom Federal financial assistance is extended, directly or through another recipient, including any successor, assign, or transferee thereof . . . . " 45 C.F.R. § 80.13(i).

As of June 30, 2018, HHS had awarded ADPH \$57,497,378 in federal funds for the fiscal year 2018, and more than \$888,807,220 in federal funds since 2008.<sup>4</sup>

Table 1 HHS Funding to ADPH

Year **HHS Funding** \$57,497,378 2018 2017 \$100,522,413 2016 \$88,156,569

<sup>&</sup>lt;sup>4</sup> See USASpending.gov, Spending by Prime Award, https://www.usaspending.gov/#/search/97ce043f27d9cf6a6a06d4895a97c315 (last visited Sept. 25, 2018) (showing HHS awards to ADPH for the years 2008 to the present).



2015	\$92,988,924
2014	\$88,718,914
2013	\$87,718,682
2012	\$91,315,903
2011	\$89,717,721
2010	\$99,801,706
2009	\$91,705,571
2008	\$663,439
Total	\$888,807,220

#### C. **Timeliness**

HHS regulations require Title VI complaints to be filed within 180 calendar days of the alleged discriminatory act, but OCR may waive these time limits. 45 C.F.R. § 80.7(b). In addition, OCR has ongoing authority to periodically review recipients' programs and activities for Title VI compliance. Id. § 80.7(a). This complaint is timely because the alleged discriminatory acts and failures to act are ongoing or within OCR's investigatory authorities. In addition to the ongoing acts and failures to act, ADPH specifically engaged in unlawful discriminatory conduct on April 9, 2018, by rejecting a peer-reviewed finding of hookworm in the county. This Complaint is timely filed both because it addresses ongoing discriminatory conduct and because it is filed within 180 days of April 9, 2018.

#### D. Other Jurisdictional and Prudential Considerations

This complaint satisfies all other jurisdictional criteria in Title VI and HHS's implementing regulations. Specifically, this complaint is in writing, describes the alleged discriminatory acts, and is filed with HHS by ACRE, an authorized representative, on behalf of residents of Lowndes County who have experienced adverse impacts as a result of ADPH and LCHD's violations of Title VI. 45 C.F.R. § 80.7(b).

#### III. FACTUAL BACKGROUND

Lowndes County lies in the "black belt" region of Alabama, a row of counties spanning the south-central portion of the state. It is positioned between the cities of Selma and Montgomery, and has long been at the forefront of the civil rights movement. In this county, which contains much of the route of the 1965 civil rights march from Selma to Montgomery, residents are still seeking equality.

For decades, Lowndes County has suffered from inadequate sanitation conditions caused by a lack of access to functional onsite sewage systems. In this county, 40-90% of residences



have no septic system or an inadequate one, and 50% of homes with septic systems are failing.<sup>5</sup> Approximately three-quarters of the population is African-American.<sup>6</sup> Within the last decade, these conditions have twice attracted international attention from the United Nations' Human Rights Council. First, in August 2011, the UN Special Rapporteur on the Human Right to Safe Drinking Water and Sanitation published a report on her visit to the United States which included personal testimony regarding the inadequate wastewater treatment in Lowndes County.<sup>7</sup> She concluded that "the right to sanitation is inaccessible for a substantial proportion of Lowndes County residents." Six years later, in December 2017, the UN Special Rapporteur on Extreme Poverty, Professor Philip Alston, personally visited Lowndes County as part of his tour of the United States. In a statement released immediately following that visit, Special Rapporteur Alston shared his observations:

In Alabama, I saw various houses in rural areas that were surrounded by cesspools of sewage that flowed out of broken or non-existent septic systems. The State Health Department had no idea of how many households exist in these conditions, despite the grave health consequences. Nor did they have any plan to find out, or devise a plan to do something about it. But since the great majority of White folks live in the cities, which are well served by government built and maintained sewerage systems, and most of the rural folks in areas like Lowndes County, are Black, the problem doesn't appear on the political or governmental radar screen.<sup>9</sup>

The black residents of Lowndes County have diminished access to adequate sanitation systems and disproportionately bear the adverse health effects associated with inadequate wastewater treatment.

# A. Lowndes County Geography and Demographics

In Alabama, the row of "black belt" counties, including Lowndes County, are largely rural and historically agricultural counties. The term "black belt" was originally coined to

<sup>&</sup>lt;sup>5</sup> United Nations General Assembly, *Report of the Special Rapporteur on the human right to safe drinking water and sanitation, Catrina de Albuquerque* at 6 (Aug. 2, 2011),

http://www2.ohchr.org/english/bodies/hrcouncil/docs/18session/A-HRC-18-33-Add4\_en.pdf ("2011 UN Report") (Ex. 1).

<sup>&</sup>lt;sup>6</sup> U.S. Census FactFinder, 2010 Census Summary File, http://factfinder.census.gov (search "Lowndes County, Alabama" then "Race and Hispanic or Latino Origin") (reporting 8,310 Black or African American residents out of 11,299 total residents, or 73.9%).

<sup>&</sup>lt;sup>7</sup> 2011 UN Report, *supra* n. 5, at 6.

<sup>&</sup>lt;sup>8</sup> *Id*. at 7.

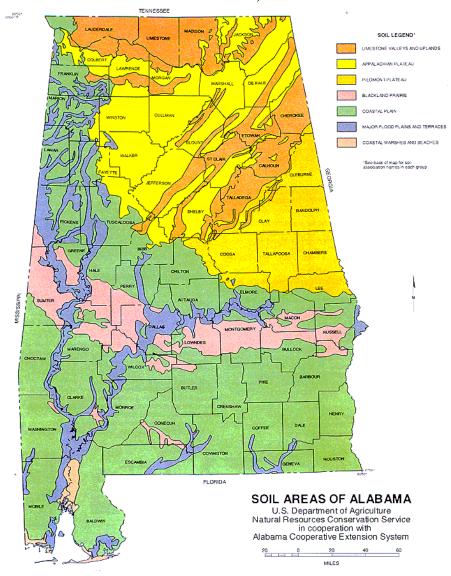
<sup>&</sup>lt;sup>9</sup> United Nations Human Rights, Office of the High Commissioner, *Statement on Visit to the USA, by Professor Philip Alston, United Nations Special Rapporteur on extreme poverty and human rights* (Dec. 15, 2017), https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=22533&LangID=E ("2017 UN Statement") (Ex. 2).



describe the black, clayey, shrink-swell soil in the area. 10 In Alabama, only the black belt counties contain this heavy, organically rich "Blackland Prairie" soil.

Fig. 1. Map of the Soils in Alabama

(Source: USDA, Natural Resources Conservation Service)

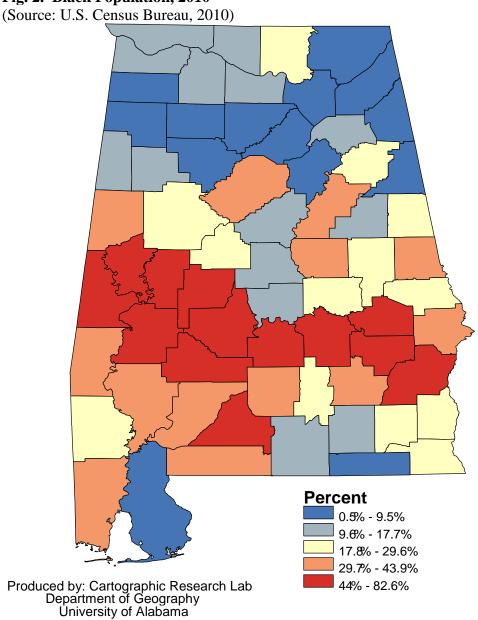


<sup>&</sup>lt;sup>10</sup> Allen Tullos, Emory University, *The Black Belt* (Apr. 19, 2004), https://southernspaces.org/2004/blackbelt.



Due to this dark, fertile soil, the black belt was a major cotton-producing region of the state during slavery. 11 As a result of the former prevalence of slave plantations in the area, the black belt region today has a majority African American population, living on this heavy soil.

Fig. 2. Black Population, 2010



<sup>&</sup>lt;sup>11</sup> White et al., Cotton Production Practices in the Black Belt Area of Alabama, Al. Polytechnic Institute at 3 (Dec. 1951), https://aurora.auburn.edu/bitstream/handle/11200/1907/1102CIRC.pdf?sequence=.



Like most of the other black belt counties, Lowndes County is deeply impoverished, with 29% of the population living below the poverty line. <sup>12</sup> Importantly, poverty in Lowndes County is starkly divided along racial lines, as only 4% of white residents, but 37% of black residents, live below the poverty line. <sup>13</sup> Similarly, the median household income for the county is only \$27,914, but white residents' median household income is nearly two times that figure, at \$52,604. <sup>14</sup> Black residents' median household income is \$21,686—substantially less than both the white residents' median household income and the overall median. <sup>15</sup>

This disparity in economic gains is not coincidental. In addition to the economic legacies of slavery itself, after emancipation, white landowners in Lowndes County shifted to an exploitative labor practice known as sharecropping, and continued to produce cotton under this model until the infestation of the boll weevil curtailed production. During the late nineteenth century and early twentieth century, white landowners in Lowndes County became wealthy through sharecropping, leaving black tenant farmers in debt. 17

At the same time, however, black residents started the Calhoun School and Calhoun Land Trust, the latter of which sold family farm parcels to black tenant farmers in the Calhoun community. In 1935, as part of the Resettlement Administration, the federal government also purchased a large plantation in the town of White Hall in Lowndes County, and gave loans to black families to buy subdivided parcels of the land. In this way, White Hall and Calhoun became the first two major black landholding communities in Lowndes County – both places with particularly low elevations. Historically, and continuing today, the minority of white families have lived in the towns of Lowndesboro (originally called McGill's Hill) and majority white neighborhoods in Fort Deposit, both of which have significantly higher elevations than

<sup>&</sup>lt;sup>12</sup> U.S. Census FactFinder, http://factfinder.census.gov (search "Lowndes County, AL," and follow "Poverty," "2016 American Community Survey," "Poverty Status in the Past 12 Months").

<sup>13</sup> *Id*.

<sup>&</sup>lt;sup>14</sup> *Id.* (follow "Guided Search," information about "people," "income & earnings," "income/earnings (households)," "Counties, Alabama, Lowndes," skip the Race/Ethnic Groups step, "Median Income in the Past 12 Months").

<sup>&</sup>lt;sup>15</sup> *Id*.

<sup>&</sup>lt;sup>16</sup> L.R. Schoenmann and R.T. Avon Burke, Bureau of Soils, U.S. Dep't of Ag., *Soil Survey of Lowndes County, Alabama* at 10-11 (1918),

https://www.nrcs.usda.gov/Internet/FSE\_MANUSCRIPTS/alabama/lowndesAL1918/lowndesAL1918.pd f ("Schoenmann and Burke").

<sup>&</sup>lt;sup>17</sup> Hasan Kwame Jeffries, *Bloody Lowndes: Civil Rights and Black Power in Alabama's Black Belt*, New York University Press at 22 (2009) ("Jeffries").

<sup>&</sup>lt;sup>18</sup> *Id.* at 23-24.

<sup>&</sup>lt;sup>19</sup> *Id*. at 24.

<sup>&</sup>lt;sup>20</sup> *Id.* at 3, 24; *see also* https://www.google.com/earth/ (providing the elevations of the various towns in Lowndes County, including the predominantly black towns of Calhoun at 99 meters, and White Hall at 63 meters). Calhoun is an unincorporated village, Jeffries, *supra* n. 17, at 3, but its elevation is based on the elevation of the intersection of Calhoun Road at County Road 33.



other towns in the county, and both of which are considered upland areas with better drainage.<sup>21</sup> Lowndes County remains a deeply segregated place, from housing to education.<sup>22</sup>

## B. Inadequate Sewage Systems

In Lowndes County, more than 80% of residents have no access to a municipal sewer system. <sup>23</sup> Lacking access to a public sewer hookup, the majority of residents in Lowndes County must use some type of septic system to dispose of household wastewater. In Alabama, the burden is on homeowners to install and maintain a state-permitted septic system. <sup>24</sup> Conventional septic systems are most common, but they are incompatible with impermeable soils because they rely on soil absorption of effluent. <sup>25</sup>

Conventional septic systems usually cost two to three thousand dollars to install, but in places with impermeable soil or other geographic constraints, homeowners must install "engineered" systems which cost between six and thirty thousand dollars. <sup>26</sup> Unsurprisingly, the clayey soil that defines the black belt region is a highly impermeable soil, and the unusual soil "vertisols" that predominate there are especially unconducive to the soil absorption required for conventional septic tanks. <sup>27</sup> As a result, residents in this area face extremely high costs to install a functioning septic system, up to as much as \$30,000. Given low incomes and high poverty rates in the area—particularly among black residents—these costs are prohibitive. In addition, 35% of Lowndes County residents live in mobile homes, including 40% of black residents, but

<sup>&</sup>lt;sup>21</sup> Jeffries, *supra* n. 17, at 3; Schoenmann and Burke, *supra* n. 16, at 6, https://www.nrcs.usda.gov/Internet/FSE\_MANUSCRIPTS/alabama/lowndesAL1918/lowndesAL1918.pd f (stating that upland soils have better drainage in Lowndes County); *see also* https://www.google.com/earth/ (providing the elevations of the various towns in Lowndes County, including the predominantly black towns of Mosses at 58 meters, Hayneville at 74 meters, Calhoun at 99 meters, and White Hall at 63 meters, but the major populations of white residents in Fort Deposit at 147 meters, and Lowndesboro at 125 meters).

<sup>&</sup>lt;sup>22</sup> For example, in the aftermath of school desegregation orders in 1966, the minority of white residents in Lowndes County created a private school called Lowndes Academy in order to continue school segregation. Jeffries, *supra* n. 17, at 114. Lowndes Academy still exists today as a "segregation academy" for white students. Regina Moore, Congressional Black Caucus Foundation, *Brown 60 Years Later: Segregation Academies in the Deep South* (May 15, 2014),

https://www.cbcfinc.org/thevillage/2014/05/15/brown-60-years-later-segregation-academies-in-the-deep-south/.

<sup>&</sup>lt;sup>23</sup> 2011 UN Report, *supra* n. 5, at 6.

<sup>&</sup>lt;sup>24</sup> See, e.g., ALA. CODE § 22-26-2; ALA. ADMIN. CODE r. 420-3-1-.02; 420-3-1-.05.

<sup>&</sup>lt;sup>25</sup> He et al., *Hydraulic management of a soil moisture controlled SDI wastewater dispersal system in an Alabama Black Belt soil*, Journal of Envt'l Mgt. at 2479 (2011) ("He et al."). <sup>26</sup> 2011 UN Report, *supra* n. 5, at 7.

<sup>&</sup>lt;sup>27</sup> He et al., *supra* n. 25, at abstract, 2483-84; *see also* University of Idaho, Dominant Soil Orders, https://www.uidaho.edu/-/media/UIdaho-Responsive/Files/cals/programs/soil-orders/dominant-soil-orders-US.pdf (map of U.S. showing soil orders and presence of vertisols in black belt of Alabama and only a few other locations) (last visited Sept. 25, 2018).



just 22% of white residents.<sup>28</sup> These mobile homes have a median value of \$23,900.<sup>29</sup> Therefore, a septic tank that functions properly in Lowndes County can cost more than many families' homes.

A significant percentage of the population in Lowndes County has either a poorly functioning septic system or no system at all. In 2011, ADPH estimated that in Lowndes County 40-90% of residences have no septic system or an inadequate one, and that 50% of homes with septic systems are failing or expected to fail, 30 although the exact figures are unknown. Many families with conventional septic systems have problems with raw sewage backing up in their yards or in their homes, and families that have abandoned their failing systems or cannot afford to install systems have historically resorted to homemade solutions such as "straight pipes." Straight pipes are generally metal or PVC pipes that lead from a home's plumbing to an outdoor area. Families that have straight pipes generally have running water and flush toilets, but the home's waste is discharged, untreated, directly to yards, ditches, woods, or various kinds of surface waters, leaving many yards contaminated with raw sewage. The pipes can be buried or visible, and they can discharge all or only some of a home's sewage. A recent survey of 289 homes in neighboring Wilcox County, Alabama revealed that 93% of residences had some form of unpermitted sewage system, 60% with a visible straight pipe and 34% with a hidden straight pipe or other form of unknown, unpermitted system.<sup>31</sup>

The prevalence of raw sewage due to inadequate access to onsite wastewater treatment has led to a hookworm outbreak. Reports and studies from the black belt region of Alabama in the last few decades indicate the presence of hookworm, which was previously believed to be mostly eradicated from this country. A 1993 study from Wilcox County revealed that approximately one-third of all children under the age of ten at one clinic in the 1991-1992 fiscal year had parasitic worms such as hookworms—a health condition associated with poor sanitation

<sup>&</sup>lt;sup>28</sup> U.S. Census FactFinder, http://factfinder.census.gov (follow "Guided Search," information about "housing," "physical characteristic," "units in structure," "Lowndes County, AL," skip the Race/Ethic groups step, then compare "units in structure," with "units in structure (black or African American alone householder)," with "units in structure (white alone householder)").

<sup>&</sup>lt;sup>29</sup> Id. (follow "Guided Search," information about "housing," "financial characteristic," "mobile home costs," "Counties, Alabama, Lowndes," skip the Race/Ethnic Groups step, "Median Value for Mobile Homes").

<sup>&</sup>lt;sup>30</sup> 2011 UN Report, supra n. 5, at 6; Apple Loveless & Leslie Corcelli, Pipe Dreams: Advancing Sustainable Development in the United States, EPA Blog (Mar. 5, 2015),

https://blog.epa.gov/blog/2015/03/pipe-dreams-advancing-sustainable-development-in-the-united-states/.

<sup>&</sup>lt;sup>31</sup> EPA Webinar, Surface Discharge of Raw Wastewater Among Unsewered Homes in Central Alabama (March 28, 2017) (citing data from Lynn and Robert Jones, Down to Earth, Inc.),

https://www.epa.gov/septic/surface-discharge-raw-wastewater-among-unsewered-homes-central-alabama; Alabama Water Resources Research Institute, Annual Technical Report, FY 2016, Onsite Wastewater Management in Hale and Wilcox Counties: Failing Septic Systems, Direct Discharge by "Straight Pipes" and Microbial Source Tracking,

https://water.usgs.gov/wrri/AnnualReports/2016/FY2016\_AL\_Annual\_Report.pdf.



conditions.<sup>32</sup> That same study found that about 35% of the residents used a sewage disposal method other than the municipal sewer or a septic tank (a straight pipe, cesspool, or other kind of system), and up to 75% of septic tanks were also non-functional in one community.<sup>33</sup> Then, in a highly startling peer-reviewed study published in 2017, nineteen of fifty-five participants (34.5%) tested positive for low levels of hookworms in Lowndes County.<sup>34</sup> The study, entitled "Human Intestinal Parasite Burden and Poor Sanitation in Rural Alabama," was conducted by a group of health researchers at Baylor University, and was published in the American Journal of Tropical Medicine and Hygiene. The study authors analyzed stool samples from participants, primarily relying on the quantitative polymerase chain reaction ("qPCR") method, which is a molecular diagnostic method used to detect intestinal parasites.<sup>35</sup> The study also included the results of a questionnaire covering demographic data, symptoms, and exposure to sewage within the home.<sup>36</sup> Many study participants reported exposure to raw sewage in the home.<sup>37</sup> Contrary to the study's findings, on April 9, 2018, ADPH announced to the public that the 2017 hookworm study did *not* find the presence of hookworm in Lowndes County.<sup>38</sup>

#### IV. LEGAL BACKGROUND

Title VI of the Civil Rights Act of 1964 prohibits recipients of federal funds from discriminating against individuals on the basis of race, color, or national origin. 42 U.S.C. § 2000d; 45 C.F.R. § 80.1. Title VI directs federal agencies granting federal assistance to issue regulations to achieve the statutory objectives. *Id.* § 2000d-1.

Under HHS's Title VI regulations, it is illegal for any recipient of their federal funds to:

- (i) Deny an individual any service, financial aid, or other benefit provided under the program;
- (ii) Provide any service, financial aid, or other benefit to an individual which is different, or is provided in a different manner, from that provided to others under the program;

<sup>&</sup>lt;sup>32</sup> Amy Badham, Wilcox County Alabama: Needs Assessment, 26, 28, 50 (June 1993), https://assets.documentcloud.org/documents/2091580/pdf1-hookworm1993.pdf.

<sup>&</sup>lt;sup>33</sup> *Id.* at 28.

<sup>&</sup>lt;sup>34</sup> McKenna et al., Human Intestinal Parasite Burden and Poor Sanitation in Rural Alabama, Am. J. of Tropical Medicine and Hygiene (Sept. 2017) ("McKenna et al."),

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5817782/pdf/tpmd170396.pdf (Ex. 3).

<sup>&</sup>lt;sup>35</sup> Id. at 1624; Elsie M. O'Connell and Thomas B. Nutman, Molecular Diagnostics for Soil-Transmitted Helminths, Am. J. of Tropical Medicine and Hygiene, 508-513 (2016) ("O'Connell and Nutman").

<sup>&</sup>lt;sup>36</sup> McKenna, et al., *supra* n. 34, at 1624.

<sup>&</sup>lt;sup>37</sup> *Id.* at 1625.

<sup>&</sup>lt;sup>38</sup> ADPH, Notice: Environmental study in Lowndes County, Alabama, fails to prove hookworm infection (Apr. 9, 2018),

http://alabamapublichealth.gov/infectiousdiseases/assets/hookworm-notice.pdf (Ex. 4).



- (iii) Subject an individual to segregation or separate treatment in any matter related to his receipt of any service, financial aid, or other benefit under the program;
- (iv) Restrict an individual in any way in the enjoyment of any advantage or privilege enjoyed by others receiving any service, financial aid, or other benefit under the program;
- (v) Treat an individual differently from others in determining whether he satisfies any admission, enrollment, quota, eligibility, membership or other requirement or condition which individuals must meet in order to be provided any service, financial aid, or other benefit provided under the program;
- (vi) Deny an individual an opportunity to participate in the program through the provision of services or otherwise or afford him an opportunity to do so which is different from that afforded others under the program (including the opportunity to participate in the program as an employee but only to the extent set forth in paragraph (c) of this section).
- (vii) Deny a person the opportunity to participate as a member of a planning or advisory body which is an integral part of the program.

45 C.F.R. § 80.3(b)(1). In addition, HHS-funded programs may not "directly or through contractual or other arrangements, utilize criteria or methods of administration which have the effect of subjecting individuals to discrimination because of their race, color, or national origin, or have the effect of defeating or substantially impairing accomplishment of the objectives of the program as respect individuals of a particular race, color, or national origin." *Id.* § 80.3(b)(2). These regulations make clear that discrimination on the basis of race is a violation of Title VI, whether discrimination is the purpose of the decision or its effect. *Id.* 

In addition, HHS regulations require correction of past discriminatory practices. The regulations state: "In administering a program regarding which the recipient has previously discriminated against persons on the ground of race, color, or national origin, the recipient *must* take affirmative action to overcome the effects of prior discrimination. Even in the absence of such prior discrimination, a recipient administering a program may take affirmative action to overcome the effects of conditions which resulted in limiting participation by persons of a particular race, color, or national origin." *Id.* § 80.3(b)(6) (emphasis added). HHS's regulations also provide an "illustrative application" of this requirement, explaining that if prior discriminatory practices continue to limit the availability of a benefit to a protected class, "it will become necessary . . . for such applicant or recipient to take additional steps to make the benefits fully available to racial and nationality groups previously subject to discrimination. This action might take the form, for example, of special arrangements for obtaining referrals or making selections which will insure that groups previously subjected to discrimination are adequately served." *Id.* § 80.5(i). The regulations alternatively provide, in cases where there has been no prior discriminatory policies:



Even though an applicant or recipient has never used discriminatory policies, the services and benefits of the program or activity it administers may not in fact be equally available to some racial or nationality groups. In such circumstances, an applicant or recipient may properly give special consideration to race, color, or national origin to make the benefits of its program more widely available to such groups, not then being adequately served. For example, where a university is not adequately serving members of a particular racial or nationality group, it may establish special recruitment policies to make its program better known and more readily available to such group, and take other steps to provide that group with more adequate service.

Id. § 80.5(j).

Finally, HHS regulations require recipients of HHS funds to "have available for the Department racial and ethnic data showing the extent to which members of minority groups are beneficiaries of and participants in federally-assisted programs." *Id.* § 80.6(b).

#### V. VIOLATIONS OF TITLE VI

Complainant alleges that ADPH and LCHD have discriminated against the predominantly black community in Lowndes County, Alabama on the basis of race by administering their onsite wastewater disposal systems program and their infectious diseases and outbreaks program in ways that cause racially disparate impacts, 45 C.F.R. § 80.3(b)(2), by failing to take affirmative action to overcome the effects of prior discrimination, id. § 80.3(b)(6), and failing to collect demographic data on the beneficiaries of its onsite wastewater disposal systems program, id. § 80.6(b). Specifically, ADPH and LCHD failed to abate known insanitary conditions, dismissed a credible outbreak of hookworm, and failed to maintain sufficient data regarding the lack of wastewater services, despite knowledge of prior discriminatory acts regarding the high rate of insufficient onsite wastewater systems in the county.

#### A. ADPH's and LCHD's Failure to Abate Insanitary Conditions and Failure to Overcome the Effects of Prior Discrimination

ADPH and the LCHD have duties under state law to correct insanitary conditions, under their infectious diseases and outbreaks program. ADPH has a duty to take "proper steps . . . to have such [insanitary conditions or conditions prejudicial to health] corrected or abated." ALA. CODE § 22-2-2(4). In addition, the county health boards have a general duty to investigate and abate nuisances to the public health, id. § 22-3-2(3), and must abate insanitary conditions at public places and residences. Id. § 22-3-2(4). Finally, the county health officer has a duty to compel the abatement of any cause of disease or condition that is detrimental to public health. Id. § 22-3-5. Separately, ADPH and LCHD have duties under state law to oversee the onsite wastewater disposal system program. ALA. ADMIN. CODE r. 420-3-1-.05; id. 420-3-1-.06.



ADPH and LCHD have utterly failed to fulfill their state law duties to abate the unacceptable raw sewage conditions in Lowndes County under either the onsite wastewater systems program or the infectious diseases and outbreaks program. ADPH and LCHD have not resolved the dire lack of sufficient onsite wastewater systems in Lowndes County. Because they have failed to exercise their obligation to abate insanitary conditions, and because this failure has a disparate impact on African Americans in Lowndes County, *see infra* part VII of this complaint, ADPH and LCHD are administering their programs in ways that have a disparate impact on African Americans in Lowndes County, in violation of Title VI.<sup>39</sup> 45 C.F.R. § 80.3(b)(2).

In addition to ADPH's legal obligation to avoid administering its programs in a way that has a disparate impact on African Americans, ADPH has a separate duty under HHS's Title VI regulations to affirmatively take action to overcome the effects of prior discrimination. *Id.* § 80.3(6)(i). ADPH has also violated this Title VI requirement because its past practice contributed to the problem. ADPH previously, and discriminatorily, used the criminal justice system to attempt to force compliance with sanitation laws. Alabama state law makes it a criminal misdemeanor to "build, maintain or use an insanitary sewage collection," meaning any system that is not a permitted septic tank. In addition to the potential for jail time, a violation of the insanitary conditions law is punishable by a fine of \$500.41 From 1999 to 2002, ADPH issued arrest warrants for at least ten Lowndes County residents for violating the insanitary sewage collection law, all of whom were African American.42 One woman even spent four days in jail for not having a septic tank.43 Because the high cost of specially engineered systems that function in Lowndes County soil is the primary barrier to onsite wastewater permits in this low-income county,44 the state's misdemeanor sewage law effectively criminalizes poverty. At a

<sup>&</sup>lt;sup>39</sup> Tile VI prohibits not only discriminatory policies and practices, but also discriminatory failures to act. *See, e.g., United States v. Maricopa Cty*, 915 F. Supp. 2d 1073, 1079 (D. Ariz. 2012) (finding a disparate impact because the recipient "failed to develop and implement policies and practices to ensure [limited English proficient] Latino inmates have equal access to jail services").

<sup>&</sup>lt;sup>40</sup> ALA. CODE § 22-26-1.

<sup>&</sup>lt;sup>41</sup> *Id.* § 22-26-6.

<sup>&</sup>lt;sup>42</sup> Jennifer Carrera, *Sanitation and Social Power in the United States*, Dissertation of Jennifer Carrera, University of Illinois at 107-08 (2014), https://core.ac.uk/download/pdf/29153060.pdf; *see also* Tr. of Public Hearing, Ramer Baptist Church, Calhoun, Lowndes County at 40-41 (Apr. 24, 2002) (identifying eleven individuals with active arrest warrants for failing to have a septic tank in Lowndes County) (available with author).

<sup>&</sup>lt;sup>43</sup> Tr. of Public Hearing, Ramer Baptist Church, Calhoun, Lowndes County at 54 (Apr. 24, 2002).

<sup>&</sup>lt;sup>44</sup> ADPH has acknowledged that most landowners in black belt counties need to install the significantly more expensive, specially engineered onsite systems. 12 WSFA, *Fight continues to tackle sewage problems across Black Belt* (Nov. 16, 2015), http://www.wsfa.com/story/30533411/fight-continues-to-tackle-black-belt-raw-sewage-problems (stating: "the Black Belt soils have been determined to be the worst type soil in placing these disposal systems. The majority of the time, homeowners will have to have an engineered system installed.") (quoting the Director of ADPH's Bureau of Environmental Services).



public hearing held in 2002, one resident spoke of the pain of being fingerprinted and "treated like a criminal" for his inability to afford a septic tank. 45 Moreover, arresting and fining individuals who will never be able to afford the up to \$30,000 for an engineered septic tank does nothing to remedy inadequate sewage systems, and counterproductively disincentivizes requests for government assistance with the problem. As another resident said at the same public hearing in 2002, her husband told authorities: "you can kill me, bury me, put me in jail, the situation gonna still be there when I get out."46 The U.S. Supreme Court has long-recognized the impermissibility of imprisoning an individual due to indigence.<sup>47</sup> The prior history of arresting African American residents of Lowndes County for inadequate sewage access is a prior discriminatory act that legally contributes to the ongoing obligation to correct previously harmful acts under Title VI. 45 C.F.R. § 80.3(b)(6). In addition, ADPH's prior arrests of black residents for their inadequate sewage treatment creates a strong disincentive for black residents to seek assistance with inadequate onsite sewage treatment, and a strong incentive to stay silent regarding insanitary conditions.

#### B. ADPH's Dismissal of Hookworm Outbreak and ADPH's and LCHD's Failure to Investigate Hookworm in Lowndes County

ADPH's State Board of Health<sup>48</sup> has a broad duty "[t]o investigate the causes, modes or propagation and means of prevention of diseases," ALA. CODE § 22-2-2. HHS broadly defines "communicable diseases" to mean "illnesses due to infectious agents or their toxic products, which may be transmitted from a reservoir to a susceptible host either directly as from an infected person or animal or indirectly through the agency of an intermediate plant or animal host, vector, or the inanimate environment." 42 C.F.R. § 70.1. In Alabama, the county boards of health<sup>49</sup> also have a general duty to investigate and abate nuisances to the public health. ALA. CODE § 22-3-2(3). The boards have a separate specific duty to investigate "notifiable diseases,"

<sup>&</sup>lt;sup>45</sup> Tr. of Public Hearing, Ramer Baptist Church, Calhoun, Lowndes County at 36 (Apr. 24, 2002).

<sup>&</sup>lt;sup>46</sup> *Id*. at 70.

<sup>&</sup>lt;sup>47</sup> See, e.g., Bearden v. Georgia, 461 U.S. 660, 661 (1983); id. at 668 ("if the probationer has made all reasonable efforts to pay the fine or restitution, and yet cannot do so through no fault of his own, it is fundamentally unfair to revoke probation automatically"); see also Griffin v. Illinois, 351 U.S. 12, 16-17 (1956) ("In criminal trials a State can no more discriminate on account of poverty than on account of religion, race, or color.").

<sup>&</sup>lt;sup>48</sup> Under Alabama law, the terms "state board of health" and "State Health Department" are used interchangeably. ALA. CODE § 22-1-1.

<sup>&</sup>lt;sup>49</sup> Under Alabama law, the term "county board of health" is interchangeable with "county committee of public health" and other names referring to the county health departments. ALA. CODE § 22-3-1 (defining "county board of health" and stating: "Whenever the name 'county committee of public health' or other name or expression referring to the county committee of public health, as such, occurs in the Code of Alabama or any other statute law of the State of Alabama, or in the constitution of the Medical Association of the State of Alabama or in the constitution of the medical society of a county in the State of Alabama, said name or expression shall include and mean the county board of health provided for in this section.").



which include "outbreaks of any kind" and "cases of potential public health importance." ALA. ADMIN. CODE r. 420-4-1, App. I; ALA. CODE § 22-3-2(2). An "outbreak" is defined by ADPH as "two or more similarly ill persons who live in different households and have a common exposure."50 The agency has not adopted a definition of "ill;" however, HHS defines "ill person" to include someone who "[h]as symptoms or other indications of communicable disease." 42 C.F.R. § 70.1.

The nineteen cases of hookworm found by the authors of the 2017 hookworm study satisfy the agency's definition of an "outbreak" because there were two or more ill individuals in different households having a common exposure to raw sewage in the home. Separately, hookworm is also a case "of potential public health importance" since the disease was believed to have been eradicated in the mid-20<sup>th</sup> century and is highly harmful to human health.<sup>51</sup> For both of these reasons, hookworm is a "notifiable disease" that requires investigation. ALA. ADMIN. CODE r. 420-4-1, App. I; ALA. CODE § 22-3-2(2). Furthermore, even if hookworm is not considered a notifiable disease, ADPH and LCHD would still have a duty to investigate and abate the condition under their general statutory obligations to investigate diseases and nuisances to public health. ALA. CODE § 22-2-2; id. § 22-3-2(3).

However, instead of investigating and abating the condition, on April 9, 2018, ADPH announced to the public that the 2017 hookworm study did not find the presence of hookworm in Lowndes County.<sup>52</sup> This public notice was posted on the homepage of ADPH's website for months.<sup>53</sup> The public notice seriously mischaracterizes and incorrectly denies the evidence of a hookworm outbreak in Lowndes County, thus endangering individual and public health.

In the notice, ADPH provides three reasons for discounting the peer-reviewed study: (1) the study failed to achieve statistical significance; (2) the microscopy analysis conducted by the Centers for Disease Control and Prevention ("CDC") found no hookworm eggs in samples; and (3) the qPCR method used in the study has not been approved by the Food and Drug Administration ("FDA"). None of these assertions accurately represent the data, and they neither individually nor collectively undermine the study's unequivocal finding of hookworm in 34.5% of study participants.

<sup>&</sup>lt;sup>50</sup> ADPH, Infectious Diseases and Outbreaks, Outbreaks,

http://www.alabamapublichealth.gov/infectiousdiseases/outbreaks.html (last updated Sept. 17, 2018).

<sup>&</sup>lt;sup>51</sup> McKenna et al., supra n. 34, at 1626; Humphreys, How four once common diseases were eliminated from the American south, 28 Health Affairs 1734-35 (2009),

https://www.healthaffairs.org/doi/pdf/10.1377/hlthaff.28.6.1734.

<sup>&</sup>lt;sup>52</sup> ADPH, Notice: Environmental study in Lowndes County, Alabama, fails to prove hookworm infection (Apr. 9, 2018).

http://alabamapublichealth.gov/infectiousdiseases/assets/hookworm-notice.pdf.

<sup>&</sup>lt;sup>53</sup> See ADPH homepage as of May 1, 2018, https://www.alabamapublichealth.gov/index.html (Ex. 5).



First, ADPH's statement that "[t]he authors concluded that the study did not obtain statistical significance"<sup>54</sup> is deceptive. The study found that nineteen of fifty-five individuals that provided stool samples for the study tested positive for hookworm.<sup>55</sup> Although the study authors acknowledge that their collection of fifty-five stool samples was a smaller sample than originally desired due to mistrust of legal liabilities associated with exposure to raw sewage, <sup>56</sup> the sample size in no way discredits the positive hookworm finding in 34.5% of the samples. Once the existence of an infection has been directly observed, the concept of statistical significance has no relevance to the question of simple presence or absence because presence has been affirmatively established. There were nineteen people infected with hookworm, and that fact is not vitiated by the small sample size. When testing for associations between the presence of a parasite and another variable, statistical significance becomes relevant. Indeed, the study authors tested for associations between the presence of hookworm and other variables in the household questionnaire, such as whether someone was male or female, whether raw sewage was reported in the house, and whether an individual suffered from asthma or diarrhea.<sup>57</sup> After analyzing these associations, the study authors concluded there was no statistically significant correlation between testing positive for hookworm and any of those other variables, due to the small sample size.<sup>58</sup> But this lack of a statistically significant correlation between hookworm and other variables does not affect the study's antecedent finding that 34.5% of study participants had hookworm. That conclusion is based on direct evidence of hookworm and does not depend on any association.

Second, the fact that the CDC microscopy analysis found no hookworm eggs does not negate the positive finding of hookworm. In this study, the authors used the molecular qPCR method to test the stool samples, but they also subsequently used two additional confirmatory methods of analysis to ensure their positive hookworm finding was not a false positive: microscopy testing and gel electrophoresis.<sup>59</sup> Gel electrophoresis, a method for size-based DNA analysis, confirmed the positive qPCR finding for all nineteen positive samples.<sup>60</sup> The microscopy test, on the other hand, did not find any hookworm eggs in the samples.<sup>61</sup> However, as the study authors explained in their paper, this negative microscopy result is likely due to the fact that the parasite burden in the study participants was calculated to be low—only one or two eggs per gram of stool—and microscopy is not sufficiently sensitive to detect eggs unless there are at least twelve or more eggs per gram of stool.<sup>62</sup> Microscopy simply means visually

<sup>&</sup>lt;sup>54</sup> ADPH, Notice: Environmental study in Lowndes County, Alabama, fails to prove hookworm infection (Apr. 9, 2018),

http://alabamapublichealth.gov/infectiousdiseases/assets/hookworm-notice.pdf.

<sup>&</sup>lt;sup>55</sup> McKenna et al., *supra* n. 34, at 1625.

<sup>&</sup>lt;sup>56</sup> *Id.* at 1624, 1626-27.

<sup>&</sup>lt;sup>57</sup> *Id.* at 1625.

<sup>&</sup>lt;sup>58</sup> *Id*.

<sup>&</sup>lt;sup>59</sup> *Id.* at 1624-25.

<sup>&</sup>lt;sup>60</sup> *Id.* at 1625.

<sup>&</sup>lt;sup>61</sup> *Id*.

<sup>&</sup>lt;sup>62</sup> *Id*. at 1626.



searching for evidence using a microscope. Microscopy is a notoriously insensitive method, and the qPCR method used by the study authors has consistently been found to be a more sensitive and accurate—method.<sup>63</sup> Moreover, because the gel electrophoresis analysis confirmed the positive qPCR finding, the study authors were able to confirm the positive finding of hookworm using qPCR—a strong conclusion which withstood the peer review process.

Lastly, ADPH's assertion that the hookworm study failed to find evidence of hookworm because the qPCR method is not FDA-approved does not hold water. Although qPCR is a newer method than microscopy, which has been used for hundreds of years, 64 the qPCR method for detecting helminths in humans was developed by scientists at the National Institutes of Health and is widely accepted to be superior in sensitivity.<sup>65</sup> Moreover, while qPCR is not an FDAapproved method for the detection of parasitic worms, this fact is essentially meaningless because FDA does not approve diagnostic methods for detecting diseases, and only approves new physical medical devices such as new manufactured diagnostic tools.<sup>66</sup> Therefore, the lack of FDA approval of the qPCR method does not undermine the credibility of the study.

In sum, the 2017 hookworm study was a peer-reviewed study using the most up-to-date and sensitive methods to detect parasitic worms in stool samples. ADPH's rejection of the study's findings misled the public by incorrectly assuring residents there is no evidence of a hookworm outbreak when in fact there is very strong evidence that a hookworm outbreak is currently occurring in Lowndes County. To the best of Complainant's knowledge, ADPH and LCHD have conducted no investigation of hookworm in response to this evidence of hookworm. The only step ADPH has taken to address health issues in Lowndes County in recent months is a three-day long "community survey" conducted in May 2018, during which health department officials went door to door asking about household water and sewage practices, illnesses, and illness prevention practices.<sup>67</sup> This community survey did not specifically address hookworm, and accordingly cannot constitute an investigation into this disease outbreak in Lowndes County. ADPH's decision to wholly dismiss the hookworm outbreak and mislead residents about the risk, as well as ADPH's and LCHD's failure to investigate this outbreak, violate Title VI.

C. ADPH's and LCHD's Failure to Maintain Sufficient Data to Comply with Title

<sup>&</sup>lt;sup>63</sup> O'Connell and Nutman, *supra* n. 35, at 508.

<sup>&</sup>lt;sup>64</sup> McKenna et al., *supra* n. 34, at 1626.

<sup>&</sup>lt;sup>65</sup> O'Connell and Nutman, *supra* n. 35, at 508.

<sup>&</sup>lt;sup>66</sup> See FDA, Device Approvals, Denials and Clearances,

https://www.fda.gov/medicaldevices/productsandmedicalprocedures/deviceapprovalsandclearances/defaul t.htm (last updated Mar. 26, 2018); telephone interview by author with FDA Division of Industry and Consumer Education (Aug. 29, 2018).

<sup>&</sup>lt;sup>67</sup> ADPH, Lowndes County Community Survey set for May 22-24 (May 18, 2018), https://www.alabamapublichealth.gov/news/2018/05/18c.html (last visited Sept. 25, 2018).



Neither ADPH nor LCHD maintain sufficient data to comply with their Title VI obligations as they relate to sanitation. ADPH collects data regarding the number of new onsite wastewater system permits and repair permits issued by local county health departments, but it does not collect data regarding the locations of failing onsite wastewater systems, <sup>68</sup> locations that lack a permitted onsite wastewater system altogether, or racial demographic data regarding the locations without a permitted system. When recently interviewed for a PBS news story, State Health Officer and ADPH official Dr. Scott Harris said the state has never conducted a survey to determine the scope of the problem and conceded they do not have a system to collect data on how many households lack adequate sewage treatment, but also admitted it is a "substantial" part of the population.<sup>69</sup> UN Special Rapporteur Alston, who recently met with officials from ADPH, similarly reported that the agency "had no idea of how many households exist in these conditions, despite the grave health consequences. Nor did they have any plan to find out, or devise a plan to do something about it." ADPH's failure to collect data about the extent and nature of this documented, and known to be racially disproportionate, problem contributes to the ongoing unresolved harm to residents and constitutes another violation of Title VI. 45 C.F.R. § 80.6(b).

#### VI. ADVERSE IMPACTS

The residents of Lowndes County experience several adverse impacts due to the inadequate access to functional onsite wastewater systems in the county.

## A. <u>Human Health Impacts</u>

The discharges of raw sewage in Lowndes County pose numerous health risks for residents. For example, these discharges include many different kinds of pathogens, including enteric viruses, Giardia cysts, and cryptosporidium oocysts. The risk of exposure to these pathogens comes not only from direct exposure to contaminated soils in yards, but also from exposure to contaminated groundwater or surface water. One study estimated that failing septic tanks cause groundwater contamination that puts approximately 340,000 low-income rural Alabamans at risk of contracting a waterborne disease. The parasites, bacteria, and viruses in

<sup>&</sup>lt;sup>68</sup> The Alabama Department of Environmental Management estimated in an undated report that 25% of septic systems throughout the state are failing. Alabama Department of Environmental Management, *Water Down Under: Alabama's Groundwater Resources*, Part 2, at 48, http://www.adem.state.al.us/MoreInfo/pubs/GWpart2.pdf.

<sup>&</sup>lt;sup>69</sup> PBS, *The Story of American Poverty, as Told by One Alabama County* at minute 6:17-6:34 (July 7, 2018), https://www.pbs.org/newshour/show/the-story-of-american-poverty-as-told-by-one-alabama-county.

<sup>&</sup>lt;sup>70</sup> 2017 UN Statement, supra n. 9.

<sup>&</sup>lt;sup>71</sup> EPA Webinar, *Surface Discharge of Raw Wastewater Among Unsewered Homes in Central Alabama* (March 28, 2017), https://www.epa.gov/septic/surface-discharge-raw-wastewater-among-unsewered-homes-central-alabama.

<sup>&</sup>lt;sup>72</sup> Winkler and Flowers, "America's Dirty Secret": The Human Right to Sanitation in Alabama's



raw sewage can cause a variety of health problems ranging from infections, to diarrhea, to intestinal worms.<sup>73</sup> As discussed previously, the presence of raw sewage has led to a hookworm outbreak in the county.

# B. <u>Impacts to Water Quality</u>

Untreated human sewage is also a significant water pollutant, regardless of whether it comes from sewer overflows in urban areas or failing septic tanks and straight pipes in rural areas. In spite of the population density difference between urban and rural areas, rural surface waters can become impaired due to pathogens associated with raw sewage, even without any large livestock sources of manure nearby. In the southeastern U.S., many rural streams and rivers are specifically listed as "impaired" under the Clean Water Act ("CWA") due to elevated fecal coliform levels, often due in large part due to straight pipes and failing septic systems. In Alabama's most recent CWA impaired waters list, forty-two water bodies are listed as impaired due to pathogens, and several of those listings specifically include onsite wastewater systems as the source of impairment. These water impairments impede the public's ability to use and recreate in surface waters.

Black Belt, 49 Columbia Human Rights L. Rev. 190 (2017) (citing Jessica Cook Wedgworth & Joe Brown, Limited Access to Safe Drinking Water and Sanitation in Alabama's Black Belt: A Cross-Sectional Case Study, 5 Water Quality, Exposure & Health 69, 71 (2013)).

<sup>&</sup>lt;sup>73</sup> National Association of Local Boards of Health, *Local Board of Health Guide to On-Site Wastewater Treatment Systems* at 10 (2006),

https://www.cdc.gov/nceh/ehs/docs/onsite\_wastewater\_nalboh.pdf.

<sup>&</sup>lt;sup>74</sup> For example, the North Fork of the Kentucky River has been under a swim advisory for years, and routinely has highly elevated levels of *E. coli*, in spite of the lack of urban areas or concentrated animal feeding operations in this part of eastern Kentucky. Kentucky Division of Water, Swimming Advisories, *Swimming Advisories to Continue at Kentucky Sites*,

http://water.ky.gov/waterquality/Pages/SwimmingAdvisories.aspx (last visited Sept. 25, 2018); Kentucky Water Resources Research Institute, *A Summary of the Kentucky River Watershed Watch*, 2016 Water Sampling Results,

 $http://www.uky.edu/krww/sites/www.uky.edu.krww/files/2016\%\\ 20KRWW\%\\ 20Summary\%\\ 20Report\_Final.pdf.$ 

<sup>&</sup>lt;sup>75</sup> See, e.g., West Virginia Dep't of Envt'l Protection, 2014 West Virginia Integrated Water Quality Monitoring and Assessment Report at 17, 20,

http://www.dep.wv.gov/WWE/watershed/IR/Documents/IR\_2014\_Documents/2014FinalIRDocuments/E PAApprovedWebDocumentOnly.pdf (naming fecal coliform as the most common cause of stream impairment in the state and providing the listed causes for bacterial impairment as "leaking or over flowing sewage collection systems, illegal homeowner sewage discharges by straight pipes or failing septic systems, and runoff from urban or residential areas and agricultural lands"). According to Food & Water Watch's factory farm map, as of 2012, there were very few factory farms in the state of West Virginia. Food & Water Watch, https://factoryfarmmap.org/ (last visited Sept. 25, 2018).

<sup>&</sup>lt;sup>76</sup> 2016 Alabama Clean Water Act sec. 303(d) List (Sept. 6, 2016),

http://adem.alabama.gov/programs/water/wquality/2016AL303dList.pdf.



# C. <u>Impacts to Quality of Life</u>

In addition to the potential acute and chronic health impacts and the related impacts to water quality, the repeated exposure to raw sewage generally reduces families' standard of living and quality of life. In the black belt counties of Alabama, a place with a long history of racial discrimination, living with raw sewage on the ground is one of the starkest forms of inequality. No parent should be forced to keep their children indoors in the summer, out of fear they will be exposed to raw sewage in the yard. These living conditions harm property values, run afoul of the most basic expectations of living conditions in this country, and ruin residents' aesthetic enjoyment of the outdoors.

#### VII. DISPROPORTIONALITY

In the United States, more than half a million households, or roughly 1.4 -1.7 million people, lack access to complete plumbing facilities, defined by the Census as access to hot and cold running water, a flush toilet, and a bathtub or shower. Economic conditions alone are not a predictor of access to complete plumbing. Instead, there is a statistically significant correlation with race, as white counties are more likely to have complete plumbing. Overall, American Indian and Alaskan Native communities are most likely to lack access to plumbing in the United States, with 4.4 percent of households lacking plumbing. In Alabama, black residents are more likely to lack plumbing, and although black residents make up only approximately 25% of the total state population, they make up more than half of all people lacking plumbing in the state. Although available Census data provides context regarding the racially disproportionate lack of access to plumbing in this country, it severely underestimates the extent of sanitation access problems because it does not include residents who have access to a flush toilet, but otherwise lack adequate or functional wastewater disposal services, including onsite systems.

More than 80% of Lowndes County residents must rely on onsite wastewater disposal systems, but access to functional, affordable onsite systems is disproportionately lacking for black residents, compared with the county's white residents. When asked whether there was a problem with the better off white part of town being connected to the sewer, but the poorer black part of town not being connected to the sewer in Lowndes County, ADPH's Health Officer Dr. Scott Harris conceded "there is a clear racial disparity here, I mean there's no question about it. I think people who are impoverished, of any color, but particularly African American people who

<sup>&</sup>lt;sup>77</sup> Gasteyer et al., *Basics Inequality: Race and Access to Complete Plumbing Facilities in the United States*, Du Bois Review at 306 (2016) (citing 2013 U.S. Census American Community Survey data) ("Gasteyer et al."); Rural Community Assistance Partnership, *Still Living Without the Basics in the 21st Century: Analyzing the Availability of Water and Sanitation Services in the United States* at Executive Summary (citing 2000 U.S. Census), https://rcap.org/wp-content/uploads/2017/05/Still-Living-Without-the-Basics-Water.pdf ("RCAP").

<sup>&</sup>lt;sup>78</sup> Gasteyer et al., *supra* n. 77, at 311-316.

<sup>&</sup>lt;sup>79</sup> *Id.* at 314; RCAP, *supra* n. 77, at 16-17.

<sup>&</sup>lt;sup>80</sup> RCAP *supra* n. 77, at 24.



are impoverished, lack the social capital to be able to get their problems addressed. They are unable to get government to answer to them in a way that people who are more well off or have better connections can do."81

The available data<sup>82</sup> support the conclusion that black residents in the black belt region are less likely to have access to onsite wastewater systems. Comparing ADPH's publicly available county-level "annual report" data for majority white counties in the black belt with majority black counties in the black belt, it is clear that black residents are receiving far fewer onsite wastewater treatment permits. The most recent figures from ADPH show that county health departments issued 3.4 new or repair permits for every 1000 residents in majority white counties in the black belt, but only 1.1 new or repair permits for every 1000 residents in majority black counties in the black belt.<sup>83</sup> By instead analyzing the same data as a function of the proportion of white residents (as opposed to the majority race in each county), ADPH's data indicate that as the proportion of white residents increases, so does the number of new or repair permits issued per every thousand residents. Conversely, as the proportion of black residents increases, the number of permits issued per every thousand residents decreases.

-

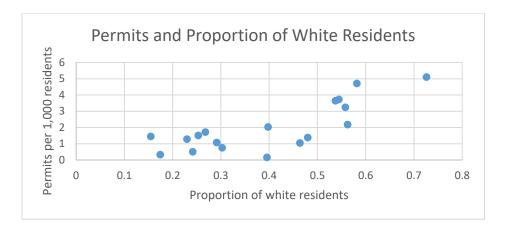
<sup>&</sup>lt;sup>81</sup> PBS, *The Story of American Poverty, as Told by One Alabama County* at minute 7:21-7:54 (July 7, 2018), https://www.pbs.org/newshour/show/the-story-of-american-poverty-as-told-by-one-alabama-county.

<sup>&</sup>lt;sup>82</sup> As noted in *supra* part V.C, ADPH does not collect data on how many families lack adequate sewage treatment in Lowndes County.

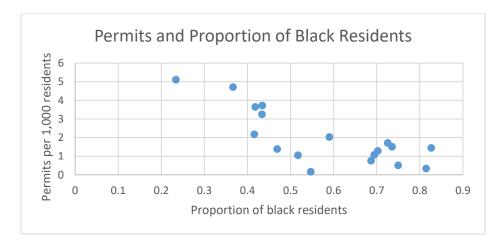
<sup>&</sup>lt;sup>83</sup> Comparing 2010 Census total population and race data, with county health department annual report data on new and repair permits, http://www.alabamapublichealth.gov/about/health-departments.html. For purposes of this data analysis, we define black belt counties to include the following eighteen counties: Barbour, Bullock, Butler, Choctaw, Crenshaw, Dallas, Greene, Hale, Lowndes, Macon, Marengo, Montgomery, Perry, Pickens, Pike, Russell, Sumer, and Wilcox. All county health department annual report data on new and repair permits is for the year 2017 except for Green, Hale, Perry, and Sumter counties, for which data is from the year 2015 because that is the most recent year for which data has been posted for these counties.



**Fig. 3.** Number of Black Belt Permits Compared with Proportion of White Residents (Source: 2010 Census, current ADPH County Annual Report)<sup>84</sup>



**Fig. 4. Number of Black Belt Permits Compared with Proportion of Black Residents** (Source: 2010 Census, current ADPH County Annual Report)<sup>85</sup>



<sup>&</sup>lt;sup>84</sup> For purposes of this data analysis, we define black belt counties to include the following eighteen counties: Barbour, Bullock, Butler, Choctaw, Crenshaw, Dallas, Greene, Hale, Lowndes, Macon, Marengo, Montgomery, Perry, Pickens, Pike, Russell, Sumer, and Wilcox. All county health department annual report data on new and repair permits is for the year 2017 except for Green, Hale, Perry, and Sumter counties, for which data is from the year 2015 because that is the most recent year for which data has been posted for these counties.

<sup>&</sup>lt;sup>85</sup> For purposes of this data analysis, we define black belt counties to include the following eighteen counties: Barbour, Bullock, Butler, Choctaw, Crenshaw, Dallas, Greene, Hale, Lowndes, Macon, Marengo, Montgomery, Perry, Pickens, Pike, Russell, Sumer, and Wilcox. All county health department annual report data on new and repair permits is for the year 2017 except for Green, Hale, Perry, and Sumter counties, for which data is from the year 2015 because that is the most recent year for which data has been posted for these counties.



Lowndes County, in particular, has some of the lowest levels of new onsite wastewater treatment permits and repair permits of all the counties within the black belt region, with only seventeen permits issued in 2017, and seven permits issued in 2015 (county data is unavailable for the year 2016).86 The dearth of new and repair permits issued for black residents in the black belt is a symptom of the disproportionate lack of access to onsite wastewater systems for these individuals.

#### LESS DISCRIMINATORY ALTERNATIVES VIII.

The following less discriminatory alternatives were available to ADPH and LCHD:

- ADPH and LCHD could have notified Lowndes County residents that nineteen cases of hookworm have been confirmed in Lowndes County;
- ADPH and LCHD could have ordered an investigation of the extent and severity of the hookworm outbreak in Lowndes County;
- ADPH and LCHD could have requested medical treatment necessary to eradicate hookworm in all infected individuals in Lowndes County; and
- ADPH and LCHD could have ordered a survey in Lowndes County that documents all homes with failing septic systems, straight pipes, or other forms of inadequate onsite wastewater disposal; and
- ADPH and LCHD could have maintained racial and ethnic data showing the extent to which members of minority groups are beneficiaries of the onsite wastewater disposal systems program.

#### IX. RELIEF

Complainant requests that the HHS Office of Civil Rights accept this complaint and investigate whether ADPH and LCHD violated Title VI of the Civil Rights Act and its implementing regulations. We also request that the Civil Rights Division of the Department of Justice play an active role in coordinating this federal investigation and any enforcement actions, consistent with the mission of the Federal Coordination & Compliance Section.

Complainant requests that ADPH and LCHD be brought into compliance by requiring them to: a) retract ADPH's public notice that there is no evidence of hookworm in Lowndes County; b) inform the residents of Lowndes County and neighboring counties about the nineteen confirmed cases of hookworm and educate the public about risks of infection and available treatment; c) request that the Centers for Disease Control and Prevention ("CDC") or another appropriate federal agency investigate the extent of hookworm in Lowndes County, including in

<sup>&</sup>lt;sup>86</sup> See 2015 Lowndes County Health Department Annual Report,

https://www.alabamapublichealth.gov/lowndes/assets/2015AnnualReport Lowndes.pdf; 2017 Lowndes County Health Department Annual Report,

https://www.alabamapublichealth.gov/lowndes/assets/Lowndes\_2017AnnualReport.pdf.



residences around wastewater treatment lagoons such as the Hayneville lagoon, and provide or facilitate access to medical treatment necessary to eradicate hookworm in all infected individuals in Lowndes County; d) request that the CDC or another appropriate federal agency conduct an independent survey of the extent of failing septic systems, straight pipes, and other forms of inadequate onsite wastewater systems without threat of fines or arrests; e) maintain racial and ethnic data showing the extent to which members of minority groups are beneficiaries of the onsite wastewater disposal systems program; f) adopt a policy of non-enforcement of the sanitation misdemeanor, ALA. CODE § 22-26-1, and recommend to the Alabama legislature that they repeal this statute; and g) support any community or federal efforts to develop and implement a program that provides adequate and functional onsite wastewater treatment systems to low-income homeowners who cannot afford adequate onsite wastewater disposal in Lowndes County, as well as other black belt counties containing soil that is incompatible with conventional septic systems.

ADPH and LCHD must take steps to correct the disproportionate lack of access to adequate onsite sewage treatment in Lowndes County and ameliorate the public health effects in this predominantly black community. As they develop the measures necessary to come into full compliance with Title VI, ADPH and LCHD should engage fully with representatives of the local community, and be guided by the community's needs.

If ADPH and LCHD do not come into compliance voluntarily, Complainant requests that HHS suspend or terminate the federal financial assistance those agencies receive.

Sincerely,

anna M. Sewell Anna Sewell **Neil Gormley** Earthjustice 1625 Massachusetts Ave. NW, Ste. 702 Washington, D.C. 20036-2243 asewell@earthjustice.org ngormley@earthjustice.org

On behalf of Alabama Center for Rural Enterprise

CC (via email):

Alex M. Azar II Secretary, U.S. Department of Health and Human Services



200 Independence Avenue, S.W. Washington, D.C. 20201 Secretary@HHS.gov

Timothy Noonan Regional Manager, Office for Civil Rights U.S. Department of Health and Human Services Sam Nunn Atlanta Federal Center, Suite 16T70 61 Forsyth Street, S.W. Atlanta, GA 30303-8909 OCRMail@hhs.gov

# Exhibit 1

United Nations A/HRC/18/33/Add.4



Distr.: General 2 August 2011

Original: English

# **Human Rights Council**

Eighteenth session
Agenda item 3
Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development

# Report of the Special Rapporteur on the human right to safe drinking water and sanitation, Catarina de Albuquerque'

Addendum

Mission to the United States of America\*\*\*

## Summary

The present report presents the findings and recommendations of the independent expert on the human rights to safe drinking water and sanitation from her country visit to the United States of America from 22 February to 4 March 2011.

In the report, the independent expert begins by outlining the international and domestic legal framework on the rights to water and sanitation. She then makes a general assessment of the enjoyment of the rights to water and sanitation in the United States of America, looking specifically at the following issues: sanitation, safety, affordability and excluded groups. This assessment is then underpinned by an analysis of the right to non-discrimination and equality. The last section examines United States official development assistance in the area of water and sanitation. She concludes the report with recommendations addressed to the Government.

<sup>\*\*\*</sup> The summary of the present report is circulated in all official languages. The report itself, contained in the annex to the summary, is circulated in the language of submission only.



<sup>\*</sup> Late submission

<sup>\*\*</sup> Throughout the present report, reference is made to the independent expert on the issue of human rights obligations related to access to safe drinking water and sanitation, which was the title of the mandate at the time that the mission was undertaken. However, in accordance with Human Rights Council resolution 16/2, adopted on 24 March 2011, the title of the mandate has been changed to Special Rapporteur on the human right to safe drinking water and sanitation.

# Annex

# Report of the Special Rapporteur on the human right to safe drinking water and sanitation on her mission to the United States of America (22 February-4 March 2011)

# Contents

			Paragraphs	Page
I.	Introduction		1–5	3
II.	International and domestic legal framework			3
III.	The	right to water and sanitation in the United States of America	14–79	5
	A.	Sanitation	19–29	6
	B.	Safety	30–46	8
	C.	Affordability	47–54	12
	D.	Excluded groups	55–69	13
	E.	Prioritization of personal and domestic uses	70–78	16
IV.	No	n-discrimination and equality	79–82	17
V.	Official development assistance		83–87	18
VI	Conclusions and recommendations		88_92	19

# I. Introduction

- 1. From 22 February to 4 March 2011, the independent expert on the issue of human rights obligations related to access to safe drinking water and sanitation, Catarina de Albuquerque, undertook an official country visit to the United States of America to assess the way in which the United States is implementing the rights to water and sanitation.
- 2. The independent expert thanks the Government of the United States of America for the cooperation extended in the preparation of and during the mission, especially the Department of State for coordinating the visit. Additionally, she thanks the representatives of the following federal government agencies: the Department of Justice; the Department of Interior; the Environmental Protection Agency; the United States Agency for International Development; the Department of Health and Human Services, including the Centers for Disease Control; the White House Council on Environmental Quality; the Department of Agriculture; and the Interagency Council on Homelessness. The independent expert also had the honour of participating in a hearing convened by the Congressional Tom Lantos Human Rights Commission on the right to water.
- 3. During the mission, the independent expert visited Washington DC; Boston and Falmouth in Massachusetts; Sacramento, Redding, including the Winnemen Wintu tribe, Seville and other communities in the San Joaquin Valley in California; and Edmonston, Maryland. In each of these locations, she had the occasion to meet with state and local authorities. The independent expert thanks them also for their time and engagement.
- 4. The independent expert convened seven public hearings in the various locations she visited, and had the honour of receiving personal testimony from all across the United States including from Alabama, Alaska, Michigan, Puerto Rico and West Virginia. She especially thanks all those individuals who travelled long distances to share their stories with her. Numerous other testimonies were submitted in writing, reflecting the experiences of other individuals and communities from other regions of the United States.
- 5. During the mission, the independent expert was particularly struck by the vibrant and active engagement of civil society working on human rights, water and sanitation issues. She is especially grateful for their initiative to connect her with affected communities and victims. She extends a special word of thanks to all those who shared their personal stories with her.

# II. International and domestic legal framework

6. At the international level, the human right to safe drinking water and sanitation derives from the right to an adequate standard of living which is protected under, inter alia, article 25 of the Universal Declaration of Human Rights, and article 11 of the International Covenant on Economic, Social and Cultural Rights. This right was also recently recognized by the General Assembly and reaffirmed by the Human Rights Council, with the support of the United States of America, which the independent expert welcomes¹. States obligation with regard to the right to safe drinking water and sanitation requires that water and sanitation be available, accessible, affordable, acceptable and of good quality for everyone without discrimination. This obligation must be progressively realized to the maximum of available resources, meaning that a State must take concrete and targeted steps towards ensuring universal access to water and sanitation. Any retrogressive measure – such as in a period of economic crisis – is presumed to be a violation of the human right unless fully

<sup>&</sup>lt;sup>1</sup> See A/RES/ 64/292, A/HRC/RES/15/9 and A/HRC/RES/16/2.

justified by the State.<sup>2</sup> There must be opportunities for meaningful participation in decision-making; there must be transparency and access to information; and accountability mechanisms must be established to address cases where these rights are violated. Ensuring the rights to water and sanitation is closely related to the enjoyment of other human rights, including the rights to education, work, health, housing and food, among others.

- 7. The legal framework governing access to water and sanitation in the United States of America is a complex amalgam of federal and state statutes and common law principles. This multi-tiered system, coupled with an array of variances available to states and private actors, make generalizations about the capacity of the United States legal framework to reflect access to safe drinking water and sanitation as human rights particularly difficult. The United States has not ratified many of the relevant treaties from which these rights are derived, including the International Covenant on Economic, Social and Cultural Rights, the Convention on the Elimination of All Forms of Discrimination against Women, the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities. The independent expert, nevertheless, notes that the United States has signed these instruments (in 1977, 1980, 1995 and 2009, respectively) and reminds the Government that upon signing, it assumed the obligation to refrain from acts that would defeat the object and purpose of these treaties, pending decision on ratification. She encourages the United States to take steps towards ratifying these instruments without reservations.
- 8. Existing federal laws generally focus on maintaining water quality rather than ensuring access for all citizens. Constitutional and statutory provisions that pertain to non-discrimination and equal protection of the law create a framework that allows citizens to enforce the rights to safe drinking water and sanitation indirectly, but without the ability to ground such claims as an explicit right, the success of such claims remain uncertain.
- 9. While there is no federally recognized right to safe drinking water and sanitation, individual states have taken the initiative to consecrate this right. For instance, the states of Massachusetts and Pennsylvania have already recognized the right to water (though not to sanitation) in their constitutions.<sup>3</sup> In California, a bill package has been introduced that recognizes the human right to water.<sup>4</sup>
- 10. The two primary federal statutes governing water in the United States are the Clean Water Act and the Safe Drinking Water Act. Additionally, a number of federal agencies play a role in regulating water, including the Environmental Protection Agency (EPA), the Department of Agriculture and the Department of the Interior.<sup>5</sup>
- 11. The Environmental Protection Agency (EPA) leads in establishing minimum standards for regulating pollution and water quality, as well as monitoring and enforcing these standards in federal waterways. The states are free to adopt their own regulations insofar as they meet, at a minimum, federal standards. For instance, states are responsible for monitoring and enforcing water quality standards at local sources, developing infrastructure and managing wastewater treatment.

<sup>&</sup>lt;sup>2</sup> See Committee on Economic, Social and Cultural Rights, general comment No. 3, para. 9.

<sup>&</sup>lt;sup>3</sup> See Constitution of the Commonwealth of Massachusetts, art. XCVII; and Constitution of the Commonwealth of Pennsylvania, art. 1, sect. 27.

See California Legislature, 2011–12 regular season, Assembly Bill No. 685 introduced by Assembly Member Mike Eng.

<sup>&</sup>lt;sup>5</sup> Additional federal agencies, such as the Department of Housing and Urban Development and the Department of Justice, play a role in preventing discrimination in terms of access to water and sanitation services.

- 12. The Clean Water Act of 1972 is a broad initiative aimed at controlling pollution in all surface waters. Among other things, the Clean Water Act bans the discharge of pollutants into navigable waters and sets water quality standards for contaminants in all surface waters. The Water Quality Standards Regulation accompanies the Clean Water Act and authorizes EPA to establish water quality standards. EPA publishes recommended criteria for various designated uses, and plans to propose amendments to its water quality standards in summer 2011. Although clear water quality standards are set, a complex system of exceptions means that often these standards are legally disregarded. Each state is responsible for reviewing, establishing and revising water quality standards for waters within its borders, within the minimum standards set by EPA. EPA has review powers over state regulations. Federally recognized American Indian tribes may also apply for eligibility to develop their own water quality standards
- 13. The Safe Drinking Water Act of 1974 sets maximum levels for contaminants in drinking water and its sources, and requires water systems to test regularly for contaminants. These standards apply to every public water system in the United States. The 1996 Amendments to the Safe Drinking Water Act allot federal funds to states to develop programmes to protect groundwater. The majority of regulations related to water quality, modelled on those promulgated by EPA, can be found in state statutes, and are enforced through state environmental agencies.

# III. The right to water and sanitation in the United States of America

- 14. People living in the United States enjoy near universal access to safe water. Nationwide, there are an estimated 161,000 public water systems<sup>6</sup>, which may be publicly or privately owned. Community water systems are public water systems that serve people year-round in their homes. The majority of people in the United States (268 million) receive their water from a community water system (54,000 systems). Approximately 15 per cent (46 million) of Americans rely on their own private drinking water supplies, and these supplies are not subject to EPA standards, although some state and local governments set rules to protect users of these wells. With no regular monitoring, the burden is on households with private systems to take precautions to ensure the protection and maintenance of their drinking water supplies. Additionally, over 53,000 rural water utilities exist, 90 per cent of which serve communities of 10,000 people or less. These figures highlight the fragmentation of the sector, which presents enormous challenges when trying to regulate, monitor and find solutions for universal access.
- 15. Twenty-five percent of all households in the U.S. have on-site wastewater treatment systems, and most others are connected to sewerage networks and wastewater treatment facilities. But according to EPA, in general, states and communities have not established adequate management programmes to assure proper functioning of onsite systems for wastewater treatment.
- 16. The United States has aging water and wastewater systems, with decreasing investment in research and development, coupled with an increase in the population. By the

The Safe Drinking Water Act defines a public water system as one that serves piped water to at least 25 persons or 15 service connections for at least 60 days each year.

United States Environmental Protection Agency, "Water on Tap: What you need to know," December 2009, p. 2, available from www.epa.gov/safewater/wot/pdfs/book\_waterontap\_full.pdf.

Environmental Protection Agency, Private Drinking Water Wells, available at http://water.epa.gov/drink/info/well/index.cfm.

year 2020, the population will likely be over 325 million and systems will need to increase capacity. Furthermore, the population is shifting geographically, requiring rapid increases in system capacity in some parts of the country, and maintenance of aging systems in other parts of the country with diminishing populations (and a diminishing rate base).

- 17. In the last 20 years, communities have spent one trillion dollars on drinking water treatment and supply and wastewater treatment and disposal. Ninety per cent of these costs are financed by consumers. However, this may not be sufficient to keep pace with infrastructure needs of the future. Hence, EPA estimates that over the next 20 years, \$200 billion to \$400 billion will be required to ensure the sustainability of water and wastewater systems. In a time of scarce financial resources, the United States needs greater efforts to ensure that available funding, including loans and grants provided through the Safe Water and Clean Water State Revolving Fund, prioritizes those who are in the most precarious situations. While acknowledging that states must provide a minimum of 15 per cent of the available funds for loans to small communities, which enables them to address the challenges faced by poor and marginalized communities to a certain extent, the possibility for a state to provide up to 30 per cent of the grant received to provide additional assistance to disadvantaged communities remains a mere "option."
- 18. The independent expert welcomes the fact that there is near universal access to water and sanitation in the United States and commends the Government for its achievements in this regard. By its nature, a human rights analysis focuses on the situation of the most marginalized and excluded. Thus, this report especially concentrates on the situation of these groups with regard to their access to water and sanitation. While these groups comprise a small proportion of the population, the independent expert emphasizes that they require priority attention.

#### A. Sanitation

- 19. In the United States, it is often the poorest and the most marginalized groups that lack access to sanitation. Without proper sanitation, human excreta contaminate drinking water sources, with severe public health implications. Ensuring access to adequate sanitation for all is not only fundamental for human dignity and privacy, but is also key to protecting water quality. States must progressively extend safe sanitation services, particularly to rural and deprived urban areas, taking into account the needs of disadvantaged groups.<sup>9</sup>
- 20. The independent expert received testimony concerning the wastewater situation in Lowndes County, Alabama. The County has a population of 12,293, of which 70.1 per cent is Black, with an annual median household income of \$30,225 and 25.4 per cent living below the poverty line. <sup>10</sup> As a mostly rural county, about 18 per cent of the population are served by conventional municipal sewer systems. The remaining 82 per cent rely on on-site wastewater systems, typically septic tanks and in-ground dispersal fields (trenches). The Alabama Department of Public Health estimates that the number of households in Lowndes County with inadequate or no septic systems range from 40 to 90 per cent; it has reported that 50 per cent of the conventional, on-site septic systems are currently failing or are expected to fail in the future.

<sup>&</sup>lt;sup>9</sup> E/C.12/2002/11, para. 29

United States Census Bureau, Lowndes County, Alabama, State & County Quick Facts, 4 November 2010, available at http://quickfacts.census.gov/qfd/states/01/01085.html.

- 21. In 1999, the Alabama Department of Public Health initiated legal action (litigations and arrests) against 41 sites for releasing raw sewage into the ground surface, despite repeated violation notices in an attempt to oblige wastewater management to meet minimum environmental and health standards. Many individuals, who could not afford to take remedial action, were arrested. They now have arrest records for not having been able to afford the costly remedy. More recently in 2008, following complaints from a neighbour, the Department of Public Health initiated steps towards the arrest of a 27-year-old single mother, who lived in a mobile home with her autistic child, for not maintaining her septic system according to applicable health standards. The septic system replacement cost was higher than her annual income of \$12,000, and she did not have the means to access funding.
- 22. Key to understanding the serious need for adequate wastewater systems and management in Lowndes County is the nature of the native soils, which consist principally of heavy clay material that does not transmit water well and results subsequently in significant effluent run-off problems. The most common on-site wastewater alternative ranges in price from \$6,000 to as much as \$30,000 money that most residents of Lowndes County do not have. As such, the right to sanitation is inaccessible for a substantial proportion of Lowndes County residents.
- 23. The independent expert welcomes recent news that EPA has issued a \$575,000 grant to the Alabama Center for Rural Enterprise to develop a master plan to address the need for access to sanitation services in Lowndes County.
- 24. The central Appalachian region of Maryland, Pennsylvania, Virginia and West Virginia faces similar challenges in realizing the right to sanitation. This rural region is populated by many communities without basic water and sewer infrastructure, and which face some of the highest poverty and lowest education attainment rates in the United States. The independent expert received testimony from communities that were forced to directly discharge untreated sewage into streams and ground surfaces, and she was informed that in West Virginia and southern Virginia, as many as two-thirds of homes were discharging raw sewage.
- 25. In Falmouth, Massachusetts, the surrounding bays and estuaries are increasingly contaminated with nitrates, and a centralized sewage system is being proposed as a solution. Should such a project move forward, those living in the community would be required to pay an estimated \$50,000 to \$60,000 to implement it. In Falmouth, however, the median annual income for over 60 per cent of the residents is \$20,000.<sup>11</sup>
- 26. Falmouth is emblematic of situations occurring all around the country. Repairing aging infrastructure in cities and building new water and sewer systems in rural areas in traditional ways is increasingly untenable and federal funding for water and sanitation tends to be structured around conventional centralized systems, resulting in per-household costs that are too high and discouraging investment in rural systems.
- 27. Consideration should be given to decentralized water and wastewater systems in rural communities. Multiple benefits could be realized with decentralized systems, including fulfilling the rights to access water and sanitation services; reaping economic and environmental savings; and providing opportunities to expand businesses that develop decentralized systems that could be used globally. Pilot projects in rural communities could

This figure was reported to the independent expert by a former Massachusetts State representative. While official census figures for 2009 indicate a median annual household income of \$30,913, the lower figure refers to the lower income portion of the population. Census figures are available at http://quickfacts.census.gov.

test innovative technology and compile information on construction costs, performance, and operation and maintenance costs. In this context, the independent expert recalls that the Government has well-developed programmes to assist rural communities through the Rural Utilities Program of the United States Department of Agriculture, among others. Nevertheless, poor, disadvantaged, minority and indigenous communities are often unable to access federal, state and local funding sources due to technical, managerial and financial capacity requirements, among others. The independent expert calls on federal, state and local governments to consider innovative and ecologically-friendly solutions to ensure sustainable systems that are affordable for the community, while recalling the need to establish adequate programmes to assure proper functioning and maintenance of on-site systems for wastewater treatment.

- 28. The independent expert notes that EPA has articulated the Clean Water and Drinking Water Infrastructure Sustainability Policy, which aims to work with states and local governments to develop guidance, provide technical assistance, and target the federal Clean Water State Revolving Fund capitalization assistance to support the increase in the sustainability of water infrastructure in the United States and the communities it serves. She also acknowledges the Alaska Native Villages and the US–Mexico Border water infrastructure programmes that are designed to address urgent infrastructure needs in two areas that are economically disadvantaged and had documented examples of untreated sewage discharges.
- 29. This is a positive development, and the gains of such policies and programmes would be enhanced if brought in line with human rights norms.

# B. Safety

- 30. Water and sanitation must be safe and of good quality, and must not pose a threat to human health. According to a report by the Environmental Working Group, since 2004, water-quality testing by utilities has found 315 pollutants in tap water; EPA has set enforceable standards for 114 pollutants. For those pollutants subject to regulation, 49 were found in one place or another at levels above EPA guidelines, exposing some 53 million people to polluted tap water. 12 Moreover, drinking-water quality analysis conducted by the Environmental Working Group found that utilities achieved 92 per cent compliance with EPA mandatory health standards for the 114 regulated contaminants, demonstrating that utilities can and do comply with regulatory standards when they exist. This finding comports with EPA's own annual performance assessment for 2010, which reported that 92 per cent of people were served by community water systems that met applicable healthbased drinking water standards. 13 Nevertheless, the goal of universal access to clean and safe water has yet to be attained. Infants, older persons, persons with certain medical conditions and other vulnerable groups remain at risk from exposure to water that does not meet federal standards. Moreover, hundreds of substances found in water remain unregulated, and some sources of water, namely private drinking-water supplies, are also unregulated.
- 31. In addition, the independent expert received worrying testimony regarding lead contamination of water in Washington DC. The presence of lead in drinking water can

Environmental Working Group, "National Assessment of Tap Water Quality," December 2009. The report analysed almost 20 million records of drinking water quality tests obtained from state water officials.

United States Environmental Protection Agency, "Highlights: Fiscal Year 2010 Financial and Program Performance," February 2011, p. 14.

cause adverse health effects. From 2001 to 2004, the District of Columbia experienced elevated lead levels in its drinking water system, triggered by a change in disinfectant. Although the change in disinfectant brought the water quality in line with EPA regulations concerning the concentration of potential carcinogens (a by-product of chlorine disinfection), it altered the chemistry of the water, causing lead to leach from pipes and elevating water lead levels in homes throughout the city.

- 32. The Water and Sewer Authority (now known as DC Water) did not notify the public until 2003. The notices were unclear and thousands were exposed to harmful lead levels. Following a story published in *The Washington Post* in 2004, the city made efforts to replace thousands of lead pipes (on public property) servicing 17,600 homes. Homeowners were responsible for authorizing and paying for the work on their property, but many did not have the financial means to do so. On the advice of the Centers for Disease Control and EPA, however, the programme was suspended in late 2008 as partial pipe replacements were found to cause spikes in water lead levels in homes.
- 33. Residents have been advised to completely replace all lead service lines, the cost of which may be prohibitively expensive for low-income residents, therefore leaving them without safe water. In this context, the independent expert notes that DC Water has offered to replace the public portion of a lead service line if a homeowner voluntarily replaces the private portion. Also, the DC Department of Housing and Community Development offers a grant programme to income-qualified property owners who are interested in replacing the private portion of their lead service line. Nevertheless, concerns remain for those households that, even with financial support from such programmes, are unable to afford lead service line replacements.
- 34. The San Joaquin Valley in central California is also experiencing enormous challenges, particularly nitrate contamination, with regard to drinking water, The Valley represents around 10 per cent of the total population of California, with a population of 3.8 million people, 20 per cent of whom live below the poverty line, and 46 per cent of whom are Latino. He While nitrates occur naturally at low levels, crop fertilizers, animal manure or septic systems can elevate nitrate levels in drinking water sources. Because it is difficult to assign responsibility for this type of pollution (non-point source pollution), no one is obliged to pay for the clean-up costs. In these circumstances, the affected community inevitably bears these costs.
- 35. The San Joaquin Valley accounts for over half of the agricultural production of California. It is populated by numerous concentrated animal feeding operations, with an estimated 1.6 million dairy cows and 161,000 beef cattle in 2008; a typical cow produces over 30 tonnes of solid manure per year. <sup>15</sup>
- 36. It is vulnerable to nitrate contamination because groundwater serves as the primary source of drinking water for almost 90 per cent of its residents. According to the United States Geological Survey, millions of pounds of nitrate (in fertilizers and manure) and pesticides are applied to cropland annually, with some of these chemicals filtering into the groundwater and thereby threatening public health. During the mission, the Department of Agriculture acknowledged the need to address the challenges posed by targeting the small

Carolina Balazs, "Just Water? Social Disparities in Nitrate Contaminated Drinking Water in California's Central Valley," PhD dissertation, University of California at Berkeley (forthcoming).

Community Water Center, "Water and Health in the Valley: Nitrate Contamination of Drinking Water and the Health of San Joaquin Valley Residents," p. 3.

<sup>16</sup> Ibid., p. 2.

Neil Dubrovsky and others, "Water Quality in the San Joaquin-Tulare Basins, California, 1992-95," US Geological Survey Circular 1159, 1998.

and disadvantaged water systems and noted some initiatives in this regard (see para. 26 above).

- 37. The independent expert visited Tulare County, the poorest county in California, where minorities comprise the majority of the local population (58.3 per cent Latino, 3.8 per cent Asian and Pacific Islander, 2.1 per cent Black, 1.9 per cent American Indian)<sup>18</sup>. One of the top three agricultural producing counties in California,<sup>19</sup> Tulare County has many public water systems with nitrate levels over the maximum contaminant level (MCL) of 45 parts per million. Approximately 20 per cent of Tulare County's small public water systems (defined as 5 to 199 service connections/homes) are unable to meet the nitrate MCL on a regular basis, and another 20 per cent are over half the nitrate MCL.<sup>20</sup>
- 38. The independent expert received testimony from various rural communities in Tulare County, representing Alpaugh, Cutler, East Orosi, Orosi, Seville and Tooleville, among others. These communities suffer from drinking water contaminated by nitrates, arsenic, banned pesticides and disinfectant by-products. Seville, a small, low-income community, is illustrative of the broader problems plaguing Tulare County.
- 39. For Seville residents, the reliance on groundwater means that when it becomes contaminated, there are no alternative water supplies. Besides paying the regular water bill, families are forced to purchase bottled water to ensure safe and clean water for drinking and cooking. The cost of bottled water thus becomes the de facto water rate, which is not including the cost of transport to the store. With a median household income of \$14,000 per year, households, in total, are devoting approximately 20 per cent of their income to water and sanitation. Households who are unable to afford alternative solutions, such as buying bottled water, uninformed about the water quality or forced to make difficult trade-offs, such as forgoing other basic needs, fall into a protection gap.
- 40. Research conducted by the University of California at Berkeley found that in smaller water systems, communities with larger percentages of Latinos and renters are potentially exposed to drinking water with higher nitrate levels, compared to communities with higher proportions of White residents and homeowners. <sup>22</sup> The independent expert expresses concerns about such racial disparities, and urges the Government to take concerted action to eliminate discrimination in practice, as well as to ensure country-wide regulation and monitoring of private drinking water supplies.
- 41. The independent expert received concerning reports on hydraulic fracturing and its impact on water. New technological developments have allowed the oil and gas industry to extract natural gas from shale resources previously believed too expensive and difficult to tap. Hydraulic fracturing has been used in the industry for over 60 years and is now utilized

United States Census Bureau, Tulare County, California, State & County Quick Facts, 4 November 2010, available at http://quickfacts.census.gov/qfd/states/06/06107.html.

United States Department of Agriculture, National Agricultural Statistics Service, "Dairy Cattle and Milk Production," Census of Agriculture 2007.

County of Tulare, "Agenda Item: Modification of the membership of the Tulare County Water Commission and the authorization of submission of a Proposition 84 grant application," 17 July 2007.

The annual water bill is around \$960 and households are spending at least an additional \$1,000 a year on bottled water. The sanitation bill is roughly \$800 to \$1,000 a year.

Carolina Balazs, "Just Water? Social Disparities in Nitrate Contaminated Drinking Water in California's Central Valley," PhD dissertation, University of California at Berkeley (forthcoming).

in around 90 per cent of the country's oil and gas wells.<sup>23</sup> Projections suggest that shale gas will comprise over 20 per cent of total gas supply in the United States by 2020.<sup>24</sup>

- 42. Hydraulic fracturing is a well-stimulation process used to extract underground resources, such as oil, natural gas and geothermal energy. In 2005 the Congress exempted this practice from regulation under the Safe Drinking Water Act,<sup>25</sup> making this the only industry allowed to inject known pollutants into the ground near water sources without federal oversight. In 2010, EPA was tasked with studying the potential adverse impacts of hydraulic fracturing on drinking water.<sup>26</sup>
- 43. Residents in regions where hydraulic fracturing occurs have reported drinking water contamination. In some cases, reports have been received of flammable tap water in a severe incident causing a home to explode.<sup>27</sup> Federal and state agencies have determined the drinking water in several rural towns, such as Dimock, Pennsylvania, and Pavilion, Wyoming, non-potable due to chemical contaminants used in nearby hydraulic fracturing operations.
- 44. Natural-gas extraction in rural areas increases the likelihood that water contamination will go undetected, as rural water supplies are difficult to monitor. The 1996 amendments to the Safe Drinking Water Act permit variances for rural utilities (less than 10,000 connections) to provide lower quality water. Moreover, as already highlighted, EPA does not have the authority to regulate private wells, which are the primary source of drinking water in many rural areas.
- 45. Large urban cities are better equipped to withstand pressure from the natural gas industry. For example, the Marcellus Shale cutting across New York and Pennsylvania is believed to contain valuable natural gas resources. This notwithstanding, the New York City Department of Environmental Protection has asserted that "hydraulic fracturing poses an unacceptable threat to the unfiltered water supply of nine million New Yorkers and cannot safely be permitted within the New York City watershed."<sup>28</sup>
- 46. A policy disconnect seems to exist between polluting activities and their ultimate impact on the safety of drinking water sources. The absence of integrated thinking has generated enormous burdens, including increased costs to public water systems to monitor and treat water to remove regulated contaminants<sup>29</sup>, and detrimental health outcomes for individuals and communities. The independent expert recommends a holistic consideration of the right to water by factoring it into policies having an impact on water quality, ranging from agriculture to chemical use in products to energy production activities.

<sup>&</sup>lt;sup>23</sup> Riverkeeper Report, "Fractured Communities: Case Studies of the Environmental Impacts of Industrial Gas Drilling," September 2010, p. 3.

United States Environmental Protection Agency, Office of Research and Development, "Hydraulic Fracturing Research Study Fact Sheet," June 2010.

<sup>&</sup>lt;sup>25</sup> Energy Policy Act of 2005, Public Law No. 109-58, sect. 1(a), 119 Stat. 594 (2005).

The final hydraulic fracturing study is expected to be released in 2012.

Ohio Department of Natural Resources, Division of Mineral Resources Management, "Expert Panel Technical Report: Subsurface Gas Invasion, Bainbridge Township, Geauga County, Ohio," June 2010.

Press Release, New York City Department of Environmental Protection, "Department of Environmental Protection Calls for Prohibition on Drilling in the New York City Watershed," 23 December 2009.

According to industry estimates, drinking water utilities spend more than \$4 billion annually on water treatment chemicals; see Environmental Working Group, "National Assessment of Tap Water Quality."

## C. Affordability

- 47. Another element of the human rights to water and sanitation is affordability, meaning that direct and indirect costs and charges associated with securing water and sanitation must not compromise the ability to pay for other essential needs guaranteed by other human rights such as the rights to food, housing, education and health.
- 48. The cost of drinking water is rising, as suppliers need to service aging infrastructure, comply with ever-stringent public health standards and expand access. In most cases, increasing costs have caused water suppliers to increase rates, or otherwise charge users for repairing and upgrading the network as described above. Nevertheless, water is generally still inexpensive compared to other utilities, such as electricity and phone service. In the United States, combined water and sewer bills average only about 0.5 per cent of household income. <sup>30</sup> EPA has elaborated voluntary affordability guidelines, suggesting that a maximum of two per cent of household income should be allocated to water services. <sup>31</sup>
- 49. Nonetheless, for lower income households, the rates for water and sanitation services fall outside the above-mentioned average and above the two per cent ceiling. These households are often faced with difficult financial choices (e.g., late or non-payment of bills, reduced service levels, etc.) in meeting basic service needs. Moreover, lower-income households often occupy substandard housing with inadequate and leaking plumbing fixtures, which contribute to costly wasted water.
- 50. The relationship between affordability of services and patterns of water shut-off policies is another concern. The independent expert received information that water shut-off policies disproportionately impact marginalized persons along race, class and gender. For example, a study by Massachusetts Global Action examined the racial impact of the water pricing and shut-off policies of the Boston Water and Sewer Commission, and found that for every one per cent increase in the city ward's percentage of people of colour, the number of threatened cut-offs increases by four per cent.<sup>32</sup>
- 51. She also received information about situations where children were separated from parents and placed into custodial care, based on applicable child protection laws that seek to safeguard the best interest of the child, because the household water supply was shut off. Water utilities must be able to collect payment for services from customers, but regarding shut-off for non-payment, the independent expert emphasizes the need for due process. The authorities should address the underlying causes of the inability to pay, instead of merely its symptoms. The principle of the best interest of the child should guide decision-making in these cases. The independent expert expresses concern about the discriminatory impact of water shut-off policies, particularly for low-income children and older persons.
- 52. In some states, legal protections are provided against water shut-offs. For example, investor-owned utilities in Massachusetts are not allowed to shut off water to households with children under 12 months, persons over 65 years or persons with certain medical conditions; unfortunately, the same does not apply to public utilities. In Rhode Island, the protection with regard to children extends to two years of age, and covers public and private utilities. In the view of the independent expert, a federal standard should be established to provide protections against water shut-offs for vulnerable and marginalized groups.

<sup>&</sup>lt;sup>30</sup> United States Environmental Protection Agency, "Water on tap: What you need to know," December 2009, p. 9.

<sup>31</sup> The World Bank has suggested a guideline of three to five per cent of household income.

Suren Moodliar and Kimberly Foltz, Massachusetts Global Action, "Human Right to Water in the United States," letter to the independent expert, 22 September 2009.

- 53. From the observations of the independent expert, it is clear that EPA voluntary guidelines on affordability are insufficient to ensure the right to water for all without discrimination. Currently, there is no federal legislation, either directly by statute or through a regulatory agency, mandating affordability standards for water and sanitation. The Federal Government has used its power in other areas to legislate minimum standards this has been the case of the Low-Income Home Energy Assistance Program. The Federal Government has also set minimum standards in relation to water quality and minimum wage standards, deriving its authority from the Commerce Clause of the Constitution. While these laws place ultimate responsibility on the Federal Government, legislation aims to build a regulatory foundation on which states may enact additional rules and take primary responsibility for monitoring and enforcing standards.
- 54. In this regard, the independent expert calls on the Government to adopt a mandatory federal standard on affordability for water and sanitation.

## D. Excluded groups

55. The independent expert met with numerous communities and groups who face challenges in accessing safe water and sanitation. The situations of homeless people and indigenous persons have particular features that warrant a specific human rights analysis.

#### Homeless people

- 56. As a part of her mission, the independent expert examined the situation of the homeless with regard to access to water and sanitation. Up to 3.5 million people experience homelessness in the United States every year, and on any given night over 800,000 people are homeless. In some cities, homelessness is being increasingly criminalized. Criminalization includes fines, arrests and severance of social protection benefits or even access to employment. Local statutes prohibiting public urination and defecation which can constitute a sexual offence in some cases –, while facially constitutional to protect public health, are often discriminatory in their effects. Such discrimination often occurs because such statutes are enforced against homeless individuals who often have no access to public restrooms and are given no alternatives. Furthermore, there is an increasing trend in local governments to limit opening hours or close entirely public restrooms. Such decisions are contrary to the need to create an enabling environment so homeless individuals can realize their rights to water and sanitation.
- 57. The independent expert notes that in 2010 the Inter-Agency Council on Homelessness published the first federal plan to end homelessness. The plan includes constructive alternatives to the criminalization of homelessness.
- 58. Because evacuation of the bowels and bladder is a necessary biological function and because denial of opportunities to do so in a lawful and dignified manner can both compromise human dignity and cause suffering, such denial could, in some cases (e.g., where it results from deliberate actions or clear neglect) amount to cruel, inhumane or degrading treatment. Individuals are sometimes compelled to go to extraordinary lengths to prevent such suffering., The independent expert visited a community of homeless people in Sacramento, California, where she met a man who called himself the "sanitation technician" for the community. He engineered a sanitation system that consists of a seat with a two-layered plastic bag underneath. Every week Tim collects the bags full of human waste, which vary in weight between 130 to 230 pounds, and hauls them on his bicycle a few miles to a local public restroom. Once a toilet becomes available, he empties the content of the bags; packs the plastic bags with leftover residue inside a third plastic bag; ties it securely and disposes of them in the garbage; then sanitizes his hands with water and

lemon. He said that even though this job is difficult, he does it for the community, especially the women.

- 59. The fact that private citizens are compelled to provide such services is an indication of failure by the State to meet its responsibilities to ensure the provision of the most fundamental of services. The remarkable contribution of this single human rights defender to assume such a burden in defence of human dignity and the human right to sanitation in no way reduces the responsibility of public authorities to correct this and similar situations elsewhere in the country.
- 60. The United States, one of the wealthiest countries in the world, must ensure that everyone, without discrimination, has physical and economic access, in all spheres of life, to sanitation which is safe, hygienic, secure, socially and culturally acceptable, and which provides privacy and ensures dignity. An immediate, interim solution is to ensure access to restrooms facilities in public places, including during the night. The long-term solution to homelessness must be to ensure adequate housing.

#### Indigenous people

- 61. There are roughly 2.7 million indigenous people, including American Indians, Alaska Natives and and Native Hawaiians, living in the United States. This number rises to 4.9 million when those who identify themselves as American Indian in combination with another race are included.<sup>33</sup> The vast majority of these belong to one of 565 recognized tribes. Approximately 50 per cent of American Indians live west of the Mississippi River and about 40 per cent live on reservations.<sup>34</sup> Many more belong to federally unrecognized tribes. In California alone, there are over 300,000 American Indians who belong to federally unrecognized tribes.
- 62. Roughly 25 per cent of American Indians live below the poverty line.<sup>35</sup> On some reservations, however, the number can be as high as 63 per cent.<sup>36</sup> The United States Census Bureau also reports that educational attainment and life expectancy in American Indian communities continue to lag behind national averages.<sup>37</sup>
- 63. American Indian communities lack access to safe drinking water and basic sanitation in disproportionate numbers. Thirteen per cent of American Indian households do not have access to safe water and/or wastewater disposal. In non-native households, this number is 0.6 per cent. 38 This disparity is particularly pronounced in Interior and Western Alaska communities and Navajo Nation. EPA estimates that 54,000 members of Navajo Nation lack access to a public water system. Around 30 per cent of Navajo households report having to haul water, which, in addition to being time-consuming and frequently unsanitary, costs them \$550 more per year than Navajo households with a connection to the

United States Department of Health and Human Services, Office of Minority Health and Millennial Housing Commission, "Native American Housing Needs & Proposed Recommendations," 2002.

<sup>34</sup> Ibid.

American Indian Relief Council, Living Conditions, available at www.nrcprograms.org/site/PageServer?pagename=airc\_livingconditions.

<sup>36</sup> Ibid.

<sup>&</sup>lt;sup>37</sup> United States Census Bureau, "We the People: American Indians and Alaska Natives in the United States," February 2006.

United States Tribal Water Access Partnership, Infrastructure Task Force Access Subgroup, "Meeting the Access Goal: Strategies for Increasing Access to Safe Drinking Water and Wastewater Treatment to American Indian and Alaska Native Homes," 2008.

Tribal Utility Authority. Alaska natives frequently transport human waste in 5-gallon "honeybuckets" from their homes to local water sources for dumping.<sup>39</sup>

- 64. The independent expert notes that in 2004 several federal agencies, including the Environmental Protection Agency, the Department of the Interior, the Department of Housing and Urban Development, the Department of Agriculture and the Indian Health Service, formed the US Tribal Water Access Partnership. The Partnership aims to improve access to safe drinking water and sanitation for American Indian households by 50 per cent by 2015. It cautions, however, that improving access in these communities is particularly costly because many live in rural or isolated areas, and that they will not meet this goal without additional funding. Additionally, EPA runs an independent Tribal Water Plan that provides financial and logistical support for small drinking-water systems on tribal lands. 40
- 65. The independent expert welcomes the decision by the United States to support the United Nations Declaration on the Rights of Indigenous Peoples. Besides being entitled to the rights to water and sanitation like everyone, indigenous people possess broader rights to water which emanate from their relationship with traditional lands and the natural resources thereof. The Declaration on the Rights of Indigenous Peoples affirms that indigenous peoples have the right to the lands, territories and resources that they have traditionally owned, occupied or otherwise used or acquired (art. 26.1); that indigenous peoples also have a right to maintain and strengthen their distinctive spiritual relationship with their traditionally owned lands, territories, water and coastal seas (art. 25).
- 66. The independent expert visited the Winnemen Wintu in Redding, California, a tribe facing challenges in accessing safe drinking water and sanitation. This tribe is not recognized by the Federal Government. Winneman means "middle water people," and water is core to their identity. The tribe inhabits ancestral territory from Mount Shasta down to the McCloud River watershed.
- 67. Tribal existence and identity do not depend on federal recognition or acknowledgment of the tribe. Federal recognition does not create tribes, but rather recognizes social/political entities that predate the United States. It creates a trust relationship between the tribe and the Federal Government, entitles tribes and their members to certain federal benefits, and activates a body of domestic law involving respect for tribal sovereignty. In practical terms, it allows tribes to make claims under federal law for example to develop gaming and other forms of economic development that take advantage of the sovereign status of the tribes. In addition, tribes can receive start-up funds and continuing federal support for their tribal governments, including law enforcement, courts and health services. Federal recognition introduces federal authority and also enables tribes to gain control over their affairs.
- 68. The Winnemen Wintu tribe currently occupies a 42-acre plot of land, on which a number of families live. This area is not within the boundaries of Redding, and thus is not connected to any public water system; it is not feasible to drill a private well. As such, the tribe must partner with the City of Redding or the county to obtain access to water. In these situations, individual households find alternative means of connecting to water sources and often rely on individual septic systems. As they are categorized as individual households (and not as a tribe), they are ineligible for virtually any financial assistance. The independent expert is concerned that unrecognized tribes fall into a protection gap, particularly with regard to the realization of the rights to water and sanitation. She is also concerned about the enjoyment of cultural rights of this tribe, particularly with regard to use

<sup>39</sup> Ibid.

Environmental Protection Agency, Tribal Water Plan, available at http://water.epa.gov/aboutow/goals\_objectives/waterplan/tribal\_index.cfm#1.

or access to water for different traditional and cultural uses, such as fisheries and religious ceremonies such as the puberty ceremony. 41 Federally recognized tribes also encounter difficulties in exercising their right to maintain and strengthen their distinctive spiritual relationship with their traditionally owned lands and water, as is the case for the Pit River tribe. 42

69. The situation of Winnemen Wintu resembles that of other tribes. For example, the independent expert received information about concerns about the Acoma and Laguna Pueblos, Chickaloon Native Village, Navajo Nation and Oglala Lakota People, among others, relating to access to safe drinking water and sanitation due to mining activities. Mining activities are reportedly leading to contamination and depletion of surrounding groundwater and surface-water resources, not only affecting access to clean drinking water, but also threatening the wildlife and plants used as traditional food sources and vital to traditional cultural practices. Additionally, the absence of accountability for pollution and clean-up harms use by future generations.

## E. Prioritization of personal and domestic uses

- 70. The latest available estimates from 2005 of water use in the United States indicated that approximately 1,552 billion litres (410 billion gallons) per day are withdrawn for eight categories of uses (public supply, domestic, irrigation, livestock, aquaculture, industrial, mining and thermoelectric power), of which freshwater withdrawals comprised 85 per cent of the total. Thermoelectric power (49 per cent) was the largest category of water use, followed by irrigation (31 per cent) and public supply (11 per cent). The remaining categories of water uses together were less than ten per cent of total water withdrawals, with domestic water use comprising just one per cent of the total. Unfortunately, no complete nationwide mapping of available water for surface and groundwater exists in the United States. The independent expert, however, notes that the United States Geological Survey is currently undertaking such a mapping and she hopes it will continue to receive the necessary funding to finish such a crucial endeavour.
- 71. The average per capita residential water use is about 340 litres of water per day. For the most part, water treated to meet drinking water standards is used to flush toilets, water lawns, and wash dishes, clothes and cars. Nearly 14 percent of the water a typical homeowner pays for is never even used, mostly due to leaky pipes and faucets.<sup>45</sup>
- 72. There are ever-increasing demands for water for energy, agriculture, industry and recreation, and the effects of climate change exacerbate these competing demands. While water for the realisation of the human right, represents a small percentage of total water use in the United States, the absence of clear legal standards to give priority to water for personal and domestic use threatens to undermine the realization of the human rights to water and sanitation for all.
- 73. An area of potential conflict between water for personal and domestic use and other uses is that of bottled water, Americans being the largest consumers of bottled water

<sup>41</sup> Winnemem Wintu, available at http://www.winnememwintu.us/.

The Pit River tribe and Calpine Corporation claim competing interests in the Medicine Lake Highlands in northeast California, and are in legal proceedings to resolve the matter.

<sup>&</sup>lt;sup>43</sup> Joan F. Kenny and others, "Estimated Use of Water in the United States in 2005," United States Geological Survey Circular 1344, 27 October 2009, p. 4.

<sup>&</sup>lt;sup>44</sup> Ibid., p. 5. The average urban water use is approximately 371 litres per day (p. 19).

United States Environmental Protection Agency, "Water on Tap: What you need to know," December 2009, p. 10.

globally (33.4 billion litres). The landscape concerning the impact of water-bottling operations on local water sources, democratic governance of local water resources and how communities have responded to these impacts has many contours. A range of concerns has been expressed, including about water availability for future generations in a context of overextraction. Moreover, there are also transparency and accountability concerns about the lack of information on the process of obtaining permits to operate and the attendant rights acquired, and the marketing practices that promote bottled water as inherently safer than tap water.

- 74. Corporate Accountability International estimates that, in the past decade, there have been new water-bottling sites proposed or operational in at least 11 states and in more than two dozen communities. Most operations that have raised concerns deal with bottled spring water or groundwater. The independent expert received testimony from individuals in California, Maine and Michigan who expressed concern about the impact and process.
- 75. Regarding impacts, concerns have been voiced about future water availability and quality, where the conditions under which a company enters a community would prioritize the rights of the company over those of the community to meet personal and domestic needs. Communities have also pointed to problems related to environmental and sustainability issues.
- 76. Regarding process, complaints regarding inadequate information and consultation were heard. The independent expert expresses concern that in some cases communities have allegedly learned about proposed deals near completion point or ex-post facto. Everyone has a right to seek, receive and impart information concerning water issues; authorities must take decisions in a transparent and fair manner, involving local populations in the process.
- 77. Another key matter concerns accountability and decision-making mechanisms that communities can use or employ to address their grievances. For example, in Mecosta, Michigan, issues were raised with the closed-door proceedings between Nestlé and public officials to issue a permit to access the watershed. Local grassroots organizations filed a lawsuit against Nestlé, which resulted in an out-of-court settlement after several years of litigation, with Nestlé agreeing to reduce water withdrawal rates and to an adjustment for seasonal environmental conditions.
- 78. As a consequence of opposition by some local communities to new water-bottling plants, in 2008, Nestlé committed to working with stakeholders on a framework to better manage their siting process and make it more transparent. The framework includes principles and specific commitments to help guide its conduct in local communities during the process of identifying sites, and to ensure better communication, dialogue and engagement with local communities.

## IV. Non-discrimination and equality

79. Although the vast majority of the population in the United States enjoys regular access to safe drinking water and sanitation, the above analysis reveals categories of people who are excluded. Individuals who do not have regular access, who face obstacles in access or are otherwise deprived of the same level of access as the general population, also generally face discrimination in society more broadly. The people with whom the independent expert met and who are facing obstacles in their enjoyment of the rights to water and sanitation were disproportionately Black, Latino, American Indian, homeless or otherwise disadvantaged.

- 80. Human rights require a focus on the most vulnerable, those who are most often excluded from progress. Often, these people are the most difficult to reach, but this cannot be justification for neglecting them on the contrary. Human rights require that there be universal access. Hence, merely addressing formal or direct discrimination will not ensure substantive equality. To eliminate discrimination in practice, special attention must be paid, and priority must be given, to groups of individuals who suffer historical or persistent prejudice, instead of merely comparing the formal treatment of individuals in similar situations.
- 81. The International Covenant on Civil and Political Rights, to which the United States is a party, states that all persons are equal before the law, and that the law shall prohibit any discrimination and guarantee to all persons equal and effective protection against discrimination on any prohibited ground (art. 26). 46 In this regard, the Human Rights Committee has noted that article 26 does not merely duplicate the guarantee already provided for in article 2 (general guarantee against non-discrimination in the exercise of Covenant rights) but provides, in itself, an autonomous right. It prohibits discrimination in law or in fact in any field regulated and protected by public authorities. Article 26 therefore is concerned with the obligations imposed on States parties with regard to their legislation and the application thereof. Moreover, the application of the principle of non-discrimination contained in article 26 is not limited to those rights that are provided for in the Covenant, but extends to economic, social and cultural rights. 47
- 82. In the view of the independent expert, the United States has achieved significant gains in eliminating formal or direct discrimination in law. Nevertheless, she remains concerned that several laws, policies and practices, while appearing neutral, disproportionately affect the enjoyment of human rights by certain groups, or are enforced without attention to specific circumstances. Moreover, the independent expert notes that there is a lack of data regarding who does and who does not have access to water and sanitation. Availability of accurate and disaggregated data is fundamental in the design of appropriate and efficient policies and programmes to address the many outstanding challenges related to water and sanitation.

## V. Official development assistance

- 83. International cooperation is a fundamental principle of human rights law. <sup>48</sup> Countries that provide official development assistance (ODA) must ensure that it is consistent with human rights norms.
- 84. Both the development and the implementation of development cooperation policy should incorporate principles of non-discrimination, participation and accountability. This is reflected in, inter alia, the Accra Agenda for Action, which declares that "developing countries and donors will ensure that their respective development practices and programmes are designed and implemented in ways consistent with the agreed international commitments on ... human rights..."

<sup>46</sup> The United States is also a State party to the Convention on the Elimination of All Forms of Racial Discrimination, which prohibits racial discrimination.

<sup>&</sup>lt;sup>47</sup> Human Rights Committee, Pauger v. Austria (Communication No. 716/1996), 25 March 1999.

Charter of the United Nations, arts. 1(3) and 56; International Covenant on Economic, Social and Cultural Rights, arts. 2(1) and 11(1); Convention on the Rights of the Child, art 4.

<sup>&</sup>lt;sup>49</sup> Accra Agenda for Action, para. 13(c); see also OECD Development Assistance Committee, "Action-Oriented Policy Paper on Human Rights and Development," 2007, principles 5 and 8.

- 85. First and foremost, donors must not negatively affect the human rights situation in their partner countries.<sup>50</sup> Moreover, they should ensure that their assistance facilitates the ability of each developing country to comply with its own human rights obligations.<sup>51</sup> They should take positive action to work with partner governments to identify how development assistance can best support that government's own efforts to realize human rights. Finally, donors have an obligation to ensure that third parties involved in the delivery and implementation of their development assistance (e.g. private contractors and technical advisers) do not interfere with the enjoyment and realization of human rights in partner countries.<sup>52</sup>
- 86. The Senator Paul Simon Water for the Poor Act (2005) sets United States foreign appropriations policy for the water sector. It is the first instance where United States water policy reflects the normative content of the human right to water, which the independent expert welcomes. The Act establishes as the policy of the United States that foreign aid for water and sanitation will "further ensure affordability and equity in the provision of access to safe water and sanitation for the very poor."
- 87. The independent expert is concerned about the implementation of the Act, particularly regarding criteria used to identify recipient countries, target poor communities, and decide on funding envelopes. The United States Agency for International Development (USAID) acknowledged difficulties in reaching the poorest of the poor, and the need for greater policy guidance in this regard. She notes that USAID is in the process of developing a strategy and criteria to target countries and communities in greatest need. In this context, she draws attention to her recent report on the Millennium Development Goals (A/65/254) and calls on the Department of State/USAID to ensure that funding of water and sanitation projects reaches those most in need, and is guided by the normative content of the rights to water and sanitation.

### VI. Conclusions and recommendations

- 88. With the introduction of centralized water and sanitation systems in the 19th century, the United States achieved enormous public health gains through the 20th century, resulting in the vast majority of people living in the United States acquiring access to clean and safe drinking water and sanitation. Aging and deteriorating water and sanitation infrastructure forces the question of whether 19th and 20th century technology appropriate at the time will carry the country into the 21st century. Estimates indicate an annual \$4 billion to \$6 billion funding gap for infrastructure in the sector. The United States needs to develop a national water policy and plan of action guided by the normative content of the rights to water and sanitation.
- 89. More concerted efforts are required to ensure targeting of policies and programmes to reach the hidden and poorest segments of the population. Problems of discrimination in the United States water and sanitation services may intensify in the coming years with climate change and competing demands for ever scarce water resources. Ensuring the rights to water and sanitation for all requires a paradigm shift towards new designs and approaches that promote human rights, that are affordable and that create more value in terms of public health improvements, community development, and global ecosystem protection.

OECD, Development Assistance Committee, "Action-Oriented Policy Paper on Human Rights and Development," 2007, principle 8.

<sup>&</sup>lt;sup>51</sup> E/C.12/2001/10, paras. 16-17.

<sup>&</sup>lt;sup>52</sup> E/C.12/2002/11, para. 33.

- 90. A holistic, systemic approach is required, whereby the water sector is not viewed in isolation from the agricultural, chemical, industrial and energy sectors. From agricultural pollution to industrial waste to pollution stemming from urban runoff, the absence of political will inevitably means poor planning and scarce funding, and ultimately leads to pollution that jeopardizes water quality and increases costs. Accordingly, a stronger regulatory system should be put in place to prevent pollution of surface and groundwater, and to ensure affordability. Already communities such Edmonston, Maryland, are undertaking low-cost and innovative initiatives ("green streets") to address challenges in the area of water and sanitation. The independent expert welcomes these and hopes they can be further replicated across the country.
- 91. Such a paradigm shift for the water and sanitation sector entails policy changes, including support for research, pilot projects and incentives, changes in engineering practices, such as integrated water management (e.g. wastewater, storm water, recycled water) and decentralized systems, and community education and empowerment.
- 92. Placing the human rights to water and sanitation at the centre of policy formulation for both domestic and international aid policies is crucial to ensure that all people in the United States, as well as those benefiting from its development assistance, have access to affordable, accessible, acceptable and safe water and sanitation in sufficient amounts to protect human health and human dignity. In this regard, the independent expert offers the following recommendations:
- (a) Ratify the International Covenant on Economic, Social and Cultural Rights and the Optional Protocol thereto, as well as the other core international human rights treaties it has not ratified thus far. To this end, the Government should reconvene the Interagency Working Group on Human Rights (Executive Order 13107);
- (b) Adopt a comprehensive federal law on water and sanitation guaranteeing the rights to safe water and sanitation without discrimination and clearly delineating the responsibilities of public officials at the federal, state and local levels. Such a law must prioritize water for personal and domestic use and set affordability standards, among others.
- (c) Formulate a national water and sanitation policy and plan of action, guided by the normative content of the rights to water and sanitation, that devote priority attention to improving aging infrastructure, as well as innovative designs and approaches that promote human rights, are affordable and create more value in terms of public health improvements, community development and sustainability;
- (d) Ensure proper regulation and monitoring of the water quality of private drinking water systems;
- (e) Exemptions under the Safe Drinking Water Act, including for the oil and gas industry, must be re-assessed and repealed if resulting in a negative impact on the enjoyment of the right to water;
- (f) Strengthen the regulatory system on water and sanitation to prevent upstream pollution (agricultural, industrial, chemical, including pharmaceutical, stormwater run-offs, etc.) as well as ensure adequate regulation of the bottled water industry;
- (g) Engage in public education and information campaigns about water quality in the languages spoken by the community to assure people of the safety of drinking tap water;

- (h) Evaluate the extent to which people living in poverty face challenges in paying for water and sanitation services, and adopt, at the federal level, a national minimum standard on affordability of water and sanitation, as well as due process guarantees in relation to disconnections;
- (i) Ensure that all municipalities provide access to safe drinking water and sanitation to homeless people, including through ensuring the opening and regular maintenance and upkeep of public restrooms, as well as availability of public water fountains, including during the night;
- (j) Engage in dialogue with homeless communities to assist these individuals to find more secure housing solutions, including stable access to adequate water and sanitation;
- (k) Enact the necessary legal action to change the status of unrecognized and terminated tribes to enable them to realize their rights to water and sanitation, as well as express religious and cultural rights;
- (l) Ensure adequate consultation and prior and informed consent of indigenous communities regarding activities affecting their access to water;
- (m) Guide the ODA by human rights principles, including the rights to water and sanitation, and devote larger proportion of aid to ensuring the human rights to water and sanitation to those who do not yet have access. Ensure that affected communities have access to information and opportunities to participate in the formulation, implementation and evaluation of projects.

21

# Exhibit 2

Q

Go to navigation | Go to content

English | Français | Español | русский | 中文



WHAT ARE HUMAN RIGHTS?

**DONATE** 

HOME

**ABOUT US** 

**ISSUES** 

HUMAN RIGHTS BY COUNTRY WHERE WE WORK HUMAN RIGHTS BODIES NEWS AND EVENTS

PUBLICATIONS AND RESOURCES

English > News and Events > DisplayNews

## Statement on Visit to the USA, by Professor Philip Alston, United Nations Special Rapporteur on extreme poverty and human rights\*

Spanish

Washington, December 15, 2017

#### I. Introduction

- 1. I have spent the past two weeks visiting the United States, at the invitation of the federal government, to look at whether the persistence of extreme poverty in America undermines the enjoyment of human rights by its citizens. In my travels through California, Alabama, Georgia, Puerto Rico, West Virginia, and Washington DC I have spoken with dozens of experts and civil society groups, met with senior state and federal government officials and talked with many people who are homeless or living in deep poverty. I am grateful to the Trump Administration for facilitating my visit and for its continuing cooperation with the UN Human Rights Council's accountability mechanisms that apply to all states.
- 2. My visit coincides with a dramatic change of direction in US policies relating to inequality and extreme poverty. The proposed tax reform package stakes out America's bid to become the most unequal society in the world, and will greatly increase the already high levels of wealth and income inequality between the richest 1% and the poorest 50% of Americans. The dramatic cuts in welfare, foreshadowed by the President and Speaker Ryan, and already beginning to be implemented by the administration, will essentially shred crucial dimensions of a safety net that is already full of holes. It is against this background that my report is presented.
- 3. The United States is one of the world's richest, most powerful and technologically innovative countries; but neither its wealth nor its power nor its technology is being harnessed to address the situation in which 40 million people continue to live in poverty.
- 4. I have seen and heard a lot over the past two weeks. I met with many people barely surviving on Skid Row in Los Angeles, I witnessed a San Francisco police officer telling a group of homeless people to move on but having no answer when asked where they could move to, I heard how thousands of poor people get minor infraction notices which seem to be intentionally designed to quickly explode into unpayable debt, incarceration, and the replenishment of municipal coffers, I saw sewage filled yards in states where governments don't consider conitation facilities to be their represcibility. I saw people who

had lost all of their teeth because adult dental care is not covered by the vast majority of programs available to the very poor, I heard about soaring death rates and family and community destruction wrought by prescription and other drug addiction, and I met with people in the South of Puerto Rico living next to a mountain of completely unprotected coal ash which rains down upon them bringing illness, disability and death.

- 5. Of course, that is not the whole story. I also saw much that is positive. I met with State and especially municipal officials who are determined to improve social protection for the poorest 20% of their communities, I saw an energized civil society in many places, I visited a Catholic Church in San Francisco (St Boniface the Gubbio Project) that opens its pews to the homeless every day between services, I saw extraordinary resilience and community solidarity in Puerto Rico, I toured an amazing community health initiative in Charleston (West Virginia) that serves 21,000 patients with free medical, dental, pharmaceutical and other services, overseen by local volunteer physicians, dentists and others (WV Health Right), and indigenous communities presenting at a US-Human Rights Network conference in Atlanta lauded Alaska's advanced health care system for indigenous peoples, designed with direct participation of the target group.
- 6. American exceptionalism was a constant theme in my conversations. But instead of realizing its founders' admirable commitments, today's United States has proved itself to be exceptional in far more problematic ways that are shockingly at odds with its immense wealth and its founding commitment to human rights. As a result, contrasts between private wealth and public squalor abound.
- 7. In talking with people in the different states and territories I was frequently asked how the US compares with other states. While such comparisons are not always perfect, a cross-section of statistical comparisons provides a relatively clear picture of the contrast between the wealth, innovative capacity, and work ethic of the US, and the social and other outcomes that have been attained.
  - By most indicators, the US is one of the world's wealthiest countries. It spends more on national defense than China, Saudi Arabia, Russia, United Kingdom, India, France, and Japan combined.
  - US health care expenditures per capita are double the OECD average and much higher than in all other countries. But there are many fewer doctors and hospital beds per person than the OECD average.
  - US infant mortality rates in 2013 were the highest in the developed world.
  - Americans can expect to live shorter and sicker lives, compared to people living in any other rich democracy, and the "health gap" between the U.S. and its peer countries continues to grow.
  - U.S. inequality levels are far higher than those in most European countries
  - Neglected tropical diseases, including Zika, are increasingly common in the USA. It has been
    estimated that 12 million Americans live with a neglected parasitic infection. A 2017 report
    documents the prevalence of hookworm in Lowndes County, Alabama.
  - The US has the highest prevalence of obesity in the developed world.
  - In terms of access to water and sanitation the US ranks 36th in the world.
  - America has the highest incarceration rate in the world, ahead of Turkmenistan, El Salvador, Cuba, Thailand and the Russian Federation. Its rate is nearly 5 times the OECD average.
  - The youth poverty rate in the United States is the highest across the OECD with one quarter of youth living in poverty compared to less than 14% across the OECD.
  - The Stanford Center on Inequality and Poverty ranks the most well-off countries in terms of labor markets, poverty, safety net, wealth inequality, and economic mobility. The US comes in last of the top 10 most well-off countries, and 18th amongst the top 21.
  - In the OECD the US ranks 35th out of 37 in terms of poverty and inequality.
  - According to the World Income Inequality Database, the US has the highest Gini rate (measuring inequality) of all Western Countries
  - The Stanford Center on Poverty and Inequality characterizes the US as "a clear and constant outlier in the child poverty league" IIS child poverty rates are the highest amongst the six richest countries

- mi and dima portore, reagant of dima portore, raced and and inglicate amongot and any monetal countries
- Canada, the United Kingdom, Ireland, Sweden and Norway.
- About 55.7% of the U.S. voting-age population cast ballots in the 2016 presidential election. In the OECD, the U.S. placed 28th in voter turnout, compared with an OECD average of 75%. Registered voters represent a much smaller share of potential voters in the U.S. than just about any other OECD country. Only about 64% of the U.S. voting-age population (and 70% of voting-age citizens) was registered in 2016, compared with 91% in Canada (2015) and the UK (2016), 96% in Sweden (2014), and nearly 99% in Japan (2014).

#### II. The human rights dimension

- 8. Successive administrations, including the present one, have determinedly rejected the idea that economic and social rights are full-fledged human rights, despite their clear recognition not only in key treaties that the US has ratified (such as the Convention on the Elimination of All Forms of Racial Discrimination), and in the Universal Declaration of Human Rights which the US has long insisted other countries must respect. But denial does not eliminate responsibility, nor does it negate obligations. International human rights law recognizes a right to education, a right to healthcare, a right to social protection for those in need, and a right to an adequate standard of living. In practice, the United States is alone among developed countries in insisting that while human rights are of fundamental importance, they do not include rights that guard against dying of hunger, dying from a lack of access to affordable healthcare, or growing up in a context of total deprivation.
- 9. Since the US has refused to recognize economic and social rights agreed by most other states (except for the right to education in state constitutions), the primary focus of the present report is on those civil and political rights reflected in the US Bill of Rights and in the International Covenant on Civil and Political Rights which the US has ratified.

#### III. Who are 'the poor'?

- 10. I have been struck by the extent to which caricatured narratives about the purported innate differences between rich and poor have been sold to the electorate by some politicians and media, and have been allowed to define the debate. The rich are industrious, entrepreneurial, patriotic, and the drivers of economic success. The poor are wasters, losers, and scammers. As a result, money spent on welfare is money down the drain. To complete the picture we are also told that the poor who want to make it in America can easily do so: they really can achieve the American dream if only they work hard enough.
- 11. The reality that I have seen, however, is very different. It is a fact that many of the wealthiest citizens do not pay taxes at the rates that others do, hoard much of their wealth off-shore, and often make their profits purely from speculation rather than contributing to the overall wealth of the American community. Who then are the poor? Racist stereotypes are usually not far beneath the surface. The poor are overwhelmingly assumed to be people of color, whether African Americans or Hispanic 'immigrants'. The reality is that there are 8 million more poor Whites than there are Blacks. Similarly, large numbers of welfare recipients are assumed to be living high on the hog. Some politicians and political appointees with whom I spoke were completely sold on the narrative of such scammers sitting on comfortable sofas, watching color TVs, while surfing on their smart phones, all paid for by welfare. I wonder how many of these politicians have ever visited poor areas, let alone spoken to those who dwell there. There are anecdotes aplenty, but evidence is nowhere to be seen. In every society, there are those who abuse the system, as much in the upper income levels, as in the lower. But the poor people I met from among the 40 million living in poverty were overwhelmingly either persons who had been born into poverty, or those who had been thrust there by circumstances largely beyond their control such as physical or mental disabilities, divorce, family breakdown, illness, old age, unlivable wages, or discrimination in the job market.
- 12. The face of poverty in America is not only Black, or Hispanic, but also White, Asian, and many other colors. Nor is it confined to a particular age group. Automation and robotization are already throwing

many middle-aged workers out of jobs in which they once believed themselves to be secure. In the economy of the twenty-first century, only a tiny percentage of the population is immune from the possibility that they could fall into poverty as a result of bad breaks beyond their own control. The American Dream is rapidly becoming the American Illusion as the US since the US now has the lowest rate of social mobility of any of the rich countries.

#### IV. The current extent of poverty in the US

- 13. There is considerable debate over the extent of poverty in the US, but for the purposes of this report principal reliance is placed upon the official government statistics, drawn up primarily by the US Census Bureau.
- 14. In order to define and quantify poverty in America, the Census Bureau uses 'poverty thresholds' or Official Poverty Measures (OPM), updated each year. In September 2017, more than one in every eight Americans were living in poverty (40 million, equal to 12.7% of the population). And almost half of those (18.5 million) were living in deep poverty, with reported family income below one-half of the poverty threshold.

#### V. Problems with existing policies

- 15. There is no magic recipe for eliminating extreme poverty, and each level of government must make its own good faith decisions. But at the end of the day, particularly in a rich country like the USA, the persistence of extreme poverty is a political choice made by those in power. With political will, it could readily be eliminated.
- 16. What is known, from long experience and in light of the government's human rights obligations, is that there are indispensable ingredients for a set of policies designed to eliminate poverty. They include: democratic decision-making, full employment policies, social protection for the vulnerable, a fair and effective justice system, gender and racial equality and respect for human dignity, responsible fiscal policies, and environmental justice.
- 17. Currently, the United States falls far short on each of these issues.

#### 1. The undermining of democracy

- 18. The foundation stone of American society is democracy, but it is being steadily undermined. The principle of one person one vote applies in theory, but it is far from the reality. In a democracy, the task of government should be to facilitate political participation by ensuring that all citizens can vote and that their votes will count equally. In the US there is overt disenfranchisement of vast numbers of felons, a rule which predominantly affects Black citizens since they are the ones whose conduct is often specifically targeted for criminalization. In addition, there are often requirement that persons who have paid their debt to society still cannot regain their right to vote until they paid off all outstanding fines and fees. Then there is covert disenfranchisement, which includes the dramatic gerrymandering of electoral districts to privilege particular groups of voters, the imposition of artificial and unnecessary voter ID requirements, the blatant manipulation of polling station locations, the relocating of DMVs to make it more difficult for certain groups to obtain IDs, and the general ramping up of obstacles to voting especially by those without resources. The net result is that people living in poverty, minorities, and other disfavored groups are being systematically deprived of their voting rights.
- 19. A common explanation is that people see no improvement in their well-being regardless of who they elect, so that voting is pointless. But the most compelling and dispiriting explanation I received came in answer to my question as to why voting rates are so extraordinarily low in West Virginia. A state official pointed to apathy, which he explained by saying that "when people are poor they just give up on the electoral system." If this is the case, as seems likely, some political elites have a strong self-interest in keeping people in poverty. As one politician remarked to me, it would be instructive to undertake a survey of the campaign appearances of politicians in overwhelmingly poor districts.

#### 2. All musury emphasis on employment

- 20. Proposals to slash the meager welfare arrangements that currently exist are now sold primarily on the basis that the poor need to get off welfare and back to work. The assumption is that there are a great many jobs out there waiting to be filled by individuals with low educational standards, often suffering disabilities of one kind or another, sometimes burdened with a criminal record (perhaps for the crime of homelessness or not being able to pay a traffic ticket), and with no training or meaningful assistance to obtain employment. It also assumes that the jobs they could get will make them independent of state assistance. Yet I spoke to workers from Walmart and other large stores who could not survive on a full-time wage without also relying on food stamps. It has been estimated that as much as \$6 billion dollars go from the SNAP program to support such workers, thus providing a huge virtual subsidy to the relevant corporations.
- 21. In terms of the employment market, the reality is very different from that portrayed by the welfare to work proponents. There has been a long-term decline in employment rates. For example, by 2017, only 89% of males from 25 to 54 years were employed. While 'supply' factors such as growing rates of disability, increasing geographic immobility, and higher incarceration rates are relevant, a 2016 report by the White House Council of Economic Advisors concluded that reductions in labor supply are far less important than reductions in labor demand in accounting for the long-run trend<sup>1</sup>. Factors such as automation and new technologies such as self-driving cars, 3D printers, and robot-staffed factories and warehouses will see a continuing decline in demand for low-skilled labor.
- 22. Reflecting on these developments, leading poverty experts have concluded that:

Because of this rising joblessness, the U.S. poverty population is becoming a more deprived and destitute class, one that's disconnected from the economy and unable to meet basic needs. ... 40 percent of the 1999 poverty population was in deep poverty ... [compared to 46 percent of the 2015 poverty population ... . Likewise, rates of extreme poverty (i.e., living on less than \$2 per day per person) are also increasing, again because of declining employment as well as growing "disconnection" from the safety net<sup>2</sup>.

#### 3. Shortcomings in basic social protection

23. There are a great many issues that could be covered under this heading. In view of space limitations I will focus on three major concerns.

#### (i) Indigenous peoples

- 24. Chiefs and representatives from both recognized and non-recognized tribes presented me with evidence of widespread extreme poverty in indigenous communities in the USA. They called for federal recognition as an essential first step to address poverty, indicating that without it their way of life is criminalised, they are disempowered, and their culture is destroyed all of which perpetuate poverty, poor health, and shockingly high suicide rates. Living conditions in Pine Ridge, Lakota, were described as comparable to Haiti, with annual incomes of less than \$12 000 and infant mortality rates three times higher than the national rate. Nine lives have been lost there to suicide in the last three months, including one six year old. Nevertheless, federally funded programmes aimed at suicide prevention have been de-funded.
- 25. Testimony also revealed an urgent need for data collection on poverty in all indigenous communities, greater access to healthcare, and stronger protection from private and corporate abuse. The Red Water Pond Navajo tribe spoke about predatory loans involving 400% interest rates, and a high incidence of kidney, liver and pancreatic cancers.

#### (ii) Children in poverty

25. A shockingly high number of children in the US live in poverty. In 2016, 18% of children – some 13.3 million – were living in poverty, with children comprising 32.6% of all people in poverty. Child poverty rates are highest in the southern states, with Mississippi, New Mexico at 30% and Louisiana at 29%.

- 26. Contrary to the stereotypical assumptions, 31% of poor children are White, 24% are Black, 36% are Hispanic, and 1% are indigenous. When looking at toddlers and infants, 42% of all Black children are poor, 32% of Hispanics, and 37% of Native American infants and toddlers are poor. The figure for Whites is 14%.
- 27. Poor children are also significantly affected by America's affordable and adequate housing crisis. Around 21% of persons experiencing homelessness are children. While most are reportedly experiencing sheltered homelessness, the lack of financial stability, high eviction rates, and high mobility rates negatively impact education, and physical and mental health.
- 28. On a positive note, most children living in poverty do have medical insurance. Due to the expansion of Medicaid and the creation of the Children's Health Insurance Program in 1997, as of 2016, some 95% of all children had health insurance. Medicaid and CHIP have lowered the rate of children without health coverage from 14% in 1997 to 5.3% in 2015.
- 29. Other support programs are also important, such as the Supplemental Nutrition Assistance Program (SNAP) which is estimated to lift some five million children out of poverty annually, while in 2015 the Earned Income Tax Credit (EITC) and the Child Tax Credit (CTC) lifted a further five million children out of poverty. By contrast, TANF is not getting to enough children, with less than 25% of all poor families that are eligible for cash assistance under TANF actually receiving it. Proposed cutbacks to most of these programs would have dramatic consequences.

### (iii) Adult dental care

30. The Affordable Care Act greatly expanded the availability of dental care to children, but the situations of adults living in poverty remains lamentable. Their only access to dental care is through the emergency room, which usually means that when the pain becomes excruciating or disabling, they are eligible to have the tooth extracted. Poor oral hygiene and disfiguring dental profiles lead to unemployability in many jobs, being shunned in the community, and being unable to function effectively. Yet there is no national program, and very few state programs, to address these issues which fundamentally affect the human dignity and ultimately the civil rights of the persons concerned.

#### 4. Reliance on criminalization to conceal the problem

- 31. Homeless estimates published by the Department of Housing and Urban Development in December 2017 show a nationwide figure of 553,742, which includes 76,500 in New York, 55,200 in Los Angeles, and 6,900 in San Francisco<sup>3</sup>. These figures are widely considered to be an undercount, as illustrated by estimates of 21,000 in San Francisco provided by various experts with whom I met.
- 32. In many cities, homeless persons are effectively criminalized for the situation in which they find themselves. Sleeping rough, sitting in public places, panhandling, public urination (in cities that provide almost zero public toilets) and myriad other offences have been devised to attack the 'blight' of homelessness. Ever more demanding and intrusive regulations lead to infraction notices, which rapidly turn into misdemeanors, leading to the issuance of warrants, incarceration, the incurring of unpayable fines, and the stigma of a criminal conviction that in turn virtually prevents subsequent employment and access to most housing. Yet the authorities in cities like Los Angeles and San Francisco often encourage this vicious circle. In Skid Row, LA., 6,696 arrests of homeless persons were reported to have been made between 2011 and 2016. Rather than responding to homeless persons as affronts to the senses and to their neighborhoods, citizens and local authorities should see in their presence a tragic indictment of community and government policies. Homelessness on this scale is far from inevitable and again reflects political choices to see law enforcement rather than low cost housing, medical treatment, psychological counselling, and job training as the solutions. But the futility of many existing approaches was all too evident as I walked around some of the worst affected areas.
- 33. In many cities and counties the criminal justice system is effectively a system for keeping the poor in

poverty while generating revenue to fund not only the justice system but diverse other programs. The use of the legal system, not to promote justice, but to raise revenue, as documented so powerfully in the Department of Justice's report on Ferguson, is pervasive around the country. So-called 'fines and fees' are piled up so that low level infractions become immensely burdensome, a process that affects only the poorest members of society who pay the vast majority of such penalties. State, county and municipal police and law enforcement agencies are not always forces for change in such settings. While they play an indispensable role in keeping the citizenry secure, they sometimes also pressure legislatures to maintain high staffing and overtime levels, at the expense of less expensive approaches which would address the social challenges constructively and effectively and eliminate the need for a law enforcement response.

- 34. Another practice which affects the poor almost exclusively is that of setting large bail bonds for a defendant who seeks to go free pending trial. Some 11 million people are admitted to local jails annually, and on any given day there are more than 730,000 people are being held, of whom almost two-thirds are awaiting trial, and thus presumed to be innocent. Yet judges have increasingly set large amounts of bail, which mean that wealthy defendants can secure their freedom, whole poor defendants are likely to stay in jail, with all of the consequences in terms of loss of their jobs, disruption of their childcare, inability to pay rent, and a dive into deeper destitution. A major movement to eliminate bail bonds is gathering steam, and needs to be embraced by anyone concerned about the utterly disproportionate impact of the justice system upon the poor.
- 35. Finally, mention must be made of the widespread practice of suspending drivers' licenses for a wide range of non-driving related offences, such as a failure to pay fines. This is a perfect way to ensure that the poor, living in communities which have steadfastly refused to invest in serious public transport systems, are unable to earn a living which might have helped to pay the outstanding debt. Two paths are open: penury, or driving illegally, thus risking even more serious and counter-productive criminalization.

#### 5. The gendered nature of poverty

36. Many statistics could be cited to demonstrate the extent to which women shoulder a particularly high burden as a result of living in poverty. They are, for example, more exposed to violence, more vulnerable to sexual harassment, discriminated against in the labor market. Luke Shafer and Kathryn Edin conclude that the number of children in single-mother households living in extreme poverty for an entire year has ballooned from fewer than 100,000 in 1995 to 895,000 in 2011 and 704,000 in 2012. But perhaps the least recognized harm is that austerity policies that shrink the services provided by the state inevitably mean that the resulting burden is imposed instead upon the primary caregivers within families, who are overwhelmingly women. Male-dominated legislatures rarely pay any heed to this consequence of the welfare cutbacks they impose.

#### 6. Racism, disability, and demonization of the poor

- 37. Demonization of the poor can take many forms. It has been internalized by many poor people who proudly resist applying for benefits to which they are entitled and struggle valiantly to survive against the odds. Racism is a constant dimension and I regret that in a report that seeks to cover so much ground there is not room to delve much more deeply into the phenomenon. Racial disparities, already great, are being entrenched and exacerbated in many contexts. In Alabama, I saw various houses in rural areas that were surrounded by cesspools of sewage that flowed out of broken or non-existent septic systems. The State Health Department had no idea of how many households exist in these conditions, despite the grave health consequences. Nor did they have any plan to find out, or devise a plan to do something about it. But since the great majority of White folks live in the cities, which are well served by government built and maintained sewerage systems, and most of the rural folks in areas like Lowndes County, are Black, the problem doesn't appear on the political or governmental radar screen.
- 38. The same applies to persons with disabilities. In the rush to claim that many beneficiaries are scamming the system, it is often asserted, albeit with little evidence, that large numbers of those

receiving disability allowances are undeserving. When I probed the very high rates of persons with disabilities in West Virginia, government officials explained that most recipients had attained low levels of education, worked in demanding manual labor jobs, and were often exposed to risks that employers were not required to guard against.

#### 7. Confused and counter-productive drug policies

39. The opioid crisis has drawn extensive attention, as it should. It has devastated many communities and the addiction often leads to heroin, methamphetamine, and other substance abuse. Many states have introduced highly punitive regimes directed against pregnant women, rather than trying to provide sympathetic treatment and to maximize the well-being of the fetus. As one submission put it:

Mothers in Alabama face criminal prosecutions which can result in years of incarceration, as well as civil child welfare proceedings that have the power to separate families and sever a person's parental rights. Families living in poverty are already disproportionately the subject of child welfare investigations in the United States. Experts have found that poor children disproportionately suffer impositions of the child welfare system, and families who receive public assistance are four times more likely than others to be investigated and have their children removed from the family home on the basis of alleged child maltreatment<sup>4</sup>.

- 40. Similarly, states are increasingly seeking to impose drug tests on recipients of welfare benefits, with programs that lead to expulsion from the program for repeat offenders. Such policies are entirely counter-productive, highly intrusive, and punitive where care is required instead. The justification offered to me in West Virginia was that the state should not be supporting someone who is addicted to drugs. It would be interesting to see if the same rationale were accepted if it was proposed that legislators and senior officials, who must keep the public trust, should also be regularly drug-tested, and punished for failure to go clean in a short time.
- 41. Similarly, the contrast between the huge sentences handed down to those using drugs such as crack cocaine, contrasts dramatically and incomprehensibly with the approach applied in most cases of opioid addiction. The key variable seems to be race. The lesson to be learned is that the generally humane and caring response to opioid users should be applied to most cases of substance addiction.

#### 8. The use of fraud as a smokescreen

42. Calls for welfare reform take place against a constant drumbeat of allegations of widespread fraud in the system. The contrast with tax reform is instructive. In that context immense faith is placed in the goodwill and altruism of the corporate beneficiaries, while with welfare reform the opposite assumptions apply. The poor are inherently lazy, dishonest, and care only about their own interests. And government officials with whom I met insisted that the states are gaming the system to defraud the federal government, individuals are constantly coming up with new lurks to live high on the welfare hog, and community groups are exaggerating the numbers. The reality, of course, is that there are good and bad corporate actors and there are good and bad welfare claimants. But while funding for the IRS to audit wealthy taxpayers has been reduced, efforts to identify welfare fraud are being greatly intensified. The answer is nuanced governmental regulation, rather than an abdication in respect to the wealthy, and a doubling down on intrusive and punitive policies towards the poor. Revelations of widespread tax avoidance by companies and high-wealth individuals draw no rebuke, only acquiescence and the maintenance of the loopholes and other arrangements designed to facilitate such arrangements. Revelation of food stamps being used for purposes other than staying alive draw howls of outrage from government officials and their media supporters.

#### 9. Privatization

43. Solutions to major social challenges in the US are increasingly seen to lie with privatization. While the firms concerned have profited handsomely, it is far from clear that optimum outcomes have been achieved for the relevant client populations. In particular, greater consideration needs to be given to the

maintain their profits at the expense of the poorest members of society. During my visit I was told of many examples. For example, bail bond corporations which exist in only one other country in the world, precisely because they distort justice, encourage excessive and often unnecessary levels of bail, and fuel and lobby for a system that by definition penalizes the poor. The rich can always pay, and can avoid the 10% or even more that bail bond companies demand as a non-refundable down-payment. I heard cases of individuals who paid thousands of dollars to post bail, and lost it all when charges were dropped a day later. If they were subsequently charged with a different offence, the whole process begins again and all previous payments are lost. Other examples include the corporations running private for-profit prisons, as well as bounty-hunters.

#### 10. Environmental sustainability

44. In Alabama and West Virginia I was informed of the high proportion of the population that was not being served by public sewerage and water supply services. Contrary to the assumption in most countries that such services should be extended systematically and eventually comprehensively to all areas by the government, in neither state was I able to obtain figures as to the magnitude of the challenge or details of any government plans to address the issues in the future.

#### VI. Principal current governmental responses

45. The analysis that follows is primarily focused on the Federal level. Federalism complicates questions of responsibility but one irony that emerged clearly from my visit is that those who fight hardest to uphold State rights, also fight hard to deny city and county rights. If the rhetoric about encouraging laboratories of innovation is to be meaningful, the freedom to innovate cannot be restricted to state politicians alone.

#### 1. Tax reform

- 46. Deep and dramatic changes look likely to be adopted in the space of the next few days as Congress considers a final unified version of the Tax Bill. From a human rights perspective, the lack of public debate, the closed nature of the negotiation, the exclusion of the representatives of almost half of the American people from the process, and the inability of elected representatives to know in any detail what they are being asked to vote for, all raise major concerns. Similarly, the proposed immediate upending of many longstanding arrangements on the basis of which citizens have planned their futures, raises important issues relating to the need for a degree of predictability and respect for reasonable expectations in adopting tax reform.
- 47. One of the overriding concerns however is the enormous impetus given to income and wealth inequality by the proposed reforms. While most other nations, and all of the major international institutions such as the OECD, the World Bank, and the IMF have acknowledged that extreme inequalities in wealth and income are economically inefficient and socially damaging, the tax reform package is essentially a bid to make the US the world champion of extreme inequality. As noted in the World Inequality Report 2018, in both Europe and the US the top 1% of adults earned around 10% of national income in 1980. In Europe that has risen today to 12%, but in the US it has reached 20%. In the same time period in the US annual income earnings for the top 1% have risen by 205%, while for the top 0.001% the figure is 636%. By comparison, the average annual wage of the bottom 50% has stagnated since 1980.
- 48. At the state level, the demonizing of taxation, as though it is inherently evil, means that legislature effectively refuse to levy taxes even when there is a desperate need. Instead they impose fees and fines through the back door, some of which fund the justice system and others of which go to fund the pet projects of legislators. This sleight of hand technique is a winner, in the sense that the politically powerful rich do not have to pay any more taxes, while the politically marginalized poor bear the burden but can do nothing about it.

#### 2. Welfare reform

49. In calculating how the proposed tax cuts can be paid for, the Treasury has explicitly listed welfare reform as an important source of revenue<sup>5</sup>. Indeed, various key officials have made the same point that major cuts will need to be made in welfare provision. Given the extensive, and in some cases unremitting, cuts that have been made in recent years, the consequences for an already overstretched and inadequate system of social protection are likely to be fatal for many programs, and possibly also for those who rely upon them.

#### 3. Healthcare reform

- 50. The Senate majority leader recently wrote that "the Senate also voted to deliver relief to low- and middle-income Americans by repealing Obamacare's individual mandate tax. For too long, families have suffered under this unpopular and unfair tax imposed under an unworkable law." Many observers with whom I spoke consider that this move will, over time, make the rest of the ACA unviable, thus removing many millions of persons from the ranks of the insured.
- 51. There have also been many references in statements by senior officials to the desirability of reducing Medicare and Medicaid expenditures. When I asked state officials what they thought the consequences would be of repealing the ACA's Medicaid expansion, the unanimous response was that it would be disastrous, not just for the individuals concerned but also for state health care systems.
- 52. In addition, there is considerable uncertainty surrounding the funding of the Children's Health Insurance Program (CHIP), on which almost 9 million low-income children depend for their primary health and dental care<sup>6</sup>. If long-term funding is not secured, those children could be left unprotected. If funding is secured, but threats to gradually decrease funding for the program over the short-term eventuate, this would also have devastating on the health of millions of poor children in America. Similarly, Federally Qualified Health Centers (FQCHs) are federally-funded, "safety-net" providers of comprehensive primary and preventive health care, regardless of the insurance status or ability to pay<sup>7</sup>. The health center program has been able to grow due to expanded Medicaid eligibility and increases in federal grant funding, including under the Affordable Care Act<sup>8</sup>. The future of these centers is, however, uncertain, with a re-funding bill having passed the House but Senate consideration being delayed. If the funding is lost, some 2,800 health centers across the country could close<sup>9</sup>, 9 million patients could lose access to primary and preventive care, more than 51,000 providers and staff could lose their jobs, and \$7.5 billion revenue will be foregone in economically distressed communities<sup>10</sup>. If the funding is decreased, one can only presume the effects will be commensurately devastating.

#### 4. New information technologies

53. The term 'new information technology' or 'new technology' is not well-defined, despite its frequent use. It is commonly used for such widely different but interrelated phenomena as the spectacular increase in computing power, 'Big Data', machine learning, algorithms, artificial intelligence and robotization, among other things. These separate terms often also lack a clear definition <sup>11</sup>. There are clear benefits to the rapid development of new information technology. A 2016 White House Report, for example, highlights the major benefits of new artificial intelligence technology "to the public in fields as diverse as health care, transportation, the environment, criminal justice, and economic inclusion" in artificial intelligence <sup>12</sup>. But the risks are also increasingly clear. Much more attention needs to be given to the ways in which new technology impacts the human rights of the poorest Americans <sup>13</sup>. This inquiry is of relevance to a much wider group since experience shows that the poor are often a testing ground for practices and policies that may then be applied to others. These are some relevant concerns.

#### (i) Coordinated entry systems

54. A coordinated entry system (CES) is, in essence, a system set up to match the homeless population with available homeless services. Such systems are gaining in popularity and their human rights impact has not yet been studied extensively<sup>14</sup>. I spoke to a range of civil society organizations and government officials in Los Angeles and San Francisco about CES.

55. In Los Angeles, CES is one of the pillars of mayor Garcetti's strategy<sup>15</sup> to tackle the homelessness

crisis in the city. The system is administered by the Los Angeles Homeless Service Authority (LAHSA). Tens of thousands of Los Angeles' homeless population have been included in the system since it was first set up in 2013. It works as follows. A homeless service caseworker or volunteer interviews a homeless individual using a survey called the Vulnerability Index-Service Priority Decision Assistance Tool (VI-SPDAT). This data is stored in a Homeless Management Information System (HMIS) that stores the data. A ranking algorithm gives the homeless respondent a vulnerability score between 1 and 17 and a second, matching, algorithm, matches the most vulnerable homeless to appropriate housing opportunities.

- 56. The CES replaces a previous system of matching the homeless to housing that was described to me by various interlocutors as dysfunctional. It is based on the principle of 'Housing First', which focuses on providing housing before anything else. But despite the good intentions of officials in Los Angeles, there is an Orwellian side to CES. Similar concerns were expressed to me about the San Francisco CES.
- 57. A first, and major, concern is that the VI-SPDAT survey asks homeless individuals to give up the most intimate details of their lives. Among many other questions, the VI-SPDAT survey requires homeless individuals to answer whether they engage in sex work, whether they have ever stolen medications, how often they have been in touch with the police and whether they have "planned activities each day other than just surviving that bring [them] happiness and fulfillment". One researcher I met with who has interviewed homeless individuals that took the VI-SPDAT survey explained that many feel they are giving up their human right to privacy in return for their human right to housing.
- 58. A civil society organization in San Francisco explained that many homeless individuals feel deeply ambivalent about the millions of dollars that are being spent on new technology to funnel them to housing that does not exist. According to some of my interlocutors, only a minority of those homeless individuals being interviewed actually acquire permanent housing, because of the chronic shortage of affordable housing and Section 8 housing vouchers in California. As one participant in a civil society town hall in San Francisco put it: "Computers and technology cannot solve homelessness".
- 59. A third concern related to access to and sharing of the wealth of data collected via coordinated entry systems and stored in HMIS. According to 2004 data standards by the Department of Housing and Urban Development, homeless organizations that record, use or process Protected Personal Information on homeless clients for a HMIS may share that information with law enforcement in a number of circumstances, including in response to "an oral request for the purpose of identifying or locating a suspect, fugitive, material witness or missing person" without the need for a warrant or any other form of judicial oversight<sup>16</sup>.
- 60. I understood from civil society organizations that homeless individuals who have been interviewed for VI-SPDAT have expressed a fear, a fear that does not seem unjustified in light of the current legal regime, that the police would access the very sensitive personal data stored in HMIS. When I met with the Executive Director of LAHSA, he assured me that LAHSA is working on a policy decision to deny the LAPD access to HMIS, which would be an important step in safeguarding the human right to privacy and other civil rights of the homeless. Other local and county officials have also assured me that the LAPD is currently not allowed access to HMIS.
- 61. However, since federal standards allow such access and given the fact that the LAPD informed me that it is "unfortunate" that they currently have no access to CES data, it is likely there will be continued pressure on LAHSA and similar agencies in other municipalities to give access to the police to this 'gold mine' of information. Access by the police to HMIS is only one policy decision away.

#### (ii) Risk assessment tools in the pre-trial phase

62. Across the United States, a movement is underway to reform the pretrial system. At the heart of the reform is an effort to disconnect pretrial detention from wealth and to tie it to risk instead. And to accomplish that goal, a growing number of jurisdictions are adopting risk assessment tools (also called

actuarial tools, or Actuarial Pretrial Risk Assessment Instruments -APRAIs<sup>1/</sup>) to assist in pretrial release and custody decisions<sup>18</sup>. This move from pretrial detention and money bail to risk assessment is widely supported, but new risks to the human rights of the poor in the United States arise with the use of risk assessment tools.

- 63. Automated risk assessment tools, take "data about the accused, feed it into a computerized algorithm, and generate a prediction of the statistical probability the person will commit some future misconduct, particularly a new crime or missed court appearance." The system will generally indicate whether the risk for the particular defendant, compared to observed outcomes among a population of individuals who share certain characteristics, is 'high', 'moderate', or 'low'. Judges maintain discretion, in theory, to ignore the risk score.
- 64. One fundamental critique is that risk assessments are based on turning individual circumstances into risk categories. The overwhelmingly poor defendants who are confronted with these new practices are turned into 'high', 'medium' or 'low' risk classes, a demeaning process for those involved which goes directly against the principle of an individualized criminal justice system.
- 65. Several interlocutors warned that these tools may seem to produce objective scores, but that the decision what risk level to qualify as 'high' or 'low' is not an objective, but a political choice, that should ultimately be decided by voters, not the, often private, developers of these tools.
- 66. Risk assessment tools pose the same risks associated with privatizing public functions that currently plague the money bail system. I met with a Division Chief in the Public Defender's Office of Los Angeles County who explained the pressure court systems are under to buy risk assessment tools 'off the shelf' from private vendors. As in other contexts, the inner workings of such tools as proprietary to the company that sells it, which leads to serious due process concerns that affect the civil rights of the poor in the criminal justice system<sup>20</sup>.

#### (iii) Access to high-speed broadband access in West Virginia

67. Civil society organizations have urged me to focus on obstacles to internet connectivity in impoverished communities in West Virginia<sup>21</sup>. This is a persistent problem in the state, where an estimated 30% of West Virginians lack access to high speed broadband (compared to 10% nationally) and 48% of rural West Virginians lack access (compared to 39% of the rural population nationally)<sup>22</sup>. But when I asked the Governor's office in West Virginia about efforts to expand broadband access in poor, rural communities, it could only point to a 2010 broadband expansion effort. It downplayed the extent of the problem by claiming that there were "some issues" with access to Internet in West Virginia's valleys.

#### 5. Puerto Rico

- 68. I spent two days of the nine days I traveled outside of Washington, DC, in Puerto Rico. I witnessed the devastation of hurricane Irma and Maria in Salinas and Guayama in the south of the island, as well as in the poor Caño Martin Peña neighborhood in San Juan. Both in the south and in San Juan I listened to individuals in poverty and civil society organizations on how these natural disasters are just the latest in a series of bad news for Puerto Ricans, which include an economic crisis, a debt crisis, an austerity crisis and, arguably, a structural political crisis.
- 69. Political rights and poverty are inextricably linked in Puerto Rico. If it were a state, Puerto Rico would be the poorest state in the Union. But Puerto Rico is not a state, it is a mere 'territory.' Puerto Ricans have no representative with full voting rights in Congress and, unless living stateside, cannot vote for the President of the United States. In a country that likes to see itself as the oldest democracy in the world and a staunch defender of political rights on the international stage, more than 3 million people who live on the island have no power in their own capital.
- 70. Puerto Rico not only has a fiscal deficit, it also has a political rights deficit, and the two are not easily disentangled. I met with the Executive Director of the Financial Oversight and Management Board that

was imposed by Congress on Puerto Rico as part of PROMESA. This statement is not the place to challenge the economics of the Board's proposed polices, but there is little indication that social protection concerns feature in any significant way in the Board's analyses. At a time when even the IMF is insisting that social protection should be explicitly factored into prescriptions for adjustment (i.e. austerity) it would seem essential that the Board take account of human rights and social protection concerns as it contemplates far-reaching decision on welfare reform, minimum wage and labor market regulation.

- 71. It is not for me to suggest any resolution to the hotly contested issue of Puerto Rico's constitutional status. But what is clear is that many, probably most, Puerto Ricans believe deeply that they are presently colonized and that the US Congress is happy to leave them in the no-man's land of no meaningful Congressional representation and no ability to really move to govern themselves. In light of recent Supreme Court jurisprudence and Congress's adoption of PROMESA there would seem to be good reason for the UN Decolonization Committee to conclude that the island is no longer a self-governing territory.
- \* I am grateful for the superb research and analysis undertaken by Christiaan van Veen, Anna Bulman, Ria Singh Sawhney, and staff of the UN Office of the High Commissioner for Human Rights, as well as the many inputs made by civil society groups, including those organized by the US Human Rights Network, and by leading scholars in the field.

#### Notes

- 1. Council of Economic Advisers, The Long-Term Decline in Prime-Age Male Labor Force Participation (2016).
- 2. Charles Varner, Marybeth Mattingly, & David Grusky, 'The Facts Behind the Visions,' Pathways, Spring 2017, p. 2.
- 3. https://www.hudexchange.info/resources/documents/2017-AHAR-Part-1.pdf
- 4. The National Advocates for Pregnant Women, Submission to the Special Rapporteur on Extreme Poverty and Human Rights (4 October 2017), at 4.
- 5. https://www.treasury.gov/press-center/press-releases/Documents/TreasuryGrowthMemo12-11-17.pdf
- 6. https://ccf.georgetown.edu/2017/08/03/what-every-policy-maker-needs-to-know-about-the-childrens-health-insurance-program-chip-a-refresher/; https://www.medicaid.gov/chip/downloads/fy-2016-childrens-enrollment-report.pdf;
- 7. National Association of Community Health Centers, http://www.nachc.org/about-our-health-centers/find-a-health-center/
- 8. Julia Paradise et al, Community Health Centers: Recent Growth and the Role of the ACA (18 January 2017),
- 9. National Association of Community Health Centers, http://www.nachc.org/wp-content/uploads/2016/02/NACHC-2017-Policy-Paper-Funding.pdf.
- 10. National Association of Community Health Centers, The Health Center Funding Cliff and its Impact, September 2017; Peter Shin et al, What are the Possible Effects of Failing to Extend the Community Health Center Fund?, RCHN Community Health Foundation Research Collaborative Policy Research Brief # 49 (21 September 2017),
- https://publichealth.gwu.edu/sites/default/files/images/GG%20Health%20Center%20Fund%20Brief\_9.18\_Final.pdf
- 11. In a written submission received by the Special Rapporteur from researchers at the Princeton University Center for Information Technology Policy, they write: "The concent of AI has been proven to be

notoriously difficult to define. A basic though popular definition of AI refers to "intelligence exhibited by machines" or "the science and engineering of making intelligent machines." These definitions assume that 'intelligence' is clearly defined itself, though it, too, is ambiguous. No commonly agreed upon definition of artificial intelligence currently exists." Available here: http://www.ohchr.org/EN/Issues/Poverty/Pages/Callforinput.aspx

- 12. Executive Office of the President National Science and Technology Council Committee on Technology', 'Preparing for the Future of Artificial Intelligence', October 2016, p.1.
- 13. Cathy O'Neil, 'The Ivory Tower Can't Keep Ignoring Tech', 14 November 2017, available from: https://www.nytimes.com/2017/11/14/opinion/academia-tech-algorithms.html
- 14. One important exception is an excellent book that will be published in January: Virginia Eubanks, *Automating Inequality: Automating Inequality How High-Tech Tools Profile, Police, and Punish the Poor* (Forthcoming, 2018)
- 15. https://www.lamayor.org/comprehensive-homelessness-strategy
- 16. https://www.hudexchange.info/resources/documents/2004HUDDataandTechnicalStandards.pdf
- 17. The Criminal Justice Policy Program (CJPP) at Harvard Law School, 'Moving Beyond Money: A Primer on Bail Reform', October 2016, p. 18.
- 18. Sandra G. Mayson, 'Bail Reform and Restraint for Dangerousness: Are Defendants a Special Case?' *Public Law Research Paper No. 16-30 Yale Law Journal* (Forthcoming DO NOT CITE WITHOUT AUTHOR'S PERMISSION), p.1, available from: https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=2826600; Human Rights Watch, 'Not in it for Justice: How California's Pretrial Detention and Bail System Unfairly Punishes Poor People', April 2017, p. 87-88.
- 19. Human Rights Watch, 'Not in it for Justice: How California's Pretrial Detention and Bail System Unfairly Punishes Poor People', April 2017, p. 88.
- 20. Written submission from the AI Now Institute: http://www.ohchr.org/EN/Issues/Poverty/Pages/Callforinput.aspx
- 21. Written submission from Access Now: http://www.ohchr.org/EN/Issues/Poverty/Pages/Callforinput.aspx
- 22. West Virginia Center on Budget and Policy & American Friends Service Committee, '2016 State of Working West Virginia: Why is West Virginia so Poor?', p. 55.

Home
Frequently Asked Questions
OHCHR on Social Media
OHCHR Memorial
Employment
Mobile App

Site Map © OHCHR 1996-2018 **CONTACT US** 

# Exhibit 3

#### Human Intestinal Parasite Burden and Poor Sanitation in Rural Alabama

Megan L. McKenna,<sup>1</sup>† Shannon McAtee,<sup>1</sup>† Patricia E. Bryan,<sup>1</sup> Rebecca Jeun,<sup>1</sup> Tabitha Ward,<sup>1</sup> Jacob Kraus,<sup>1</sup> Maria E. Bottazzi,<sup>1</sup> Peter J. Hotez,<sup>1</sup> Catherine C. Flowers,<sup>2</sup> and Rojelio Mejia<sup>1</sup>\*

<sup>1</sup>Departments of Pediatrics and Medicine, National School of Tropical Medicine, Baylor College of Medicine, Houston, Texas; <sup>2</sup>Alabama Center for Rural Enterprise, Montgomery, Alabama

Abstract. Hookworm infection affects 430 million people worldwide, causing iron deficiency, impaired cognitive development, and stunting in children. Because of the environmental conditions needed for the hookworm life-cycle, this parasite is endemic to resource-limited countries. Necator americanus was endemic in the southern United States before improvement of sewage disposal systems and eradication programs. With continued poverty, poor sanitation, and an environment suitable for the hookworm life-cycle in some regions of the southern United States, a current prevalence study using modern molecular diagnostics is warranted. Lowndes County, Alabama, was chosen as the study site given previous high hookworm burdens, degree of poverty, and use of open-sewage systems. Participants were interviewed, and stool, serum, and soil samples were tested for nine intestinal parasites using a multiparallel quantitative real-time PCR (qPCR) and enzyme-linked immunosorbent assays. We found that, among 24 households, 42.4% reported exposure to raw sewage within their home, and from 55 stool samples, 19 (34.5%) tested positive for N. americanus, four (7.3%) for Strongyloides stercoralis, and one (1.8%) for Entamoeba histolytica. Stool tested positive for N. americanus contained low levels of parasite DNA (geometric mean 0.0302 fg/µL). Soil studies detected one (2.9%) Cryptosporidium species, and Toxocara serology assay detected one (5.2%) positive in this population. Individuals living in this high-risk environment within the United States continue to have stool samples positive for N. americanus. Gastrointestinal parasites known to be endemic to developing countries are identifiable in American poverty regions, and areas with lower disease burden are more likely to be identified by using qPCR.

#### INTRODUCTION

Intestinal parasitic infections have a significant impact on health outcomes and morbidity in adults and children worldwide, ranging from diarrhea and stunting in children to impaired cognitive development from iron deficiency anemia.<sup>1</sup> Globally, approximately 430 million people are infected with hookworm (Ancylostoma duodenale and Necator americanus).<sup>2</sup> Among those infected with intestinal nematodes, hookworm infections are associated with the greatest years lived with disability (YLDs), with recent estimates indicating that human hookworm disease is associated with 4.1 million disability-adjusted life years.3 This large contribution of hookworm infections to the YLDs among those with nematode infections is due to the link between hookworm disease and anemia in children. 4-6 Beyond its health impact, the anemia it induces is linked to a moderate economic burden ranging up to \$139 billion annually.3

Necator americanus is the major hookworm species in the Americas. Transmission requires fecal contamination of soil and dermal penetration of human hosts. Conditions for larval survival, include moist and temperate environments. These soil-transmitted helminths are mainly found in areas where sanitation and hygiene are poor, most commonly in resource-limited countries. However, in the early 1930s, the southern United States had a high prevalence of hookworm infections caused by N. americanus. The initial surveys found 53.6% of the population to be infected with hookworm; in some areas, the prevalence rose as high as 76%. To control the disease, thousands of individuals were treated, decreasing prevalence to 39%. After these interventions, there were increases in

school enrolment, attendance, and literacy, and those within

According to the Alabama Center for Rural Enterprise (ACRE), an organization that addresses poverty and economic development in one of the poorest areas of the nation, <sup>16</sup> there continue to be residences without adequate sanitation systems, increasing exposure to open sewage near dwellings. The "Black-Belt" soil native to this area is composed of a firm sedimentary limestone bed overlain with a layer of dark, rich soils, <sup>17</sup> which requires expensive septic systems for proper waste disposal. In Lowndes County, Alabama, where the per capita income is \$18,046, and 31.4% of the population lives below the poverty line, <sup>18</sup> sanitation systems are unaffordable. For rural, impoverished individuals, the main form of waste removal involves use of "straight piping," a method involving a series of ditches or crudely constructed piping systems to

the treated cohort had substantial gains in long-term incomes. 10 However, because of posttreatment reinfection and widespread transmission, hookworm infection and disease continued to persist in the southern United States, especially in areas of extreme poverty. 11 According to a study in the 1950s, rural Alabama still suffered from a high prevalence of hookworm infection in schoolchildren, with some counties having 60% infection. 12 With improved sanitation and waste disposal infrastructure, in association with aggressive economic development in the southern United States, the prevalence of hookworm infection decreased. In the 1990s, surveillance studies for enteropathogens in southern Alabama show a 30% prevalence for all soil-transmitted helminths combined, including Ascaris lumbricoides, N. americanus, and Enterobius vermicularis. 13 This part of the United States was identified as one at high risk for intestinal helminth infections. 14 A more recent systematic review, however, found that few surveys for intestinal helminth infections have been conducted in recent decades, with limited information about these diseases, 15 especially in poor rural and southern United

<sup>\*</sup>Address correspondence to Rojelio Mejia, Laboratory of Clinical Parasitology and Diagnostics, National School of Tropical Medicine, One Baylor Plaza, Baylor College of Medicine 113, Houston, TX 77030. E-mail: rojelio.mejia@bcm.edu

<sup>†</sup>These authors contributed equally to this work.

guide human waste away from the residence. Most pipes never reach more than 10 meters in length, and during rainstorms or flooding, the residents report visible stool entering their homes (reported by ACRE, unpublished data).

While the prevalence of intestinal parasites has decreased in the past 85 years, conditions amenable to the parasite lifecycle and transmission persist. Because of these conditions, a more current investigation using modern molecular diagnostics is warranted to determine the burden of intestinal parasitic infection. The goal of this study seeks to address the current prevalence of helminthic and protozoan infections and determines correlation with sewage exposure in an economically challenged region of the southern United States. Given continued poverty in these areas such as Lowndes County, lack of access to contained septic systems, and potential exposure to raw sewage, intestinal helminth infection likely persists despite previous interventions. The results of this study will provide insight into disease burden within this community and a basis for further study on possible risk factors, intervention, and effects on the community.

#### **METHODS**

Sample population. The study was performed in Lowndes County, an area in Alabama known to have low per capita income. According to the 2010 US Census, Lowndes County, has 5,270 houses with a 11,299 total population. 18 ACRE reports approximately 50% of households have a failing or no sewage system (ACRE, unpublished data). Dwellings and individuals were preselected by ACRE organizers from areas with poor sanitation and used open sewage systems as a means of waste management. Enrolment goals of 100 subjects were planned, all subjects enrolled were African American. A total of 66 subjects were enrolled in the study from a total of 24 homes. There were single individuals from seven homes, four homes with two subjects, seven homes with three subjects, three homes with four subjects, one home each with five, six, and eight subjects, respectively. The research team and those assisting from ACRE visited the selected dwellings, interviewed residents using a questionnaire to obtain data regarding their dwelling and health, and collected soil from the surrounding areas and stool samples from participants. The questionnaire included information regarding sex, age, previous travel outside the United States, prior history of parasitic infections, exposure to sewage within the home, asthma, and diarrheal symptoms. Before participating in the study, each participant or guardian signed a written consent form. Participants were excluded if they have ever traveled outside the United States or were under 2 years of age, pregnant, HIVpositive, or immunocompromised. This study was approved by the Baylor College of Medicine Institutional Review Board and the Alabama Department of Public Health.

Sample collection. Stool samples were self-collected by the individual participants after instructions were provided verbally and in writing, and soil samples were obtained near areas of sewage collections or run-off by research team members. Participants were instructed to fill stool containers with approximately 5 grams of stool and store in provided opaque double-sealed biohazard bags in the refrigerator overnight, or if possible, the same day as the scheduled interview and collection. All samples were stored in dry ice coolers after collection and transported to the Laboratory of

Clinical Parasitology and Diagnostics, Baylor College of Medicine within 5 days of collection, and stored in  $-20^{\circ}$ C freezers.

Molecular methods. DNA was extracted from the frozen stool samples the following week after collection using MP FastPrep® spin kits for soil (MP Biomedicals, Santa Ana, CA) after a modified method was developed by the primary investigator, as previously described, for Trichuris trichiura DNA. 19 Parasite DNA was detected using a multiparallel quantitative real-time PCR (qPCR) protocol. 19 Species-specific primers and 6-carboxyfluorescein-labeled Minor groove binder probes (Applied Biosystems, Foster City, CA) were selected for each of the eight parasites tested, including helminths (Ascaris lumbricoides, Trichuris trichiura, Strongyloides stercoralis, Ancylostoma duodenale, and N.americanus), and protozoa (Giardia lamblia, Cryptosporidium species, and Entamoeba histolytica)<sup>19</sup> (Supplemental Table 1). Samples were analyzed on an ABI ViiA 7 Real-Time PCR System (Applied Biosystems) using default parameters for fast chemistry and 40 cycles. 19 DNA concentrations were calculated using parasite plasmid standard curves. 19 All controls (positive, negative, and a pBR322 plasmid internal control) were performed in triplicate with subject samples in duplicate. Samples were repeated for discordant results. The threshold for positivity was set at 38 cycle thresholds (Ct), which was the limit of detection for our dynamic range of positive standard curves. 19 Fifty grams of top soil was collected at sites close to the opening of "straight pipes," and the same protocol used for stool was implemented for extracting DNA from soil samples.

Additional analysis. A subsequent serological evaluation using an enzyme-linked immunosorbent assay (ELISA) protocol for the detection of Toxocara species was performed on 11 patients who were found to be positive for N. americanus and had serum available for study. Because of logistical restraints, blood from only those positive for any parasite was requested, and only 11 subjects consented. A commercially available Toxocara ELISA was used per manufacturer protocol (Abnova, Taiwan) with positive absorbance readings accepted as greater than or equal to 0.3 optical density units. For the detection of Strongyloides stercoralis, a previously described NIE-ELISA protocol<sup>20</sup> was implemented using serum from the same 11 participants who were tested for Toxocara species. Unfortunately, subject's stool positive for Strongyloides by qPCR declined further serum work up. Any positive laboratory result (qPCR, microscopy, ELISA) was communicated to the subject and their primary care provider, who decided what clinical course to take.

Gel electrophoresis with 4% agarose gel was also used in this study as a confirmatory tool for positive results. Sample standards were used, as well as positive and negative controls. Bands were visualized by ultraviolet fluorescent detection. Those testing positive for *N. americanus* infection had their stool sent to the Centers for Disease Control (CDC) for ova and parasites, and concentration microscopic evaluation.

**Data analysis.** All statistical analyses were performed using Prism software version 5.0d (GraphPad, La Jolla, CA). The level of significance was set at P < 0.05 for all analyses, and all statistical tests were two-sided. Descriptive statistics were computed to describe data for sample characteristics. Frequency distribution and measures of central tendency and dispersion were expressed by geometric means, medians, standard deviations, and proportions. Fisher's exact test was

used to compare categorical variables and proportions. All qPCR positive samples were reported as parasite DNA concentrations measured in femtograms per microliter (fg/ $\mu$ L). Data were generated by detecting which parasites were present in each person. Linear regression was used to calculate fg/ $\mu$ L to hookworm eggs per gram (epg) of stool by microscopy in a previous study, which provides a good representation of parasitic infections within a population. <sup>21</sup>

#### **RESULTS**

The questionnaires were collected for 67 individuals, but given exclusion criteria, only 66 were included in this study. Not all questions were answered, therefore, the questionnaire results were evaluated separately in a subgroup analysis (Figure 1). Age ranged from 2 to 85 years, with a mean of 34.2 years of age. The participants included 36 females and 25 males. No one reported a previous diagnosis of a parasitic infection. Only six individuals reported having diarrhea in the past 7 days, and eight reported having asthma in the past 30 days. Twenty-eight individuals reported having exposure to raw sewage inside their domicile (42.4% of those answering the questionnaire within this study population).

Stool samples were collected for 55 individuals. Of these, 19 (34.5%) were positive for N. americanus, four (7.3%) for Strongyloides stercoralis, and one (1.8%) for Entamoeba histolytica (Figure 2). Polyparasitism was identified in two stool samples, both of which were positive for N. americanus and Strongyloides stercoralis. All 55 samples were negative for Giardia lamblia, Cryptosporidium species, Ascaris lumbricoides, and Trichirus trichiura. Stool samples positive for N. americanus contained low levels of parasite DNA (range of 0.013-0.059 fg/µL), and the estimated epg, based on calculations from a previous study,21 ranged from 0.474 to 2.14 epg of stool. Microscopy performed on qPCR positive stool samples were negative for ova or parasites. The 19 N. americanus positive samples detected by qPCR were run on 4% agarose gel electrophoresis with sample standards, and all 19 samples had bands corresponding to the appropriate size using a DNA ladder (New England Biolabs, Ipswich, MA) (Supplemental Figure 1). None of the hookworm samples were positive for Ancylostoma duodenale.

Eleven of the 23 participants with stool samples positive for any parasite consented to further serology assays. Of these 11 participants, one (5.2%) tested positive for *Toxocara* species. None tested positive for *Strongyloides stercoralis* IgG antibodies based on ELISA. Of the 34 soil samples collected, one (2.9%) tested positive for the protozoa, *Cryptosporidium* species.

Further subanalysis was performed on 26 individuals with fully completed questionnaires and qPCR stool testing. Those meeting these criteria included 10 males and 16 females. Stool samples tested negative for 15 patients, N. americanus positive for 11 patients, and N. americanus and Strongyloides stercoralis coinfection positive for two patients. Females comprised 61.5% of this subgroup analysis. There was no statistically significant difference between males and females with or without N. americanus infection (P = 0.68) (Table 1). Raw sewage was reported inside the home for 73.1% of individuals included within this subanalysis, but there was no statistically significant difference between those testing positive and negative for Necator americanus (P = 0.61). Three individuals reported a diagnosis of asthma, and one reported an episode of diarrhea within the past 7 days, but were not statistically different between the uninfected and those infected with *N. americanus* ( $P \ge 0.99$ ) (Table 1).

#### DISCUSSION

Using field-tested molecular assays, 34.5% of individuals living in a high-risk environment within a region of the southern United States were found to have stool samples testing positive for *N. americanus* (hookworm). Even though the parasite burden was low, with up to 0.059 fg/µL of parasite DNA and an estimated egg burden up to 2.1 epg of stool, there is evidence of endemic and autochthonous infection within this population. In addition, 73% of Lowndes County residents who were tested and completed the questionnaire reported exposure to raw sewage inside their home, and even though not statistically significant (likely due to small sample size), 72.7% with this exposure tested positive for parasitic infection. By using qPCR, gastrointestinal parasites known to be endemic to developing countries have now been identified

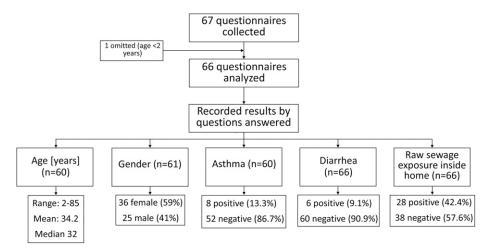


FIGURE 1. Flow diagram of questionnaires collected, questions answered, and results of the data available.

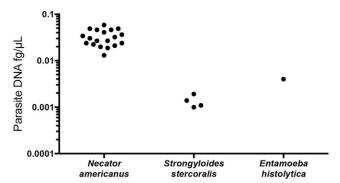


FIGURE 2. Parasite DNA fg/ $\mu L$  in positive stool samples from rural Alabama.

in a resource-limited county in Alabama, among people who have never traveled abroad, likely from autochthonous infection.

Despite decreased hookworm prevalence reported by previous soil helminth eradication programs, infection is still present within this population. During the last century, repeat surveys were performed to track the improvement of helminth infections among local populations, but these studies used microscopy as the diagnostic modality, which is limited by time requirements, manpower, and need for skilled microscopists. Even among those with ample training and experience within the field of microscopy, sensitivity for ova and parasite detection is 50-85%.<sup>22</sup> In addition, detection of ova and parasites is severely limited by the burden of disease—those with less parasite burden are less likely to test positive via microscopy. Given these limitations, this study was unable to provide a correlation between the detection of parasite DNA and the microscopy analysis of qPCR positive stool samples. This was most likely due to the low N. americanus egg burden (calculated 1–2 epg of stool), which is below the microscopy limits of detection (12 epg). <sup>21,23,24</sup> These limitations further justify the utility of qPCR as a method for detection of intestinal parasite infections within these resource-limited communities, where the burden of disease might be too low to accurately detect via microscopy. A new method for parasite detection could provide a more sensitive diagnostic approach for those within these communities with a continued risk of low hookworm burden and other parasitic infections. These constraints explain why qPCR is a desirable method to use with the potential of multiplexing samples for varied infections.<sup>23</sup> Moreover, qPCR requires less skilled operators, and has a significantly higher sensitivity for detection of parasite DNA, especially those with a low burden of disease, detecting levels as low as 100 attograms [1  $\times$  10  $^{-18}$ ] of DNA.  $^{19,21}$  The limit of detection for qPCR and its specificity effectively rule out

A. duodenale hookworm DNA in the samples, together with a historical record showing an absence of A. duodenale infections in the southern United States. Together with the positive gel bands (Supplemental Figure 1), strengthens the likelihood that the positive DNA signals for N. americanus hookworm in this study do not reflect false positives and that transmission continues in the modern era.

As shown in the 1950s Alabama study, hookworm infection rates were as high as 60% in some of the more povertystricken communities. In association with overall economic development in the years during and after Franklin Delano Roosevelt's New Deal legislation, together with improvements in sanitation, urbanization, and industrialization, these pockets of infection were thought to have resolved.9 However, given continued poor sanitation and advancement of detection methods (improved sensitivity with PCR compared with microscopy), low burdens of infection have now been discovered in the United States among populations with autochthonous transmission. Further testing is necessary as hookworm continues to be a problem in areas with poor sanitation, allowing recurrent infections due to repeat exposure. Other areas in the United States have also been found to harbor significant pockets of parasitic infections thought only endemic to developing countries. Strongyloides stercoralis has also been found in some Appalachian mountain communities, 25 as well as in Kentucky 26 and rural Tennessee. 27 Interestingly, we detected a 5.2% Toxocara IgG serological prevalence, which coincides with predicted national prevalence for this parasite among African Americans.<sup>28</sup> While the soil sampling did not reveal the presence of helminths, this was likely because of the limitations of random sampling; however a single Cryptsporidium species sample was detected and reinforces the perception that human or animal fecal contamination occurs near these houses. Another limitation of soil was that no concentration steps were performed, only 50 mg of soil per 50 gm soil sample was processed for DNA extraction. This small amount of soil and low sample numbers likely contributed to low-parasite positive samples. The discovery of these parasitic diseases within the United States begins to shift the idea behind global health. One concept is blue marble health,<sup>29</sup> which reveals that many of the world's neglected tropical diseases are paradoxically found in some of the wealthiest countries, especially in these regions of extreme poverty. With the introduction of more advanced diagnostic techniques, emergence of rare, endemic infections may eventually become less defined by geographic location, but more by economic status.

Unfortunately, because of the mistrust stemming from the illegalities of the self-constructed "straight pipe" waste

Table 1

Questionnaire subanalysis for patients with fully completed questionnaires and qPCR stool testing

Characteristic	Parasite infection			
	Uninfected [N = 15 (%)*]	Necator only infection [N = 9 (%)*]	Any infection [N = 11 (%)*]	P value†
Sex (N = 26)				
Male 10 (38.5%)	5 (33.3%)	4 (44.4%)	5 (45.5%)	0.679
Female 16 (61.5%)	10 (66.7%)	5 (55.6%)	6 (54.5%)	_
Raw sewage in home	11 (73.3%)	8 (88.9%)	8 (72.7%)	0.615
Asthma or other lung disease	3 (20.0%)	2 (22.2%)	2 (18.2%)	> 0.999
Diarrhea in past week	1 (6.7%)	1 (11.1%)	1 (9.1%)	> 0.999

<sup>\*</sup> Percentage of individuals within each infection group.

<sup>†</sup> P values derived from Fisher's exact test for association between uninfected and Necator infection. All P values were above 0.05 comparing uninfected to any infection groups.

disposal systems, as well as toward the medical community, the number of individuals included in this study was much smaller than expected. By working with the ACRE organization, which has fostered trust and worked with several members within the community, the research team was able to include more participants, but some of the data obtained from the questionnaires were incomplete because of different individuals performing the interviews. This should be considered when interpreting the results of this study. Performing subgroup analyses with the information provided some baseline data that could be assessed and compared among those being tested for infection. These incomplete forms were still included in data analyses given the difficulty of obtaining this information by other means and to provide further insight into the local population.

This preliminary study demonstrates that gastrointestinal parasites are present in > 30% of this at-risk population in Lowndes County, Alabama. Further testing in this community is vital to better comprehend the parasitic burden in this population, and additional studies should be initiated to further understand the implications and effects on health and the community. Parasitic testing needs to be expanded to include more households to determine the prevalence and quantitative parasitic burden. Hemoglobin monitoring should be performed among those testing positive for infection, against a negative control group, to determine if there is an impact on health with low parasitic burdens or a correlation between parasitic burden and hemoglobin levels. Hookworm (N. americanus) has also been shown to impair immune recovery (CD4+ cells) in HIV-infected individuals by, an average of, 102 cells/µL fewer CD4+ cells in those infected with Necator. 30 Interestingly, the participants of that study also had low Necator burden of infection (0.025 fg/µL, 0.72 epg) and similar to the Alabama findings. 30 According to 2014 data, the rates of HIV infection in Lowndes county is 758 per 100,000 African Americans and is an area with some of the highest rates of HIV infections in the United States.<sup>31</sup> The combination of HIV and subclinical hookworm infections in Alabama could have an impact on immune recovery. Also, previous studies found a correlation between treatment and substantial gains in long-term income, as well as improvement of school enrolment, attendance, and literacy after hookworm eradication programs.<sup>10</sup> By monitoring for changes in median income, standard of living, and economic status within this population after treatment, correlations of these socioeconomic endpoints to infection, even among those with a low burden of disease, could be determined. Further understanding of the disease process and parasitic burden is vital for future public health initiatives, decreasing hookworm infection, treatment, and improvement of health outcomes, with the overall goal of eradicating this neglected tropical disease in the United States and worldwide.

Received May 19, 2017. Accepted for publication July 4, 2017. Published online September 5, 2017.

Note: Supplemental figure and table appear at www.ajtmh.org.

Financial support: Funding provided by the Texas Children's Hospital Center for Vaccine Development, and the National School of Tropical Medicine, Baylor College of Medicine. Disclosure: R. M. has received travel support from Romark Pharmaceuticals, the makers of nitazoxanide. This study was completed before the association and was not

influenced by this relationship. P. J. H. and M. E. B. are principal investigators and patent-holders on vaccines for hookworm and schistosomiasis, currently in clinical trials, as well as several other neglected tropical medicine disease vaccines currently in development. Other authors report no conflicts of interests, have participated in the study, and concur with the submission.

Authors' addresses: Megan L. McKenna, Shannon McAtee, Patricia E. Bryan, Rebecca Jeun, Tabitha Ward, Jacob Kraus, Maria E. Bottazzi, Peter J. Hotez, and Rojelio Mejia, National School of Tropical Medicine, Baylor College of Medicine, Houston, TX, E-mails: mmckenna@bcm.edu, shannon.mcatee@gmail.com, patricia.e.bryan@uth.tmc.edu, rjeun1@jhmi.edu, tabitha.ward@bcm.edu, jcbkraus@gmail.com, bottazzi@bcm.edu, hotez@bcm.edu, and rojelio.mejia@bcm.edu. Catherine C. Flowers, Alabama Center for Rural Enterprise, Montgomery, AL. E-mail: catherineflowers@aol.com.

This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.

#### **REFERENCES**

- Checkley W, Buckley G, Gilman RH, Assis AM, Guerrant RL, Morris SS, Melbak K, Valentiner-Branth P, Lanata CF, Black RE, 2008. Multi-country analysis of the effects of diarrhoea on childhood stunting. Int J Epidemiol 37: 816–830.
- GBD 2015 Disease and Injury Incidence and Prevalence Collaborators, 2016. Global, regional, and national incidence, prevalence, and years lived with disability for 310 diseases and injuries, 1990–2015: a systematic analysis for the Global Burden of Disease Study 2015. *Lancet 388*: 1545–1602.
- Bartsch SM, Hotez PJ, Asti L, Zapf KM, Bottazzi ME, Diemert DJ, Lee BY, 2016. The global economic and health burden of human hookworm infection. PLoS Negl Trop Dis 10: e0004922.
- Brooker S, Hotez PJ, Bundy DAP, 2008. Hookworm-related anaemia among pregnant women: a systematic review. PLoS Neal Trop Dis 2: e291.
- Smith JL, Brooker S, 2010. Impact of hookworm infection and deworming on anaemia in non-pregnant populations: a systematic review. *Trop Med Int Health* 15: 776–795.
- Hotez PJ, Brooker S, Bethony JM, Bottazzi ME, Loukas A, Xiao S, 2004. Hookworm infection. N Engl J Med 351: 799.
- CDC, Global Health Division of Parasitic Diseases, 2013. Parasites. Available at: https://www.cdc.gov/parasites/sth/. Accessed December 15, 2016.
- Smith WHY, McAlpine JG, Gill DG, 1937. Intestinal parasite survey in Alabama. A comparative study of two hookworm anthelmintics. Am J Public Health 27: 471–475.
- Humphreys M, 2009. How four once common diseases were eliminated from the American south. Health Aff 28: 1734–1744.
- Bleakley H, 2007. Disease and development: evidence from hookworm eradication in the American south. Q J Econ 122: 73–117.
- 11. Hotez P, 2007. Hookworm and poverty. *Ann N Y Acad Sci 1136:* 38–44.
- 12. Hosty TS, Wells DM, Freear MA, Whitfield NK, 1954. Hookworm in Alabama. *J Med Assoc State Ala* 23: 179–182.
- Badham AL, 1993. Wilcox County Alabama: Needs Assessment, Doctoral Dissertation. Birmingham, AL: University of Alabama at Birmingham. Available at: https://assets.documentcloud. org/documents/2091580/pdf1-hookworm1993.pdf. Accessed December 15, 2016.
- 14. Hotez PJ, 2008. Neglected infections of poverty in the United States of America. *PLoS Negl Trop Dis 2*: e256.
- Starr MC, Montgomery SP, 2011. Soil-transmitted helminthiasis in the United States: a systematic review-1940–2010. Am J Trop Med Hyg 85: 680–684.
- ACRE, Alabama Center for Rural Enterprise CDC Inc., 2017.
   ACRE CDC, Inc. Overview. Available at: http://acrecdc.com/. Accessed May 15, 2017.
- Winemiller TL, 2009. Black Belt Region in Alabama. Encyclopedia of Alabama. Auburn University at Montgomery. Available at: http://www.encyclopediaofalabama.org/article/h-2458. Accessed December 15, 2016.

- United States Census Bureau, 2010–2014. Lowndes County Alabama: Income and Poverty. Available at: http://www. census.gov/quickfacts/table/INC110214/01085. Accessed December 15, 2016.
- Mejia R, Vicuña Y, Broncano N, Sandoval C, Vaca M, Chico M, Cooper PJ, Nutman TB, 2013. A novel, multi-parallel, real-time polymerase chain reaction approach for eight gastrointestinal parasites provides improved diagnostic capabilities to resource-limited at-risk populations. Am J Trop Med Hyg 88: 1041–1047.
- Nabha L, Krishnan S, Ramanathan R, Mejia R, Roby G, Sheikh V, McAuliffe I, Nutman T, Sereti I, 2012. Prevalence of Strongyloides stercoralis in an urban USAIDS cohort. Pathog Glob Health 106: 238–244.
- 21. Cimino RO, Jeun R, Juarez M, Cajal PS, Vargas P, Echazú A, Bryan PE, Nasser J, Krolewiecki A, Mejia R, 2015. Identification of human intestinal parasites affecting an asymptomatic periurban Argentinian population using multi-parallel quantitative real-time polymerase chain reaction. *Parasit Vectors 8:* 380.
- Mosli M, Gregor J, Chande N, Lannigan R, 2012. Nonutility of routine testing of stool for ova and parasites in a tertiary care Canadian centre. Can J Microbiol 58: 653–659.
- Basuni M, Mohamed Z, Ahmad M, Zakaria NZ, Noordin R, 2012.
   Detection of selected intestinal helminths and protozoa at Hospital Universiti Sains Malaysia using multiplex real-time PCR. Trop Biomed 29: 434–442.
- 24. Verweij JJ, Brienen EA, Ziem J, Yelifari L, Polderman AM, Van Lieshout L, 2007. Simultaneous detection and quantification

- of Ancylostoma duodenale, Necator americanus, and Oesophagostomum bifurcum in fecal samples using multiplex real-time PCR. Am J Trop Med Hyg 77: 685–690.
- Segarra-Newnham M, 2007. Manifestations, diagnosis, and treatment of Strongyloides stercoralis infection. Ann Pharmacother 41: 1992–2001.
- Fulmer HS, Huempfner HR, 1965. Intestinal helminths in eastern Kentucky: a survey in three rural counties. Am J Trop Med Hyg 14: 269–275.
- Berk SL, Verghese A, Alvarez S, Hall K, Smith B, 1987. Clinical and epidemiologic features of strongyloidiasis. A prospective study in rural Tennessee. *Arch Intern Med 147*: 1257–1261.
- 28. Congdon P, Lloyd P, 2011. *Toxocara* infection in the United States: the relevance of poverty, geography and demography as risk factors, and implications for estimating county prevalence. *Inter J Pubc Health* 56: 15–24.
- Hotez PJ, 2013. NTDs V.2.0: "Blue Marble Health"-neglected tropical disease control and elimination in a shifting health policy landscape. PLoS Negl Trop Dis 7: e2570.
- Morawski BM, Yunus M, Kerukadho E, Turyasingura G, Barbra L, Ojok AM, DiNardo AR, Sowinski S, Boulware DR, Mejia R, 2017. Hookworm infection is associated with decreased CD4<sup>+</sup> T cell counts in HIV-infected adult Ugandans. *PLoS Negl Trop Dis 11:* e0005634.
- Sullivan P, 2017. AIDSVu Interactive Online HIV Prevalence Map Based on U.S. Centers for Disease Control and Prevention's National HIV Surveillance Database. Available at: https://aidsvu.org. Accessed June 30, 2017.

# Exhibit 4

## Notice: Environmental study in Lowndes County, Alabama, fails to prove hookworm infection

A recent published study of hookworm disease in rural Alabama did not achieve statistical significance. The Alabama Department of Public Health (ADPH) has reviewed the study, "Human Intestinal Parasite Burden and Poor Sanitation in Rural Alabama," published in the November 2017 issue of American Journal of Tropical Medicine and Hygiene. This study used an experimental technology that was not FDA-approved in order to determine whether hookworm genetic material could be identified in stool specimens of residents who resided in Lowndes County, Alabama. ADPH was actively involved in the development of the study, which was approved by the Baylor University and ADPH Institutional Review Boards. The authors concluded that the study did not obtain statistical significance.

In an attempt to validate the results of the study, 9 of 20 individuals identified as positive in the study submitted specimens for additional testing via microscopy for ova and parasites (O & P), which is the benchmark confirmatory testing procedure. This confirmatory testing was performed by the Centers for Disease Control and Prevention (CDC). All specimens tested were negative for O & P, and thus no evidence of hookworm infection was found in any of the residents of Lowndes County who were tested.

While ADPH continues to monitor the counties in the West Central and Southwestern districts of Alabama for evidence of gastrointestinal (GI) outbreaks, there is currently no evidence of an increased incidence of GI outbreaks in these ADPH Districts (which include, among others, the counties of Lowndes, Dallas, Hale, Perry, Wilcox, Marengo, Choctaw, and Sumter) than in other parts of Alabama.

Montgomery, Alabama, April 9, 2018

Contact: Dr. Mary G. McIntyre, (334) 206-5200

1. Am J Trop Med Hyg. 2017 Nov;97(5):1623-1628. doi: 10.4269/ajtmh.17-0396.

# Exhibit 5



Screenshot of ADPH's Homepage as of May 1, 2018